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EVIDENCE REVIEW IN ENGLAND, WALES, AND NORTHERN IRELAND

Inequalities in Dementia: Unveiling the Evidence and Forging a Path Towards Greater Understanding

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Commissioned by:
Alzheimer's Society

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Executive Summary

An estimated 982,000 people in the UK are living with dementia, rising to 1.4 million by 2040. This high prevalence means that approximately 1 in 2 people will be affected by dementia (that is, living with dementia, or being the informal carer of someone living with dementia) during their lifetime. Improving our understanding of inequalities in the context of dementia is not only desirable, but also essential to achieve one of the four core purposes of Integrated Care Systems established by NHS England in 2022: *tackling inequalities in outcomes, experience, and access.*

Our research identified the current evidence on inequalities related to people affected by dementia in England, Wales, and Northern Ireland. The available literature suggests that there are inequalities across multiple characteristics, and circumstances and in various parts of the health and care system. We also explored methods to measure a selection of these inequalities, using publicly available data. Finally, we made recommendations for improving the measurement of inequalities, which are essential tools to monitor progress and evaluate policy impacts.

Our literature review identified 110 inequalities for people affected by dementia: 82 inequalities related to health and social care were found for people living with dementia, and 28 inequalities related to health, and health and social care were found for informal carers of people living with dementia.

Inequalities across people living with dementia include those linking *location, deprivation, socioeconomic status, age, culture,* and *ethnicity* with *access to and experience of diagnosis and other healthcare, including A&E attendances, hospital admissions, drug prescribing, and inclusion in clinical trials*. Inequalities of informal carers of people living with dementia were mainly related to *gender, financial pressures, health and well-being*, and *structural issues within the health system*.

We found reliable data to estimate the inequalities and obtain meaningful results for two of the four case studies explored.

The first case study with meaningful results (Case Study 2) explored the inequality related to access to a diagnosis of dementia in rural areas compared to less rural areas. We proposed two measures: the 'rurality gap' (gap in diagnosis rates between the most and least rural areas) and the 'concentration index' (the extent to which diagnosis rates are distributed disproportionately between less or more rural areas). The rurality gap suggested that diagnosis rates were between approximately 5 and 8 percentage points lower in rural areas between 2018 and 2023, with the concentration index supporting this evidence of lower diagnosis rates in rural areas.

The second case study with meaningful results (Case Study 4) explored financial pressures for informal carers as a result of funding care to meet complex needs and/or leave work to provide informal care, compared to the general population. We found evidence that about 41% of informal carers of people living with dementia experience financial difficulties based on survey results from 2021-22, and around 21% were out of the labour force due to caring responsibilities based on survey results in 2016-17 and 2018-19, radically increasing in 2021-22)

The literature review identified important research gaps that need to be filled to improve the understanding of inequalities in dementia and allow for these to be effectively tackled. For example, there is a lack of consensus around the definition of the elements that make up the dementia diagnosis pathway. The case study results highlighted the need to develop robust measures for a set of priority inequalities in dementia, to provide tools to monitor them over time.

In light of the evidence collected and assessed in our report, we recommend to:

- Increase quantitative research that can robustly establish the presence of inequalities in dementia and assess changes over time. Particularly important is the need to develop methods to identify and measure inequalities *in health outcomes* for people living with dementia.
- Increase quantitative and qualitative research exploring the *factors causing inequalities* in dementia and the relationships between inequalities.
- Update and enhance *dementia prevalence estimates* used to calculate diagnosis rates.
- Remove the *disparities in data* that is collected and published in England versus Wales and Northern Ireland.
- Begin data collection of measures that assess all relevant stages along the *time to diagnosis* pathway.

Definitions

Term	Definition
People living with dementia	People living with the symptoms of one of the several diseases that affect memory, thinking, and ability to perform daily activities (WHO, 2023) categorised as dementia. In our research, we do not include individuals with mild cognitive impairment (MCI).
People affected by dementia	Includes people living with dementia (see definition of people living with dementia) and their informal carers.
Health inequalities (HI)	Differences in health across the population and between different groups within society which are unfair and avoidable (Office for Health Improvement and Disparities, 2022) These inequalities are typically referred to final outcomes (such as mortality, well-being, or health-related quality of life).
Health and social care inequalities (HSCI)	Differences in the access to and experience of health and social care services and resources across the population and between different groups within society which are unfair and avoidable. Health and social care inequalities can lead to health inequalities. These inequalities are typically referred to intermediate outcomes (such as access to healthcare, diagnosis, or social care support).
Formal care	Formal care is funded care. The care can be paid for by the individual receiving care (or their friends or family) or can be state-funded. (Besley et al., 2023)
Informal care	Informal care is unpaid care, often provided by family, friends or other loved ones. (Besley et al., 2023)
Dementia change points	Our dementia change points are based upon the six change points outlined in Alzheimer's Society's Impact Framework. Informed by evidence, they reflect the key changes people affected by dementia can face during and following a diagnosis of dementia. Different health and social care services are likely to be required at each change point.
Diagnosis *(As a key dementia change point)*	The identification of a disease that causes dementia as being the root cause of a person's symptoms.
Adjusting to living with dementia *(As a key dementia change point)*	Support provided to enable people to continue to live with their usual daily life outside of the informal and formal carer support. For example, this may include mechanisms for coping or information and resources beyond clinical diagnostic information (e.g., information on how to access financial support).
Carer support *As a key dementia change point)*	Refers to the provision of both informal care and formal care provided in domiciliary settings (i.e., a person's own home and not a care home).
Healthcare and treatment	Contact with the health system for the management of co-morbidities or to manage the symptoms of dementia.

Term	Definition
(As a key dementia change point)	In the long run, this stage would also include contact with the health system to access disease-modifying treatments. When mapping inequalities to dementia change points, we have included inequalities relating to research and clinical trials to this change point. Clinical trials involve contact with the health system, and inequalities observed during clinical trials are likely to translate to inequalities during contact with the health system after the successful implementation of new technologies into clinical practice. 'Healthcare and treatment' is significantly broader than the 'hospitalisation' change point outlined in Alzheimer's Society's Impact Framework. This enables us to take a more inclusive approach to identifying inequalities related to receiving healthcare (i.e., it captures contact with the health system beyond that provided in hospitals, such as primary care sought for reasons other than diagnosis).
Alternative home *(As a key dementia change point)*	May refer to assisted living, sheltered housing, residential care homes or nursing homes where carer support is provided by staff or other formal carers.
End of life *(As a key dementia change point)*	Support provided in the later stages of a life-limiting condition (including both dementia and other co-morbid life-limiting conditions) to enable the person living with dementia to live as well as possible until they die. (Alzheimer's Society, 2021)
Comparators	To identify the presence of inequalities, by definition, there must be an unfair and avoidable difference between (groups of) the population. This implies that a comparison must be made between different people in/groups of the population to determine that there are differences. The groups that we compare the people living with dementia/informal carers to are referred to as our comparators.
Factors	This term is used to describe determinants of the observed health and social care inequalities and health inequalities.
Ethnicity	A biological construct based on the ancestry and genetic background of the individual.
Culture	A social construct based on the beliefs, traditions and customs that influence the behaviours of a particular group of the population.
Access	An individual's ability to obtain and receive health and social care. It captures availability (geographic, queueing, waiting times), acceptability (patient willingness to accept care and provider willingness to provide health and/or social care), and awareness (knowledge of service availability and benefits of care and support).
Experience	An individual's experience of their interactions with the health and social care system, including health and social care professionals and the care environment, in the process of obtaining and receiving health and social care. There is overlap between the definitions of experience of and access to health and social care, as some elements of the health and social care experience may act as barriers to access.
Sub-Integrated Care Board (sub-ICB)	Sub-groupings within an Integrated Care Board (ICB), which is a statutory organisation which organises the delivery of NHS primary and secondary care services within a local area. (NHS Digital, 2023f)
Lower Layer Super Output Area (LSOA)	Small geographical areas in England and Wales with a mean population of approximately 1500. (NHS, 2023)

Term	Definition
Index of Multiple Deprivation (IMD)	A small area measure of relative deprivation across the country at the LSOA (England and Wales) and Super Output Area (Northern Ireland)
Settlement Development Limit	Statistical classification and delineation of settlements in Northern Ireland defined by the Planning Service. SDL boundaries are available for settlements with a population of greater than 1,000.
Prevalence	A measure of the frequency or current number of cases of a disease or health condition in a population at a particular point in time.
Incidence	A measure of the number of newly diagnosed cases of a disease or health condition within a particular time period.
Diagnosis rate	The proportion of the estimated number of people living with dementia in a population who currently have a diagnosis.
CFAS	Cognitive Function and Ageing Studies
THIN	The Health Improvement Network
CPRD	Clinical Practice Research Datalink

1. Introduction

In recent years, substantial research and policy debate has centred on inequalities, addressing both theoretical aspects (definition and measurement) and practical approaches (how to implement policy interventions to tackle them and monitor progress to reduce the differences observed). This debate has influenced political decisions, such as incorporating the focus on inequalities in the NHS Long Term Plan (NHS, 2019), and prioritising the reduction of inequalities as a core objective of the Integrated Care Systems in NHS England (NHS England, 2021).

In this research, we explore published evidence on inequalities in the context of dementia in England, Wales, and Northern Ireland and discuss the next steps required to enable the identified inequalities to be effectively tackled. An estimated 982,00 people in the UK are estimated to be living with dementia, rising to 1.4 million by 2040 (Alzheimer's Society, 2024). This high prevalence means that approximately 1 in 2 people will be affected by dementia during their lifetime (Besley et al., 2023) and demonstrates the importance of improving understanding of inequalities in the context of dementia. Our research focuses on inequalities relating to people affected by dementia. We define people affected by dementia as people living with dementia and their informal carers. Informal carers are unpaid carers and are often family, friends or other loved ones (Besley et al., 2023).

We define health inequalities as unfair and avoidable differences in health status across the population (Office for Health Improvement and Disparities, 2022). We differentiate between health inequalities (HI) and health and social care inequalities (HSCI). In some definitions of health inequalities, these interrelated concepts are combined (The King's Fund, 2022). We distinguish between the two, to separate where groups not only experience unfair and avoidable differences in health status but to unpack the unfair and avoidable differences in health and social care provision which are inevitably likely to lead to differences in health status for people affected by dementia. In doing so, we begin to determine where it may be possible to take meaningful steps to improve the lives of people affected by dementia.

HEALTH INEQUALITIES (HI)

Health inequalities are defined as differences in health **status** (physical, mental, and well-being) across the population, and between different groups within society that are unfair and avoidable.

HEALTH AND SOCIAL CARE INEQUALITIES (HSCI)

We define *health and social care inequalities* as differences in the **access to** and **experience of** health and social care **services** and **resources** across the population, and between different groups within society that are unfair and avoidable. These health and social care inequalities can lead to HI.

We focus on inequalities experienced by people living with dementia and their informal carers *once dementia symptoms begin*. We recognise that the inequalities experienced by people living with dementia and their informal carers may be linked to inequalities resulting in differing likelihoods of developing dementia across the population. For example, the risk of dementia is higher among people in lower socio-economic groups (Klee et al., 2023). HSCI can exacerbate these existing pre-symptomatic HI. However, in our identification of inequalities, we do not consider how inequalities can impact the risk of developing dementia.

In section 2 of this report, we identify HSCI in the context of dementia by considering two research questions:

- What HSCI are identified in the literature for people living with dementia?
- What HSCI and HI are identified in the literature for informal carers of people living with dementia?

We are primarily interested in identifying inequalities related to health and social care services and resources (HSCI), not unfair and avoidable differences in underlying health (HI) for people living with dementia. We also recognise that HSCI are likely to lead to HI (whether that is generating new HI or exacerbating existing HI), but despite there being literature identifying HI for people living with dementia, there is limited causal evidence linking specific HSCI to HI. To focus our literature search on health and social care system-related inequalities in the context of dementia, where it should be clearer to identify actionable changes that can be made to reduce inequalities, we only considered HSCI for people living with dementia. For carers, impacts on health status may be considered a direct result of their interaction (or lack thereof) with health and social care services, so we did not exclude HI from the literature search.

In section 3 of this report, we explore the measurement of four of the identified inequalities to answer an additional research question:

- Can HSCI and HI in the context of dementia be accurately measured?

In this section, we acknowledge that pre-existing HI may impact dementia prevalence and, therefore, HSCI measures for people living with dementia. As a result, we account for dementia risk factors within the population in our analysis.

Section 4 of this report provides a discussion of existing gaps in the understanding of inequalities in dementia, and section 5 provides a conclusion.

2. What do we Currently Know about Inequalities from the Literature?

2.1 Aim

The literature review aims to identify grey and peer-reviewed literature to understand what is currently known about HSCI for people living with dementia. In addition, we also capture information on HSCI and HI for informal carers of people living with dementia.

2.2 Methodology

2.2.1 Identifying Literature

A rapid evidence assessment was conducted to obtain relevant grey and academic literature. The scope of this literature search was limited to identifying inequalities in England, Wales, and Northern Ireland. However, information on inequalities in the United Kingdom (UK) was also identified by our searches to capture information relating to three nations within scope. We identify literature published between January 2000 and July 2023.

2.2.1.1 Academic Literature

The academic literature search was conducted using Ovid Online, which provided us with access to Ovid Journals, EMBASE, Global Health, OVID Emcare and OVID MEDLINE.

Our searches were restricted to only identifying terms that are included in the title or abstract of the paper. We also restricted our search to papers that are published in the English language and considered humans (that is, focused on individuals rather than systems or structures).

We conducted four searches (see Table 1). Two searches (one for people living with dementia and one for informal carers) were conducted from a top-down approach, including terms directly referring to inequalities (or related terms). The purpose of the top-down approach was to identify the academic evidence and discussion on known inequalities in the dementia space. The other two searches used a bottom-up approach, using search terms to describe the inequalities and dementia change points (such as access, experience, diagnosis, care, and treatment). The purpose of the bottom-up approach was to identify underlying inequalities that may not have been labelled as such. Similar to the top-down approach, the bottom-up search was conducted for both people living with dementia and for informal carers. The full search terms are included in Appendix 1[1].

TABLE 1: ACADEMIC LITERATURE SEARCHES

	Top-down approach	Bottom-up approach
People Living with Dementia	Search 1	Search 2
Informal Carers	Search 3	Search 4

[1] *Mild cognitive impairment (MCI) was beyond the scope of this research and so was not included in our search terms.*

2.2.1.2 Grey Literature

To identify relevant grey literature we conducted searches of key websites such as NHS England, NHS Wales, Health and Social Care Northern Ireland, The King's Fund, NICE, Dementia UK, Alzheimer's Research UK, and The Health Foundation.

In addition, we conducted a Google search to identify policy reports using search terms such as 'inequalities in dementia'. To identify additional information related to carers, we also conducted a Google search using terms such as 'carer inequalities' and 'dementia'. These searches supplemented a list of relevant grey literature provided by the Alzheimer's Society.

Finally, we conducted a search on the Patient Experience Library. We considered articles that included the terms 'dementia' and 'inequalities' in the title and/or description.

2.2.2 Identifying Inequalities

When assessing the literature, we focused on collecting information relating to HSCI inequalities for people living with dementia and both HSCI and HI for informal carers.

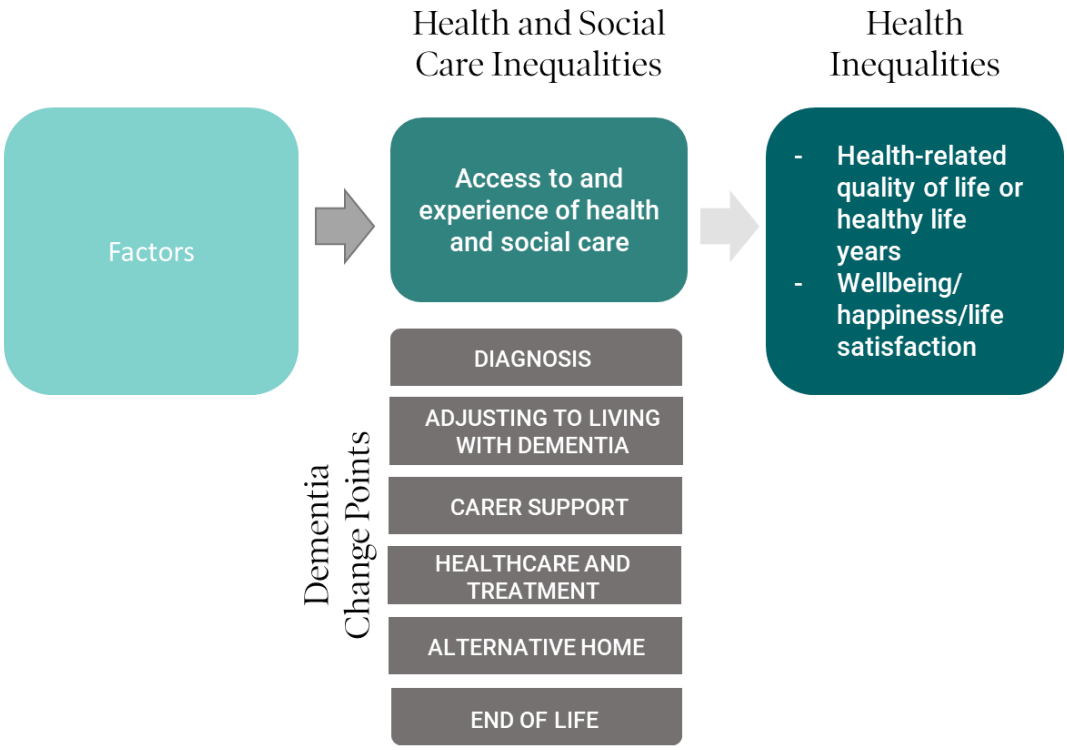
By definition, a person living with dementia will experience a disease that affects memory, thinking and the ability to perform daily activities (WHO, 2023). A literature search including the term 'dementia' and terms used to describe health, such as 'quality of life', will return thousands of results. However, it is difficult to disentangle the health impacts on people living with dementia which are unfair and avoidable, from those which are just the nature of having the disease. So, many of these vast search results will not contain clear evidence of an inequality in health outcomes. Therefore, for people living with dementia, we sought to identify any discussion of access to and experience of health and social care at different dementia change points in England, Northern Ireland and Wales, i.e., the HSCI. This also enables us to get closer to identifying the practical steps that can be taken to tackle inequalities in the health and social care system.

Our dementia change points are outlined in Figure 1: Flow of inequalities and the dementia Change PointsFigure 1 and are based upon the six key change points for people living with dementia outlined in Alzheimer's Society's Impact Framework that reflect the experiences that have the biggest impact on people affected by dementia (Alzheimer's Society, 2023)[2]. These change points are not a linear journey; people living with dementia may experience one or more of these changes at a time and may be experienced for extended periods of time. Different health and social care services may be required at different change points. Therefore, to help us identify HSCI using a bottom-up approach, terms from the dementia change points were included in search 2. We have then attributed each HSCI identified in the literature to at least one dementia changepoint. A detailed explanation of the dementia change points is provided in the 'Definitions' section at the beginning of this report.

When mapping the inequalities identified in the literature to dementia change points, we attributed inequalities relating to research and clinical trials to the healthcare and treatment stage. Clinical trials involve contact with the health system, and inequalities observed during clinical trials are likely to translate to inequalities during contact with the health system after the successful implementation of new technologies into clinical practice.

[2] *Healthcare and treatment is significantly broader than the 'hospitalisation' change point outlined in Alzheimer's Society's Impact Framework. This enables us to take a more inclusive approach to identifying inequalities related to receiving healthcare, (i.e., it captures contact with the health system beyond that provided in hospitals, such as primary care sought for reasons other than diagnosis).*

FIGURE 1: FLOW OF INEQUALITIES AND THE DEMENTIA CHANGE POINTS



For each inequality discussed in the literature, we identified the comparator.

WHAT DO WE MEAN BY COMPARATOR?

To identify the presence of inequalities, by definition, there must be unfair and avoidable difference between (groups of) the population. This implies that a comparison must be made between different people in/groups of the population to determine that there are differences. The groups that we compare the people living with dementia/carers to are referred to as our 'comparators'.

There are three potential options for comparators for both people living with dementia and informal carers of people living with dementia, as shown in Table 2.

TABLE 2: COMPARATORS FOR PEOPLE LIVING WITH DEMENTIA AND INFORMAL CARERS

Population of interest: People living with dementia	Population of interest: Informal carers of people living with dementia
Inequalities between people living with dementia (and other people living with dementia)	Inequalities between carers of people living with dementia (and other carers of people living with dementia)
Inequalities between people living with dementia and people with other diseases	Inequalities between carers of people living with dementia and carers of people with other diseases
Inequalities between people living with dementia and people in the general population (who may or may not have other diseases)	Inequalities between carers of people living with dementia and people in the general population (who may or may not be carers of people with other diseases)

Figure 1 also shows that there are factors that cause HSCI which then lead to HI. For example, Hanna et al. (2022) found that there was a reduction in social service provision for people living with dementia during the initial stages of the COVID-19 pandemic (the factor). This led to a reduction in access to social support services for people living with dementia, resulting in an unmet need and a HSCI compared to the general population. Ultimately, the research determined that this led to a significant mental and emotional impact on people living with dementia, which is a HI for people living with dementia compared to the general population. However, although the relationship between HSCI and HI can often be logically inferred, there is limited research identifying causal links between HSCI and HI, which is likely in part due to the previously discussed challenge of determining HI for people living with dementia.

As previously mentioned, we also sought to identify both HI and HSCI for informal carers of people living with dementia. Informal carers can be impacted by the level of healthcare offered to people living with dementia and the informal carer's involvement in healthcare decisions but are also impacted by the level of support provided to the carer, which we include as part of the HSCI. HI identified in this context relate to the health-related quality of life of informal carers and other aspects of their well-being, including happiness, life satisfaction and other aspects of their mental health.

2.2.3 Evidence Quality Assessment

For the inequalities identified in the academic articles, policy reports and other grey literature, we conducted a quality assessment of the literature. We applied a colour-scoring assessment where each identified inequality was assessed using three criteria: publication quantity, publication quality, and publisher quality.

A summary of the evidence-quality assessment is shown in Table 3 below. The scoring scheme criteria are explained in the following sections.

TABLE 3: SCORING CRITERIA FOR THE EVIDENCE QUALITY ASSESSMENT

	Green	Amber	Red
Publication Quantity	The inequality is mentioned in a large volume of literature search results (>6)	The inequality is mentioned in a sufficient volume of literature search results (4-6)	The inequality is mentioned in only a few literature search results (1-3)
Publication Quality	The inequality is mentioned in at least one publication with quality of evidence level 4 or 5	The inequality is mentioned in at least one publication with quality of evidence level 3	The inequality is only mentioned in publications with quality of evidence level 1 or 2
Publisher Quality	The inequality is mentioned by at least one high-impact publisher	The inequality is not mentioned by any high-impact publisher	*n/a [data not extracted]*

2.2.3.1 Publication Quantity

The purpose of our literature review is to identify the most important inequalities among all the inequalities retrieved from our literature search. Publication quantity allowed us to assess the volume of literature that discusses the inequality in dementia.

TABLE 4: PUBLICATION QUANTITY CRITERIA

	Green	Amber	Red
Publication Quantity	The inequality is mentioned in a large volume of literature search results (n > 6)	The inequality is mentioned in a sufficient volume of literature search results (3 < n <= 6)	The inequality is mentioned in only a few literature search results (n <=3)

2.2.3.2 Publication Quality

The quality of the evidence provided by the academic publications is categorised on a scale from 1 (weak evidence) to 5 (very strong evidence), as shown in Table 5. The classification relates to the research technique used in the analysis. Qualitative research can be very informative for identifying inequalities, with relatively higher rankings (a maximum of 3) being given to qualitative research with a larger number of surveys, focus groups, or showing a large proportion of the population under study. However, the highest rankings were reserved for quantitative research which identifies a robust link between the factor and the existence (or absence) of an inequality for people living with dementia or informal carers (for example, randomised control trials or econometric techniques of causation such as the so-called 'treatment effects' literature).

For each academic publication, we first identified the 'prior' quality of evidence, depending on the type of research method. We allowed for small 'deviations' with respect to the 'prior' assessment of quality. For example, a paper interviewing a small number of individuals (<30) was categorised as 'level 3' if the sample represents a good share of the population of interest (for example, n = 14 care home managers in Northern Ireland).

The grey literature was ranked based on the quality of the research, in line with the ranking system for the academic literature. It was first identified whether the grey literature contained any of the relevant analysis types (literature review or original research), and these sources were ranked 1-5 in accordance with the type and quality of the analysis. Grey literature that did not contain either a review of the literature or original research was ranked as a 1.

TABLE 5: SCALES FOR THE QUALITY EVIDENCE

Type or research method	Rank	Deviations
Targeted Literature Review*	1	2 if the review is high quality with an excellent discussion where authors are adding good insights
Systematic Literature Review*	2	
Original Research – Descriptive	1	
Original Research – Qualitative analysis: interview, focus group, etc	2/3	2 if there is no clear comparator 3 if interviews to n > 12 3 if surveys to n > 30 3 if focus groups n > 2 *Overall note: assess the sample size as % representation of the population of interest*
Original Research – Quantitative analysis: correlation	¾	3 if there is no clear comparator or sample size <200 4 if there is a good set of controls and robust analysis
Original Research – Quantitative analysis: causation	5	4 if there is no clear comparator or sample size <200

*records identified in the literature reviews which were considered highly relevant for our research were added to the pool of papers to extract (when not already there)

For each inequality, we assess the overall quality of evidence as in Table 6.

TABLE 6: PUBLICATION QUALITY CRITERIA

	Green	Amber	Red
Publication Quantity	The inequality is mentioned in at least one publication with quality of evidence level 4 or 5	The inequality is mentioned in at least one publication with quality of evidence level 3	The inequality is only mentioned in publications with quality of evidence level 1 or 2

2.2.3.3 Publisher quality (impact)

To assess publisher quality, we assessed the perceived impact of the publisher. The academic literature was assessed in terms of the impact of the journal. From the Scimago Journal & Country Rank (SJR) for 'Medicine', 'Health Policy', 'Economics and Econometrics', and 'Cognitive Neuroscience', we considered journals 'high impact' that top in the relevant rankings, i.e., with SRJ = 5 or above.

Table 7 shows a few examples from the journals used for extracting the literature.

TABLE 7: JOURNAL IMPACT EXAMPLES

Journals	SJR	High impact?
New England Journal of Medicine	26.01	Yes
The Lancet	14.61	Yes
JAMA	6.69	Yes
JAMA Psychiatry	6.57	Yes
The Lancet Digital Health	6.43	Yes
Trends in Cognitive Sciences	5.61	Yes
PLOS Medicine	4.22	No
JAMA Ophthalmology	2.35	No
BMC Medicine	3.45	No
PLOS One	0.89	No

The grey literature was assessed in terms of impact depending on the type of content and who it was published by. Literature was considered high impact if it included advice, guidance or information provided by the UK government, the NHS, or the National Institute for Health and Care Excellence (NICE).

For each inequality, we assessed the publisher quality (impact) of evidence according to the criteria in Table 8.

TABLE 8: PUBLICATION QUALITY CRITERIA

	Green	Amber
Publisher Quality	The inequality is mentioned by at least one high-impact publisher	The inequality is not mentioned by any high-impact publisher

Note that our selection of the grey literature sources excluded those which were not considered relevant for our project (for example, personal blogs or unknown sources). Therefore, information from grey literature potentially classified under the red colour was not extracted.

2.3 Results

2.3.1 Identified Inequalities

After the removal of duplicates from our search results and the completion of title and abstract screening, we identified 268 academic papers that contained potentially relevant information on HSCI for people living with dementia and/or HSCI/HI for informal carers. An additional five academic literature results that met the eligibility criteria were also identified from reference tracking. Finally, 46 grey literature articles were identified. Therefore, a total of 314 articles were used to identify inequalities in the context of dementia.

A PRISMA diagram that details the breakdown of the number of papers identified through the different stages of our grey and academic literature searches and screening process can be found in Appendix 2.

In the remainder of this section, we present the inequalities identified by comparator, including the quality assessment for each inequality. We have attributed each inequality to at least one dementia change point. For people living with dementia, we identified whether the inequality is related to intermediate outcomes that are aspects of an individual's interaction with health and social care systems: access or experience. Access refers to an individual's ability to obtain and receive health and social care. It captures availability (geographic, queueing, waiting times), acceptability (patient willingness to accept care and provider willingness to provide health and/or social care), and awareness (knowledge of service availability and benefits of care and support). Experience refers to an individual's experience of their interactions with the health and social care system, including health and social care professionals and the care environment, in the process of obtaining and receiving health and social care. There is an overlap between the experience of and access to health and social care as some elements of the health and social care experience may act as barriers to access.

From the literature, we identified 110 inequalities. As shown in Table 9, 82 HSCI were identified for people living with dementia, whilst 28 HSCI and HI were identified for informal carers.

TABLE 9: INEQUALITIES BY POPULATION OF INTEREST AND COMPARATOR

Inequality for	Comparator	Inequalities Identified
People Living with Dementia	Other people living with dementia	38
	General Population	24
	Other Diseases	20
Informal Carers of People Living with Dementia	Carers of other people living with dementia	10
	General Population	13
	Carers of people with other Diseases	5

Table 10 identifies the groups of HSCI identified for people living with dementia compared to other people living with dementia, the general population, and people living with other diseases for each dementia change point. The quality assessment was carried out for each inequality and the full list of HSCI identified for all three comparators for PLWD alongside the associated evidence quality

assessment can be found in Table A1-A3 in Appendix 3: Full Literature Results for people living with dementia.

Inequalities were only identified for all three comparators for inequalities relating to structure and the carer support change point. For HSCI for people living with dementia compared to other people living with dementia, the inequality that ranks among the highest according to our quality assessment criteria comes from the inequality group and is that BAME people living with dementia are less likely to have access to timely diagnosis and present later for assessment than White British people living with dementia. This inequality was identified in many papers in the literature, including those high-quality publications and so is assessed as our highest-ranking category of 'green' for both publication quantity and quality. Other high-ranking inequalities identified were the lower diagnosis rate for Asian, Black and other ethnic minority groups people living with dementia, compared to White people living with dementia which falls into both the culture and ethnicity inequality group and that BAME people living with dementia are less likely to access support services when compared to the White dementia patients, which falls into the culture inequality group. These two inequalities were given the highest assessment of green for both publication and publisher quality.

People living with dementia experience less access to interventions compared to the general population, such as COVID-19 treatments, treatments for age-related muscular degeneration, pain management for fractured neck of femur and oral anticoagulant (OAC) for nonvalvular atrial fibrillation (NVAF). This inequality falls into the structural inequality group and was assessed to have been identified by literature with high publication and publisher quality (i.e., ranked green across these two criteria). Similarly, the only inequality ranked green across two dimensions for people living with dementia compared to other diseases is the identification of gaps in services available following diagnosis, falling into the structural inequality group and ranking green for both publication and publisher quality.

TABLE 10: INEQUALITY GROUPS IDENTIFIED FOR PEOPLE LIVING WITH DEMENTIA CATEGORISED BY COMPARATOR

People Living with Dementia							
		Change Points					
		Diagnosis	Adjusting to Living with Dementia	Carer Support	Healthcare and Treatment	Alternative Home	End of Life
Inequality Group	Age	●	●	●			
	Communication, Consent and Decision Making	●	●	● ●	●	●	●
	Culture	●	●	●	●		
	Demetia Type				●		
	Disabilities	●			●		●
	Environment		●				
	Ethnicity	●		●	●		
	Gender	●		●	● ●		
	Geography	●	●	●	●	●	●
	Insufficient Investments/Public Funding			●			
	Socio-economic	●		●	●		
	Structural	● ●	● ●	● ● ●	● ●	● ●	● ●
	Technology	●				●	

Key
= Inequalities compared to people living with dementia
= Inequalities compared to people living with other diseases
= Inequalities compared to the general population

Table 11 identifies the groups of HI identified for informal carers of people living with dementia. Again, it is only structural inequalities that are identified for all three comparators – namely other informal carers of people living with dementia, the general population, and carers of people living with other diseases, respectively. For carers, the only inequality that was assessed as green for more than one criterion related to the health and wellbeing group. The literature identified that carers of people living with dementia are more likely to experience negative emotions and mental health problems such as depression and anxiety disorders compared to the general population. Ultimately, this can impact their ability to continue to provide care. This inequality ranked green for publication quantity and quality.

The full list of HI identified for all informal carers of people living with dementia can be found in Table A4-6 of Appendix 3: Full Literature Results for people living with dementia.

TABLE 11: INEQUALITY GROUPS IDENTIFIED FOR INFORMAL CARERS OF PEOPLE LIVING WITH DEMENTIA CATEGORISED BY COMPARATOR

Informal Carers			
Inequality Group	**Comparator**	**Inequality Group**	**Comparator**
Age		Gender	
Comorbidities		Health and Well-being	
Dementia Stage		Socioeconomic	
Dementia Type		Structural	
Finances			

Key
= Inequalities compared to carers of other people living with dementia
= Inequalities compared to carers of people living with other diseases
= Inequalities compared to the general population

2.3.1 Marmot Review Comparison

To identify whether the literature we identified captures well-known inequalities that may be relevant in the context of dementia, we consulted the Marmot review (Marmot, 2010). We compared the inequalities identified in the Marmot Review with those identified in our literature review.

Our findings are presented in Table 12. We identified 13 groups of inequalities identified in the Marmot review. Of these, ten groups of inequalities were covered by the literature. The remaining three inequality groups (addiction, childhood experiences, and education) were not featured in our search results. Our literature review features the majority of the inequality groups captured in the Marmot review.

TABLE 12: COMPARISON OF OUR LITERATURE REVIEW RESULTS WITH THE MARMOT REVIEW

Inequalities identified in the Marmot review	Covered by our Literature Review?	Population - Comparator					
		People living with dementia - people living with dementia	People living with dementia - general population	People living with dementia - other Diseases	Carer - people living with dementia	Carer- population	Carer - other diseases
Socioeconomic	✓	○	-	○	-	-	-
Geography	✓	○	-	-	-	-	-
Gender	✓	○	○	-	-	-	-
Ethnicity	✓	○	-	-	-	-	-
Community/social support	✓	○	○	○	○	○	○
Mental health	✓	-	-	-	○	○	-
Transport	✓	○	○	-	-	-	-
Employment & working conditions	✓	○	○	-	-	-	-
Nutrition	✓	○	-	-	-	-	-
Environment (built and natural)	✓	-	○	-	-	-	-
Addiction	-	-	-	-	-	-	-
Childhood experiences	-	-	-	-	-	-	-
Education	-	-	-	-	-	-	-

3. Can we Measure Inequalities in the Context of Dementia?

3.1 Aims

In this section, we discuss methods for quantifying and monitoring inequalities in dementia over time. We present four case studies relating to four inequalities identified during the evidence review phase:

1. Socioeconomic status and access to diagnosis - less access to diagnosis in deprived areas.
2. Geography and access to diagnosis- less access to diagnosis in rural areas compared to non-rural areas, resulting in a higher average diagnosis age.
3. Ethnicity and experience of diagnosis - lower diagnosis rates for Asian, Black, and other ethnic minority groups people living with dementia compared to White people living with dementia.
4. Carers - financial pressures as a result of needing to fund care to meet complex needs and/or leave work to provide informal care.

Section 3 is structured as indicated in the box below:

Section 3.2: Outlining 'Time to Diagnosis'

Sources of delay to a diagnosis in the context of dementia are explored with an illustration of 'time to diagnosis'.

Sections 3.3 – 3.6: The four Case Studies

Each case study is analysed separately, and contains the following:

- A summary of the evidence retrieved from the literature, identifying related inequality measures.
- A recommended potential way to measure the inequality over time using data in England
- A discussion of the data limitations and whether the measure of inequality is valid, given these data limitations.
- Recommendations to improve the measurement with data which are not publicly available or currently collected.

Section 3.7: Data Comparison to Wales and Northern Ireland

Exploring whether there are data available to calculate the measurement using publicly available data for Wales and Northern Ireland.

3.2 Outlining Time to Diagnosis

Of the four case studies, three relate to diagnosis, of which two relate to **access** to a diagnosis, and one relates to the **experience** of a diagnosis. Here, we explore the time to diagnosis for dementia and different sources of delay to a diagnosis.

Figure 2 maps the time to diagnosis from the pathological onset of a disease that causes dementia through to the individual being diagnosed with dementia. In this report, we focus on the diagnosis of the individual's symptoms as dementia, but as treatment options for specific diseases that cause dementia symptoms are developed and become available, diagnosis not only of dementia but the underlying disease that causes the dementia symptoms will become more important. Similar timelines have been created for other diseases, such as cancer (see Hansen et al., 2011). However, the timeline developed here reflects the more complex medical and social factors that are at play with a diagnosis of a disease that causes dementia. Figure 2 is an illustrative example, so the gaps between points do not necessarily represent the time between each of these points, as these will vary for each individual. For example, the point on the timeline where the individual presents to the services with dementia symptoms could be very soon after the individual links their symptoms to dementia or much later on in the diagnostic timeline.

In Figure 2 below, the symptomatic diagnosis period covers the time between the patient having their first dementia symptoms and the patient being diagnosed with a disease that causes dementia. The asymptomatic diagnosis period begins even before dementia symptoms have developed, but biological changes in the diseases that cause dementia may have taken place. The time between dementia pathology onset and the first dementia symptom can be diagnosed using cerebrospinal fluid (CSF) biomarkers, PET brain scanning and MRI brain scanning. There is also promising evidence that in the future, diseases that cause dementia could be diagnosed through blood-based biomarkers (Teunissen et al., 2022).

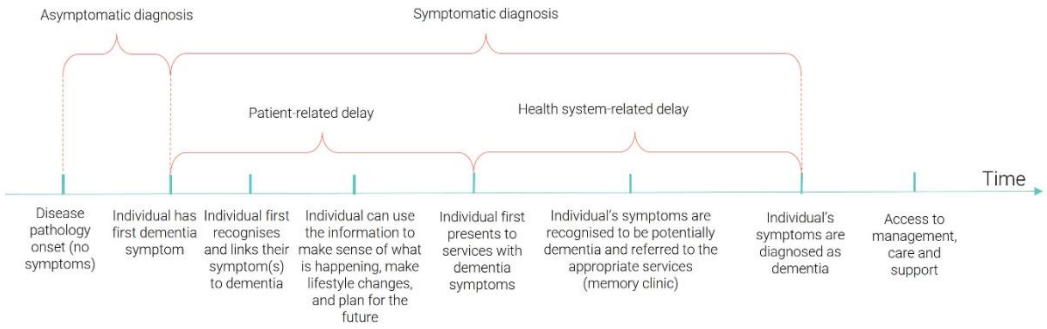
We define 'health system-related delay' to cover any source of delay between the individual first presenting to services and receipt of a diagnosis. However, not all causes of health system-related delays are due to lack of awareness by the healthcare professional, long waiting times or availability of services. Health system delay may also reflect balanced judgements being made by healthcare professionals about the needs of the patient on delivery of a diagnosis, as a diagnosis at the earliest possible opportunity may not necessarily always be better for a person living with dementia. This could be because of the lack of treatment when diagnosed or the emotional distress and anxiety outweighing the benefit of a diagnosis (Dhedhi, Swinglehurst and Russell, 2014) and so some individuals may place a lower value on obtaining a diagnosis of a disease that causes dementia than anticipated by government policy (Henley et al., 2023).

'Patient-related delay' covers any source of delay between the first dementia symptom and the individual first presenting to health services. Some of the causes of this delay may be justified by the individual. However, some causes of delay may be considered unfair and avoidable, such as an individual not having enough information to recognise their symptoms as dementia and potentially attributing the symptoms to other causes (such as ageing) or barriers to a patient accessing services (such as stigma surrounding dementia).

Between the first symptom and the first time an individual recognises the symptom as being linked to dementia, we consider this to be an unjust source of delay (e.g. due to lack of awareness around symptoms). Any delays between the individual recognising a dementia symptom and being able to use the information to make sense of what is happening, make lifestyle changes and plan for the future (i.e. the individual deems it useful to investigate symptoms), may be considered justified by the individual. Barriers resulting in a delay between it being useful for the individual to investigate

symptoms and first presenting to services are considered to be unjust sources of delay (e.g. influence of stigma or fear). Figure 2 aims to capture and summarise the nuanced stages throughout the dementia diagnostic process and immediate follow-up. This figure is a theoretical illustration, regardless of whether it is currently possible to measure these stages quantitatively. This figure is a theoretical illustration, regardless of whether it is currently possible to measure these stages quantitatively. It would be difficult to measure the point at which an individual can use the information to make sense of what is happening and it would be useful to further investigate symptoms (an individual, latent change) separately from the point at which they present to services with symptoms (which we can objectively observe).

FIGURE 2: TIME TO DIAGNOSIS FOR A PERSON LIVING WITH DEMENTIA



In the dementia literature, there is also discussion around the concepts of both 'early' and 'timely' diagnosis. In general, early diagnosis refers to a diagnosis which takes place as early as possible. This could be symptomatic or asymptomatic.

Timely diagnosis of dementia is more nuanced. In the dementia literature, slightly different definitions are proposed for timely diagnosis. One definition is from the time that an individual will first find it useful to or be ready to investigate symptoms, which will be different for each individual (Dhedhi, Swinglehurst and Russell, 2014; Dubois et al., 2016). Another definition considers timely diagnosis from the time when individuals first decide to seek help and present to healthcare services (Dubois et al., 2016). The heterogeneity in definitions of a timely diagnosis illustrates that there is a lack of consensus in the dementia literature on how best to define a timely diagnosis. Furthermore, the definition of a timely diagnosis may be subject to further change in future as treatments develop, and the benefits and costs associated with receiving a diagnosis will also change.

Clinically defined measures such as severity inform us about the delay in diagnosis from disease onset and so align more with the concept of early diagnosis, but the concept of a timely diagnosis is more nuanced, though regularly cited in dementia literature. In the future, as treatment options develop and early intervention becomes more effective, a timely diagnosis will more consistently be one that takes place as early as possible.

3.3 Case study 1: Deprivation and access to diagnosis

Case Study 1 (CS1) explores the healthcare inequality identified in the literature "less access to diagnosis in deprived areas". We therefore need to construct a measure which captures deprivation-related inequality in access to diagnosis.

CS1 key takeaway: The most accurate inequality measure shows no difference in access to diagnosis in more deprived areas. However, these results should be **interpreted with caution** as the measure of access to diagnosis may be overestimated in more deprived areas, and the additional measures we add to the model to take account of dementia risk factors may not be sufficient to correct for this bias.

3.3.1 Relevant evidence about the inequality

Table 13 summarises the evidence we have identified from two sources: relevant results retrieved from the initial literature search (see Appendix 1), and results from an additional targeted search of metrics which quantify deprivation-related inequality in access to diagnosis (note that the new search was not restricted to England, Wales and Northern Ireland).

TABLE 13: EVIDENCE FROM THE LITERATURE ON THE MEASUREMENT OF DEPRIVATION-RELATED INEQUALITIES IN ACCESS TO DIAGNOSIS

Academic Reference	Grey Literature Reference	Health or Health and Social Care Inequalities Observed	How it is Measured/Presented
(Gamble et al., 2022)		People who live in deprived areas are less likely to have a diagnosis of a disease that causes dementia.	Using data from the CFAS I and II study in Wales, where participants of the study are assessed for undiagnosed dementia. Individuals in the study in the most deprived group were **4.34 times more likely to be undiagnosed** than in the least deprived group.
	(Hopson, 2023)	Those from deprived areas less likely to have timely access to a quality diagnosis.	Themes and observations from three roundtable discussions with key stakeholders in the field of dementia care and research. **No quantitative metric presented.**
	(Arblaster, 2021)	(1) Deprivation may present challenges for identifying dementia due to other comorbid conditions taking priority, or less of a support system in areas of high deprivation. (2) Higher levels of deprivation associated with a higher diagnosis rate (the proportion of the estimated dementia population currently with a diagnosis), indicating increased access in more deprived areas.	(1) Engagement with commissioners, memory services, dementia support services and other health and care professionals involved in diagnosis of a disease that causes dementia. **No quantitative metric presented.** (2) References to studies, including their own analysis, showing that higher levels of deprivation were associated with a higher diagnosis rate. One referenced study is Walker, Lord and Farragher, (2017)

	(APPG on Medical Research, 2023)*	The data shows a moderately strong association between estimated dementia diagnosis rates and socioeconomic deprivation, with estimated dementia diagnosis rates generally decreasing as deprivation decreases (suggesting increased access in more deprived areas)	Association between estimated **dementia diagnosis rates and levels of deprivation**
(Walker, Lord and Farragher, 2017)*		Higher levels of deprivation associated with a higher diagnosis rate, suggesting increased access in more deprived areas.	**Diagnosis rates of dementia were 8% higher in the most deprived quintile** of practices in England, compared to the least deprived.
(Connolly A. et al., 2011)*		Higher levels of deprivation associated with a higher diagnosis rate, suggesting increased access in more deprived areas.	Greater levels of socio-economic deprivation were associated with **higher diagnosis rates** in practices in Greater Manchester.

** Additional literature is indicated with an asterisk* next to the reference. CFAS: Cognitive Function and Ageing Study.*

In general, there is mixed empirical evidence on the association between deprivation and access to a diagnosis of a disease that causes dementia. One study which evaluates deprivation-related inequality in access to a dementia diagnosis (which more accurately means diagnosis of a disease that causes dementia) estimates levels of undiagnosed dementia. Measurement of undiagnosed dementia (Gamble et al., 2022) involves individual assessment of participants to determine if they have dementia; however, studies such as these are not regularly carried out on nationally representative samples in England, Wales and Northern Ireland to be able to generate and track this metric over time.

Diagnosis rates provide a measure of the prevalence of dementia within a population, as a proportion of the estimated dementia prevalence within the population. Though most qualitative and anecdotal discussions suggest that there are increased barriers to diagnosis in deprived areas, multiple studies which use diagnosis rates show that there are higher diagnosis rates in deprived areas. This could mean one of two things: (1) the measure is accurate and there is increased access in deprived areas, which could be due to higher morbidity rates in deprived areas, meaning that people access primary care more often and this provides additional opportunities to detect dementia (Arblaster, 2021); or, (2) the use of diagnosis rates to create a measure of deprivation-related inequality in access to diagnosis produces biased estimates or does not fully capture the access to diagnosis picture.

The issues in the estimation of diagnosis rates and limitations of the use of this indicator as a measure of access to diagnosis are further explored later in this case study.

3.3.2 How can we measure the inequality using publicly available data?

We present two measures of deprivation-related inequality that are possible using publicly available data.

3.3.2.1 Data – England

To construct a measure of deprivation-related inequality in access to diagnosis, we need: (1) a measure of access to diagnosis, and (2) a measure of deprivation.

Table 14 summarises the measures of (1) access to diagnosis and (2) deprivation used to estimate the inequality metric and the area-level at which they are available.

TABLE 14: MEASURES OF DEPRIVATION AND ACCESS TO DIAGNOSIS

What we want to measure	Access to diagnosis	Deprivation
What we can use to measure it	Diagnosis rate = $\frac{\textit{Persons with a dementia diagnosis aged 65+}}{\textit{Persons aged 65+ estimated to have dementia given the age/gender characteristics of the population}}$*100%	% of patients living in the most deprived decile
Unit of measurement available	Sub-Integrated Care Board (ICB), annually	Sub-ICB, annually

Access to diagnosis

We use diagnosis rates as an annual, sub-ICB measure of access to diagnosis. The diagnosis rate is equal to the number of individuals aged 65 and over within a population who currently have a diagnosis of a disease that causes dementia, as a percentage of the number of individuals aged 65 and over within the population *who are estimated to currently have dementia*.

Appendix 4 includes more detail on the data sources for diagnosis rates. It is important to note that the numerator is actual, **recorded** diagnoses and the denominator is **estimated** based on the age and sex-specific prevalence rates of the Cognitive Function and Ageing Study II (CFAS, 2023a; Matthews et al., 2013). The appropriateness of this study in estimating prevalence rates, given it is widely used to estimate diagnosis rates, is addressed in later sections on the assessment of these measures.

A higher diagnosis rate indicates better access to diagnosis within a sub-ICB, as more cases in the population are identified.

Deprivation

We use the percentage of patients living in the most deprived neighbourhood as an annual, sub-ICB level measure of deprivation.

Deprivation is measured by the Index of Multiple Deprivation (IMD). The IMD measures relative levels of deprivation in neighbourhoods in England, across different domains of deprivation (income, employment, health, education, crime barriers to housing and living environment), which are combined and weighted to form the IMD. Appendix 5 contains more detail on how this measure is calculated and the data sources used.

A higher percentage of patients living in the most deprived neighbourhood indicates a more deprived sub-ICB.

Risk factors

For the analysis that adjusts for risk factors of dementia, we use data from the Quality and Outcomes Framework (NHS Digital, 2023e) on the prevalence of dementia risk factors, including hypertension, stroke and obesity. For each year in our analysis, the risk factor variables use prevalence data from one year prior. Data on smoking prevalence was not collected during 2020, so for comparability of results over time, was not included in the regression analysis in this report. Data on depression prevalence was excluded from the analysis due to multicollinearity. Additionally, we control for rurality, measured by the percentage of patients living in a rural area in April of each year of data (details on how this measure is created can be found in Appendix 6).

Using these data, we implement two methods to construct measures of deprivation-related inequality in access to diagnosis: the Deprivation Gap and the Concentration Index.

3.3.2.2 Method 1: Deprivation Gap

We can calculate the 'deprivation gap' as an indicator of the gap in diagnosis rates between the most and least deprived sub-ICBs. To do this, we calculate the average diagnosis rate in the most deprived 20% of English sub-ICBs. We then calculate the average diagnosis rate for the least deprived 20% of English sub-ICBs. The difference between these two averages is equal to the diagnosis rate 'deprivation gap'. This measure is unadjusted for other risk factors.

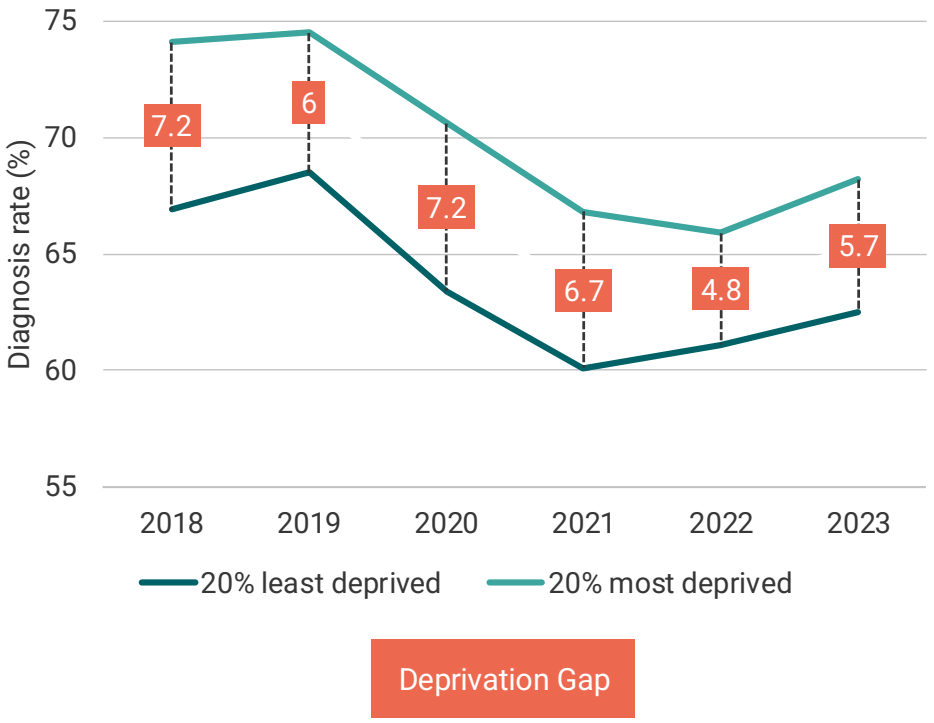
3.3.2.3 Results 1: Deprivation Gap

Summary of results (Deprivation Gap): The 'deprivation gap' measure indicates **better** access to diagnosis in **more** deprived areas, using diagnosis rates as a measure of access. However, there are concerns over bias with this measure which are explored in the following sections.

Figure 3 plots the average diagnosis in the 20% most deprived sub-ICBs and the 20% least deprived sub-ICBs between 2018 and 2023, and the deprivation gap (the difference between the two groups).

Diagnosis rates are higher in the most deprived sub-ICBs. A deprivation gap of 5.7 indicates that diagnosis rates are 5.7 percentage points higher in the most deprived group, compared to the least deprived group. This relationship of higher diagnosis rates in more deprived areas is consistent with other studies (Walker, Lord and Farragher, 2017; Connolly A. et al., 2011).

FIGURE 3: AVERAGE DIAGNOSIS RATES IN THE 20% MOST AND LEAST DEPRIVED GROUPS



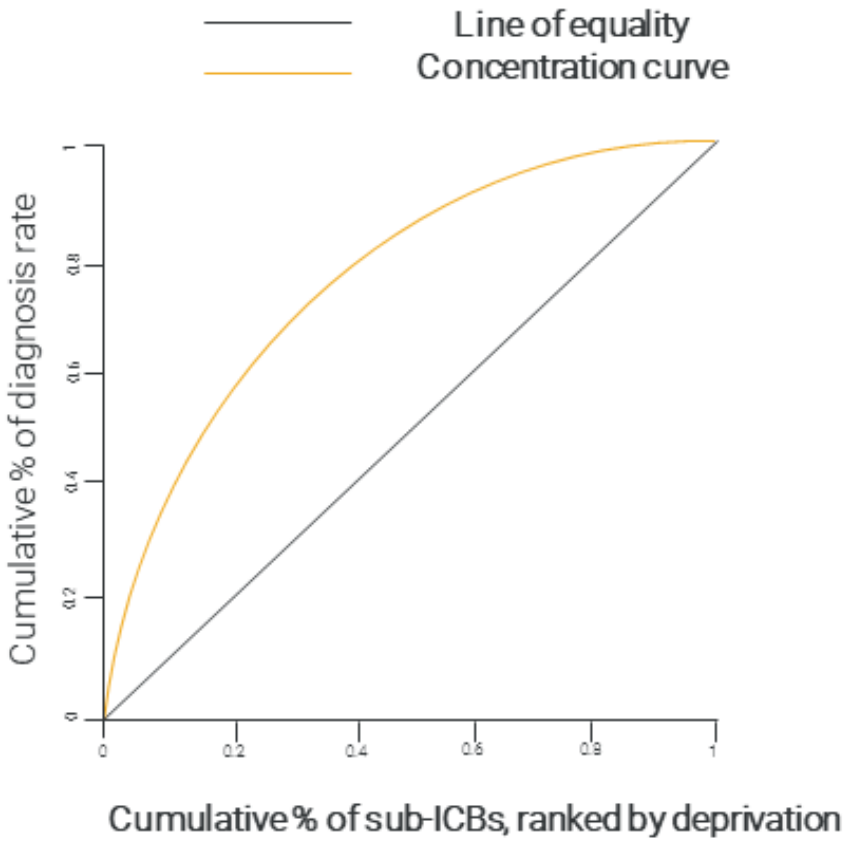
3.3.2.4 Method 2: Concentration Index

A concentration index measures the extent to which a variable (such as diagnosis rates) is distributed disproportionately across different segments of the population (less or more deprived areas). Therefore, with this measure, we are able to estimate the degree of inequality in diagnosis rates across areas in terms of their deprivation, over time, and adjust for additional factors that may be affecting different diagnosis rates (such as dementia risk factors).

Concentration indices are frequently used in the literature to measure health-related inequalities (see, for example, Wagstaff (2000); Wagstaff, Van Doorslaer and Watanabe (2001); Gwatkin et al. (2007); van Doorslaer et al. (1997)). A concentration index improves on the deprivation gap measure in three main ways: it takes into account the entire distribution of the population (not just differences between the top and bottom groups); it gives a measure of the intensity of the inequality; and it is easily comparable across different contexts.

The clearest way to illustrate the value of a concentration index is with a concentration curve, shown in Figure 4 To create the concentration curve, the cumulative percentage of sub-ICBs, ranked by deprivation, is compared against the cumulative percentage of the diagnosis rate. The concentration index is equal to twice the area between the curve and the 45-degree line.

FIGURE 4: CONCENTRATION CURVE TO ILLUSTRATE DEPRIVATION-RELATED CONCENTRATION INDEX



The concentration index provides a value between 0 (no inequality) and 1 (high diagnosis rates completely concentrated in the most deprived areas) or -1 (high diagnosis rates completely concentrated in the least deprived areas). Visually (see Figure 4), a concentration index of 0 is

provided when both the 45 degrees line and the curve overlap (and therefore there is no inequality); and there is full inequality if the concentration curve takes the shape of a triangle, giving 100% of the diagnosis rate to the most deprived (index of 1) or least deprived (index of -1).

We estimate the concentration index using Ordinary Least Squares (OLS) regression analysis. We run two models: 'unadjusted' (i.e., not including any control in the analysis), and 'adjusted' (i.e., including controls for the dementia risk factors outlined in data sections). 'Adjusted' results are expected to represent more accurately differences in access to a diagnosis (rather than differences in risk factors). A comparison of 'unadjusted' and 'adjusted' results is informative, in the sense that we can identify how important the controls are, and in which direction the unadjusted model may be biased See Appendix 7 for more detail on the calculation of the deprivation concentration index measure.

3.3.2.5 Results 2: Concentration Index

Summary of results (Concentration Index): The adjusted concentration index measure suggests that people living with dementia in **more deprived** areas are **not** less likely to have access to a diagnosis. This result should be interpreted with caution, as the measure of access to diagnosis is likely to be overestimated in more deprived areas, and the adjusted model may not sufficiently capture the relevant risk factors for dementia to remove this bias.

Unadjusted results

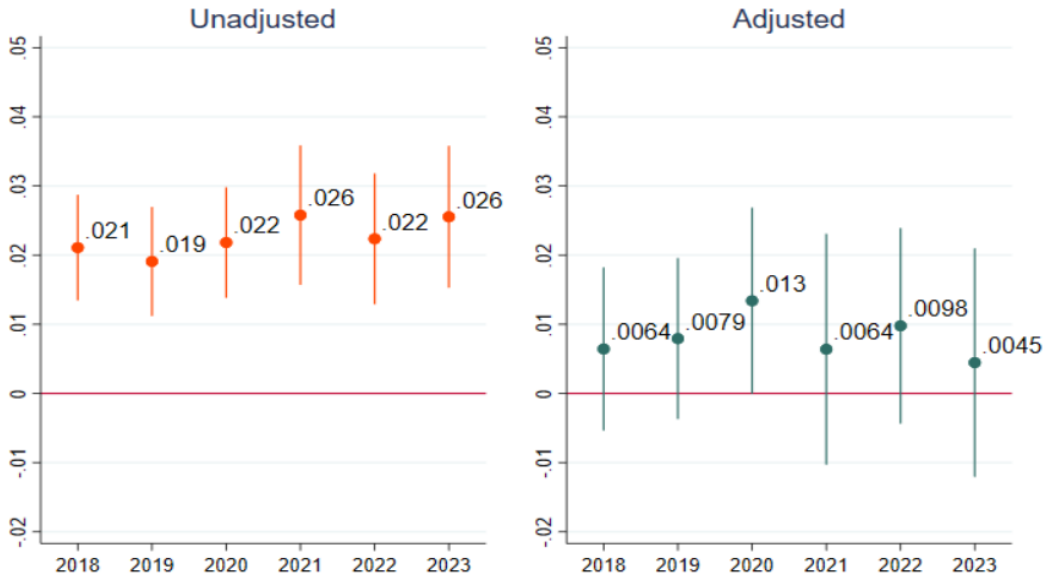
The unadjusted analysis again shows that higher diagnosis rates are more concentrated in deprived areas. For example, a deprivation-related concentration index of 0.026 in 2023 indicates that high diagnosis rates are slightly more concentrated in more deprived areas (see Figure 5, 'Unadjusted'). This result is consistent with studies which evaluate diagnosis rates in deprived areas and may indicate increased access to diagnosis of a disease that causes dementia in more deprived areas. Potential reasons for this could be that there is higher morbidity of chronic conditions in deprived areas, so individuals in deprived areas interact with health services more frequently and are more likely to be diagnosed (Connolly A. et al., 2011; Watt, Raymond and Rachet-Jacquet, 2022). However, this result is inconsistent with an individual-level study which finds that deprivation is associated with an increased likelihood of undiagnosed dementia (Gamble et al., 2022). The study by Gamble et al. (2022) identifies undiagnosed dementia as study participants in the CFAS Wales study (CFAS, 2023b) are assessed for dementia, and this is compared to whether they have a clinical, recorded, diagnosis. In comparison, our study uses an imperfect, estimated, area-level measure to capture undiagnosed dementia in the English population, by applying the estimates of dementia prevalence from the sample of the CFAS II study to the English population. The unadjusted results are also inconsistent with qualitative and anecdotal evidence that there are more barriers to access of a diagnosis in more deprived areas (Hopson, 2023; Arblaster, 2021).

The unadjusted concentration index measure of deprivation-related inequality shows slight fluctuations, but is generally stable over time, ranging between 0.019 and 0.026.

Adjusted results

Once the concentration indices are adjusted for both sub-ICB deprivation, and dementia risk factors (i.e., the adjusted analysis), the estimated concentration index is much smaller (between 0.0045 and 0.013), and 95% confidence interval includes zero, that is, the estimated concentration index is not statistically significantly different from zero – and, therefore, no deprivation-related inequality is detected in access to diagnosis.

FIGURE 5: DEPRIVATION CONCENTRATION INDICES OVER TIME (REGRESSION COEFFICIENT PLOTS)



The coefficient estimate is indicated with a circular marker, the vertical lines indicate the 95% confidence interval. The red horizontal line indicates 0. Adjusted concentration indices control for rurality, diabetes prevalence, hypertension prevalence, stroke prevalence and obesity prevalence. See Appendix 8 Table A7: Deprivation concentration indices over time (regression coefficients) for the full table of coefficients and confidence intervals.

3.3.3 Are the Measures Valid?

Summary of validity: The main challenge behind the use of unadjusted diagnosis rates is that the diagnosis rates ('estimated dementia prevalence') are only based on the *age* and *gender* of the population; therefore, they do not account for higher risk factors of diseases that cause dementia in more deprived populations. As a consequence, diagnosis rates may be overestimated in deprived areas.

The data we use to adjust for dementia risk factors in an area may not adequately remove this bias. Therefore, this measure should not be used as evidence that there is no inequality in access to a diagnosis in more deprived areas, without access to better data to improve the measure.

Our results are in line with other studies which compare estimated dementia diagnosis rates with deprivation, using the same diagnosis rate data (APPG on Medical Research, 2023)

Diagnosis rates may be biased due to limitations with the methods and data used to estimate dementia prevalence within the sub-ICB. Firstly, the estimated population with dementia is derived from the CFAS II study, which has not been updated since 2011. Secondly, the population with dementia is estimated only taking into account age and gender. Therefore, diagnosis rates may be overestimated in deprived areas (and underestimated in less deprived areas).

In the analysis where we adjust for dementia risk factors (diabetes, hypertension, stroke, obesity prevalence) and rurality of the patients within the sub-ICBs, the concentration index measure no longer detects deprivation-related inequality in any year of data. This suggests that accounting for

the presence of increased dementia risk factors in deprived areas may reduce some of the bias in comparing diagnosis rates between areas of varying deprivation levels and that the unadjusted measure is upwardly biased. It is worth noting that we repeated the analysis for this case study using only the income deprivation index, and the results are similar to those retrieved by using the overall deprivation index (see Appendix 9).

An accurate metric of deprivation-related inequality in access to diagnosis should guarantee that all dementia risk factors which determine prevalence have been comprehensively adjusted for. Although the prevalence indicators account for dementia risk factors to some degree, these variables do not account for all relevant dementia risk factors of the individuals in the population and only account for a crude measure of risk factors as sub-ICB-level prevalence of certain conditions in the year prior (rather than individual-specific risk factors prior to a diagnosis).

3.3.5 Recommendations (across England, Wales, NI)

3.3.5.1 How could the Publicly Available Measures be Improved?

Improvements to estimated diagnoses of diseases that cause dementia used to estimate the diagnosis rate would improve the quality of the analysis that uses diagnosis rates as a measure of access to diagnosis. The prevalence study which is used to inform NHS-published dementia diagnosis rates, the CFAS II study, is outdated. More recent prevalence studies have been published after the time our evidence review was completed (see Alzheimer's Society, 2024). The application of studies showing updated prevalence estimates for different geographical areas of the UK (or individual data) would improve the accuracy of the diagnosis rate measure. Furthermore, only age and sex are used to estimate dementia prevalence at the sub-ICB level, which raises questions about the most appropriate method to translate the data from the CFAS II study to the local level. Any future studies should examine other characteristics (such as ethnicity), which would be useful to give a more complete estimate of inequalities.

In addition, more granular data by dementia type would allow for greater exploration of the inequalities in access to diagnosis and improvements that need to be made for different types of dementia. Future data collection could also include people with young-onset dementia (individuals with dementia under the age of 65).

3.3.5.2 How could Measures be Improved using Unpublished, but Existing Data?

Measurement of the inequality could be improved with access to richer, individual-level datasets. Individual-level data on deprivation would improve the measure, as area-level data may mask inequalities within the same area. Example datasets include Clinical Practice Research Datalink (CPRD) (CPRD, 2023), Hospital Episode Statistics (HES) or The Health Improvement Network (THIN) (THIN, 2023), where detailed patient information would be available, and provide information on individual dementia-risk factors. Data on the severity of dementia at the point of diagnosis would be an informative indicator of an 'early' diagnosis. Data on waiting time after first presenting to services until receiving a diagnosis would provide information on the health-system delay.

3.3.5.3 Are there data which currently do not exist which would improve the measurement of this inequality?

Alternative measures of access to a diagnosis could improve the measurement of this inequality in England, Wales and Northern Ireland. There is currently no waiting time data which is either published or can be derived from administrative datasets, which would be able to identify the point in which the patient would first find it useful or be ready to investigate symptoms further. This is due to the highly individual nature of this stage. However, survey data provided by people living with dementia, informal carers or family members could potentially be useful in deriving data on the

timing of a diagnosis at the right time for the individual by exploring questions such as "did you feel there were avoidable delays in receiving a dementia diagnosis". Furthermore, more detailed data on the severity at diagnosis or age at diagnosis would be useful to capture how early the individual received a diagnosis.

3.4 Case Study 2: Rurality and Access to Diagnosis

Case Study 2 (CS2) explores the healthcare inequality "less access to diagnosis in rural areas, compared to non-rural areas". For that purpose, we construct a measure which captures rurality-related inequality in access to diagnosis.

CS2 key takeaway: All our rurality inequality measures show the existence of **lower access to diagnosis** in **more rural** areas compared to less rural areas.

3.4.1 Relevant evidence about the inequality

Table 15 summarises the evidence we have identified from two sources: relevant results retrieved from the initial literature search (see Appendix 1), and results from an additional targeted search of metrics which quantify rurality-related inequality in access to diagnosis (note that the new search includes evidence from any country and was not restricted to England, Wales and Northern Ireland).

TABLE 15: EVIDENCE FROM THE LITERATURE ON THE MEASUREMENT OF RURALITY-RELATED INEQUALITIES IN ACCESS TO DIAGNOSIS

Academic Reference	Grey Literature Reference	Health or Health and Social Care Inequalities Observed	How it is Measured/Presented
	(Slogget, 2022)	(1) Less access to timely diagnosis in rural areas compared to non-rural areas (2) Access to diagnostic equipment is not equitably distributed across the country	(1) 82% of CCGs in England in the upper quintile of **undiagnosed dementia** have above average rurality (2) Reference to the National Memory Services Audit
	(Hopson, 2023)	(1) Less access to timely diagnosis in rural areas compared to non-rural areas (2) Geographical variation in the delivery of memory assessment services.	(1) Roundtable discussion from experts in England, Wales and Northern Ireland. 'Variation in diagnosis rates' (2) Roundtable discussion.
	(Arblaster, 2021)	People living in rural communities may find it harder to access to services involved in diagnosis, such as GP practices or memory services	CCGs in urban areas had **a higher diagnosis rate**. Those situated in rural areas tended to have a lower diagnosis rate.
(Rahman et al., 2021)*		Dementia underdiagnosis in rural communities compared to urban	US study using Medicare claims data. **Risk adjusted diagnostic incidence** was higher in urban areas despite lower prevalence
(Wackerbarth and Johnson, 2002)*		More barriers to access for caregivers seeking memory assessments in rural areas	**Barriers to assessment score** constructed from survey data from 2 (urban and rural) clinics in the US.

			Higher barriers score reported for the rural clinic.
(Antonelli Incalzi et al., 1992)*		Rurality associated with later stage diagnosis	Study of 18 dementia patients in Italy. Rural residence significantly correlated with **later stage diagnosis**

** Additional literature is indicated with an asterisk* next to the reference. CCGs: Clinical Commissioning Groups*

In general, measures which quantify inequalities in access to diagnosis related to rurality include measures of undiagnosed dementia, risk-adjusted incidence compared to prevalence, creation of a barrier to diagnosis score (using survey data), and assessment of levels of later-stage diagnosis.

Some reports referenced timely diagnosis. However, the measures used in the reports relating to undiagnosed dementia (Slogget, 2022; Hopson, 2023) are unable to capture the timeliness of diagnosis (see Figure 2).

In addition, one study did not provide any quantitative evidence but referenced anecdotal evidence from expert roundtable discussions (Hopson, 2023). Studies in other countries (Rahman et al., 2021; Wackerbarth and Johnson, 2002; Antonelli Incalzi et al., 1992) used single datasets specific to that study, and so these measures cannot be used to track the inequality overtime.

3.4.2 How can we measure the inequality using publicly available data?

We present two measures of rurality-related inequality that are possible using publicly available data.

3.4.2.1 Data – England

To construct a measure of rurality-related inequality in access to diagnosis, we need: (1) a measure of access to diagnosis, and (2) a measure of rurality.

Table 16 summarises the measures of (1) access to diagnosis and (2) rurality used to estimate the rurality-related inequality metric and the area-level at which they are available.

TABLE 16: MEASURES OF RURALITY AND ACCESS TO DIAGNOSIS OF A DISEASE THAT CAUSES DEMENTIA

What we want to measure	Access to diagnosis	Rurality
What we can use to measure it	Diagnosis rate = $\frac{\textit{Persons with a dementia diagnosis}}{\textit{Persons estimated to have dementia given the age/gender characteristics of the population}}$ *100%	% of patients living in a rural area
Unit of measurement available	Sub-Integrated Care Board (ICB), annually	Sub-ICB, annually

Access to diagnosis

As in Case Study 1 (CS1), we use annual diagnosis rates at the sub-ICB level as a proxy measure of access to diagnosis. A higher diagnosis rate reflects increased access to diagnosis. For further details on the calculation of the diagnosis rate, see Appendix 4.

Rurality

We use the percentage of patients living in a rural area, as an annual, sub-ICB level measure of rurality. The most rural sub-ICB is the one with the highest percentage of registered patients living in a rural neighbourhood. See Appendix 6 for more detail on how the rurality measure was created.

Risk factors

For the risk-adjusted analysis that we carry out, we again use the Quality and Outcomes Framework prevalence data on dementia risk factors (NHS Digital, 2023e) including stroke, diabetes, obesity, depression, and hypertension. For each year in our analysis, the risk factor variables are prevalence indicators for the previous year. Additionally, we control for deprivation, using the % of patients in the most deprived decile measure (see Appendix 5 for more detail). Using these data, we can again construct two measures of access to diagnosis: the rurality gap, and a concentration index.

3.4.2.2 Method 1: Rurality Gap

The first method is to calculate the 'rurality gap' as an indicator of the gap in diagnosis rates between the sub-ICBs with the most and least patients living in a rural area.

To do this, we calculate the average diagnosis rate in 20% of sub-ICBs with the most rural patients. We then calculate the average diagnosis rate for the 20% of sub-ICBs with the least rural patients. The difference between these two averages is equal to the diagnosis rate rurality gap and provides a measure of the difference in diagnosis rates between the 20% of sub-ICBS with most and least patients living in rural areas.

This measure is not adjusted for risk factors.

3.4.2.3 Results 1: Rurality Gap

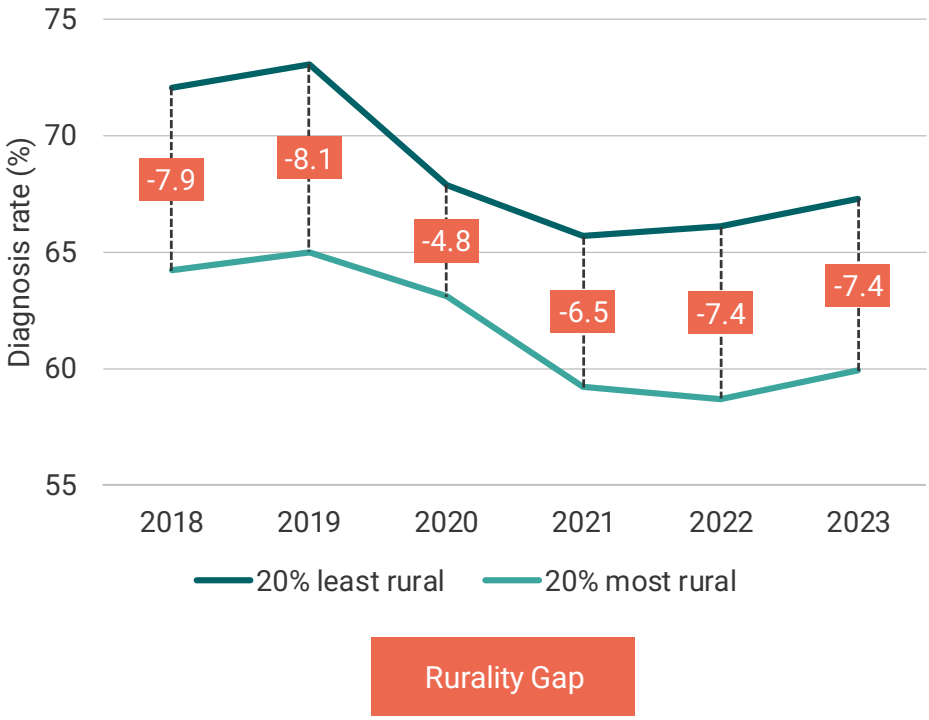
Summary of results (Rurality Gap): The rurality gap measure indicates the existence of **lower** access to diagnosis in **more** rural areas, using diagnosis rates as a measure of access. However, this measure does not account for different risk factors of dementia in rural vs urban populations, and therefore may underestimate or overestimate the true rurality gap.

Figure 6 plots the average diagnosis rates in the 20% of ICBs with the most patients living in rural areas and the 20% of sub-ICBs with the least patients living in rural areas between 2018 and 2023, and the rurality gap (the difference between the two groups).

Diagnosis rates are lower in the ICBs with the most rural patients. A rurality gap of -7.4 indicates that diagnosis rates are 7.4 percentage points lower in the most rural group, compared to the least rural group.

The rurality gap decreased with the onset of the pandemic, as diagnosis rates dropped more for the least rural group than for the most rural group. Furthermore, the diagnosis gap has remained stable over the last two years, at a rate similar to pre-pandemic levels.

FIGURE 6: AVERAGE DIAGNOSIS RATES IN THE 20% MOST AND LEAST RURAL GROUPS



3.4.2.4 Method 2: Concentration Index

Rurality-related inequality in access to diagnosis can also be estimated using a concentration index. For rurality, the concentration index will measure the extent to which diagnosis rates are distributed disproportionately across less or more rural areas. The benefits of using this measure are the same as for the previous case study (see section 3.3.2.4 for more details).

Using regression analysis, we can additionally control for the dementia risk factors outlined in the Data section above (i.e., the adjusted analysis), so that the diagnosis rate inequality measure more accurately represents differences in access to a diagnosis (rather than differences in risk factors).

The concentration index will provide a value between 0 (no rurality-related inequality) and 1 (high diagnosis rates completely concentrated in the most rural areas in terms of the patient population) or -1 (high diagnosis rates completely concentrated in the least rural areas).

The specific research objective using this method is to estimate the concentration index, to measure the degree of inequality in diagnosis rates across areas in terms of their rurality, over time.

See Appendix 10 for more details on the estimation of the rurality concentration index measure.

3.4.2.5 Results 2: Concentration Index

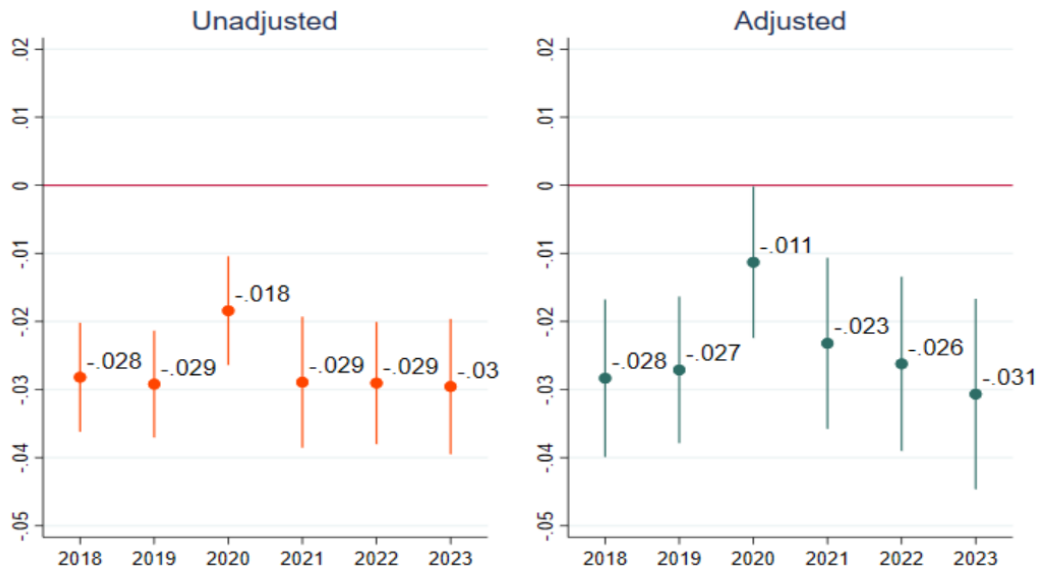
Summary of results (Concentration Index): Access to diagnosis is **lower** in areas with **more patients living in a rural area,** even after taking into account the dementia risk factors within the patient population.

In the unadjusted analysis, the concentration index of -0.03 in 2023 (Figure 7) represents that low diagnosis rates are slightly more concentrated in sub-ICBs with more patients living in rural LSOAs; however, the size of the inequality is small.

The adjusted analysis shows that the concentration index is robust to the inclusion of dementia-risk factors and supports the unadjusted analysis of a small degree of rurality-related inequality in access to diagnosis, with low diagnosis rates being slightly more concentrated in sub-ICBs with more patients living in rural areas.

The interpretation of this result is that there is a larger undiagnosed population in rural areas than in urban areas, indicating poorer access to a diagnosis in these areas. This relationship is found in the most robust estimate which accounts for dementia risk factors in the patient population.

FIGURE 7: RURALITY CONCENTRATION INDICES, OVER TIME (REGRESSION COEFFICIENTS)



The coefficient estimate is indicated with a circular marker, the vertical lines indicate the 95% confidence interval. The red horizontal line indicates 0. Adjusted concentration indices control for deprivation, diabetes prevalence hypertension prevalence, stroke prevalence, obesity prevalence and depression prevalence. See Appendix 8 Table A8: RURALITY CONCENTRATION INDICES, OVER TIME (REGRESSION COEFFICIENTS) for the full table of coefficients and confidence intervals.

3.4.3 Are the Measures Valid?

Summary of validity: The rurality measures may also be subject to bias, as the diagnosis rate measure of access to diagnosis does not take into account rurality when estimating dementia prevalence. However, we still find similar results when taking account of the dementia risk factors within the area. Furthermore, given the potential direction of the bias, our estimates may even underestimate the true level of inequality.

This measure may also be subject to bias due to the relationship between rurality and dementia risk factors (as was the case in CS1); however, adjusting the concentration index analysis for the dementia risk factors using available data shows that the size, direction, and statistical significance of the concentration index effect is consistent even after controlling for these variables. This provides reassurance in the use of diagnosis rates to measure this inequality. Furthermore, if this

measure suffers from bias due to estimated dementia prevalence (the denominator of the diagnosis rate) being underestimated in more rural areas and overestimated in less rural areas, and the dementia risk factors do not adequately control for this, then the concentration index measure would be upwardly biased. Therefore, the true effect may be an even more negative estimate of the concentration index, such that there is even more inequality than the measure identifies (but the direction of the inequality is the same).

This case study illustrates that rurality-related inequality in access to diagnosis can be measured in England using publicly available data. Furthermore, the data sources used to construct the measure are regularly updated and so can be tracked going forward.

3.4.5 Recommendations (across England, Wales, NI)

The recommendations for improving the measurement of rurality-related inequalities in access to diagnosis are mainly focused on improvements to the measurement of stages along the time to diagnosis (i.e. a diagnosis made at the right time for the individual), and hence are repeated from the previous case study (Section 3.3.5).

3.5 Case Study 3: Ethnicity and Experience of Diagnosis

Case Study 3 (CS3) explores differences in experience of diagnosis by ethnic group. In particular, we focus on the healthcare inequality identified in the literature related to lower diagnosis rates identified for Asian, Black and other ethnic minority groups, compared to White people living with dementia.

CS3 key takeaway: Publicly available data sources provide unreliable estimates of ethnicity-related inequality in experience of diagnosis, due to data quality and availability issues.

3.5.1 Relevant evidence about the inequality

Table 17 summarises the evidence we have identified from two sources: relevant results retrieved from the initial literature search (see Appendix 1), and results from an additional targeted search of metrics which quantify the inequalities related to ethnicity and experience of diagnosis (note that the new search was not restricted to England, Wales and Northern Ireland).

TABLE 17: EVIDENCE FROM THE LITERATURE ON THE MEASUREMENT OF ETHNICITY-RELATED INEQUALITIES IN EXPERIENCE TO DIAGNOSIS

Academic Reference	Grey Literature Reference	Health or Health and Social Care Inequalities Observed	How it is Measured/Presented
(Chithiramohan T. et al., 2023)		Lower diagnosis rates for dementia in Asian and Black patients, compared to White patients.	**The diagnosis rate** for dementia in White patients was 90.4%, compared to 61.6% of Asian patients and 74.3% of Black patients
	(Fenton, 2016)	People from ethnic minority groups are less likely to receive a diagnosis of a disease that causes dementia for a number of reasons such as difficulties in accessing health services, poorer understanding and	Anecdotal, **no quantitative metric**

		awareness of dementia, stigma may be greater in some communities.	
(Pham T.M. et al., 2018)		Compared with the White ethnic group, Asian men and women were less likely to have a new diagnosis of a disease that causes dementia. Black men with dementia were less likely to receive a diagnosis compared to White men.	Using primary care electronic health records from THIN database. Based on diagnosis incidence in the THIN data and projections of incidence from community cohort studies (CFAS II) **diagnosis rates based on incidence** were estimated. The metric did not allow for it to be determined if differences observed were due to lower incidence in the populations or underdiagnosis.
(Dodd E. et al., 2022)		Some areas of diagnostic service provision show evidence of inequality.	30 cases referred to a dementia service from BAME groups, matched to White British group. **Likelihood of receiving services compared between the groups**. People from BAME communities less likely to receive a cognitive assessment, and equally likely to have a CT scan.
(Baghirathan S. et al., 2020)		People from many BAME communities experience dementia in a markedly different way to their White British counterparts.	**Qualitative interviews** with 27 participants and eight focus groups. Additional interviews with 16 staff and volunteers working for dementia organisations. An emerging theme was identified that participants feared 'diminishment' from the provision of services that did not meet their cultural needs.
(Mukadam et al., 2011)*		Minority ethnic carer beliefs were an important barrier to early diagnosis.	**Qualitative interviews** with 18 UK family carers from different ethnic groups. Interview responses suggest that minority ethnic carers in contrast to the indigenous population, tended to delay help-seeking until they could not cope or others commented on the problems.

** Additional literature is indicated with an asterisk* next to the reference. CFAS: Cognitive Function and Ageing Study. THIN: The Health Improvement Network.*

This search identified two possible quantitative metrics for comparing the experience of a diagnosis (other studies identified the inequality from qualitative interviews or anecdotal evidence). The first quantitative measure of the inequality was differences in the likelihood of receiving a service, between ethnic groups (Dodd E. et al., 2022). In that study, participants were matched between ethnic groups based on age and gender only. As no further clinical data on the diagnosis of a disease that causes dementia were used to match the individuals, a limitation of this measure is that we cannot know whether the differences identified are due to inequalities in experience of diagnosis, or to differences in need between the populations that are compared. Furthermore, this study includes a very small sample size, which makes it more difficult to map its findings to the general population.

Diagnosis rates are also discussed in the context of differential experiences of diagnosis in Chithiramohan T. et al. (2023). Similarly, Pham T.M. et al. (2018) examined differences in the estimated percentage of the population developing dementia who were diagnosed, between ethnic groups. This measure is effectively the diagnosis rate, introduced in the previous case studies. However, the diagnosis rate is estimated based on incidence, i.e., new cases, whereas the previous

case studies evaluated diagnosis rates based on prevalence, i.e., total number of cases. The study only evaluates differences in diagnosis rates for 2015, and, again, relies on data from the CFAS II study from the same year.

3.5.2 How can we measure the inequality using publicly available data?

Overall, for this inequality, we seek to capture whether there are differences in the experiences of diagnosis for different ethnic groups. One way to do this would be to explore the evidence that diagnosis rates differ for different ethnic groups.

We are not able to present differences in diagnosis rates for different ethnic groups due to a lack of publicly available data sources. In addition, the ethnicity data that are currently published in England are poorly reported. This means that the results presented in this case study should be interpreted with extreme caution and mainly serve to highlight the current issues in the recording of published ethnicity data for dementia in England.

As the diagnosis rates (proportion of the expected dementia population with a diagnosis) are not regularly published by ethnic group in England, Wales, or Northern Ireland, it is only possible to estimate an approximate measure of dementia prevalence (proportion of the population with a diagnosis) by ethnic group, over time, by sub-ICB in England.

Note that, although this case study considers 'experience' as opposed to 'access', there is overlap in the measures outlined for experience and access. Whether someone with dementia receives a diagnosis is a function of their access and their experience once they present to the health service. This means that our measures of access in CS1 and CS2 will also capture elements of the experience of a diagnosis, and vice versa.

3.5.2.1 Data – England

Dementia prevalence

In NHS England data, prevalence is presented as the number of recorded dementia cases for those aged 65 and over as a proportion of the total number of individuals in a population aged 65 and over. By ethnic group, there is data available on the number of diagnoses, over time, by sub-ICB (although there are data quality issues with this reported data) (NHS Digital, 2023d). However, data is not available on the total number of individuals in a population aged 65 and over time, by ethnic group. We can however use data from the 2021 census on the number of people of all ages by ethnic group, at the sub-ICB level (Office for National Statistics, 2021).

Risk factors

We adjust for sub-ICB level covariates (as outlined in the previous case studies) of dementia risk factors (Quality and Outcomes Framework (QOF) prevalence data), deprivation, and rurality. Additionally, we control for the age and gender composition within a sub-ICB, using NHS digital data on patients registered at a GP practice (NHS Digital, 2023b). We did not previously control for age and gender in the analyses which examined diagnosis rates, as the age and gender of the population were implicitly accounted for in the calculation of the diagnosis rate. It is worth noting that although we can adjust for these sub-ICB-level covariates, these are for *all* patients within a sub-ICB, and are not available separately by ethnic group.

3.5.2.2 Methods

We will compare dementia prevalence per 1,000 in the population, comparing the prevalence in each minority ethnic group (Asian or Asian British, Black or African or Caribbean or Black British, Mixed or Multiple Ethic Groups) to that in the White ethnic group. For brevity, we will refer to these groups as Asian, Black, Mixed and White.

We use OLS regression analysis to estimate the differences in prevalence rates between groups, estimated for each year, separately. Excluding the dementia risk factor variables from the regression produces the unadjusted estimates, and including produces the adjusted estimates. See Appendix 11 for more detail on the methods used.

3.5.2.3 Results

Summary of results: Results show that dementia prevalence is lower for the Black, Asian and Mixed ethnic groups compared to the White ethnic group. The results are unaffected by adjusting for overall dementia risk factors in the area (across all ethnic groups). There is a large issue with missing data which is likely to affect these results.

Figure 8 shows the average number of diagnoses by ethnic group. This table highlights the main drawback in CS3, which is a large number of missing data: the largest category of recorded diagnoses on average is the group 'not defined'.

Furthermore, there may be systematic bias in the categories which have non-White ethnicity reported (see for instance Saunders et al., 2013), and in the not-stated category (Dembosky et al., 2019).

FIGURE 8: AVERAGE TOTAL NUMBER OF RECORDED DIAGNOSES IN A SUB-ICB BY ETHNIC GROUP, ACROSS ALL YEARS OF DATA, INCLUDING UNDEFINED CATEGORIES

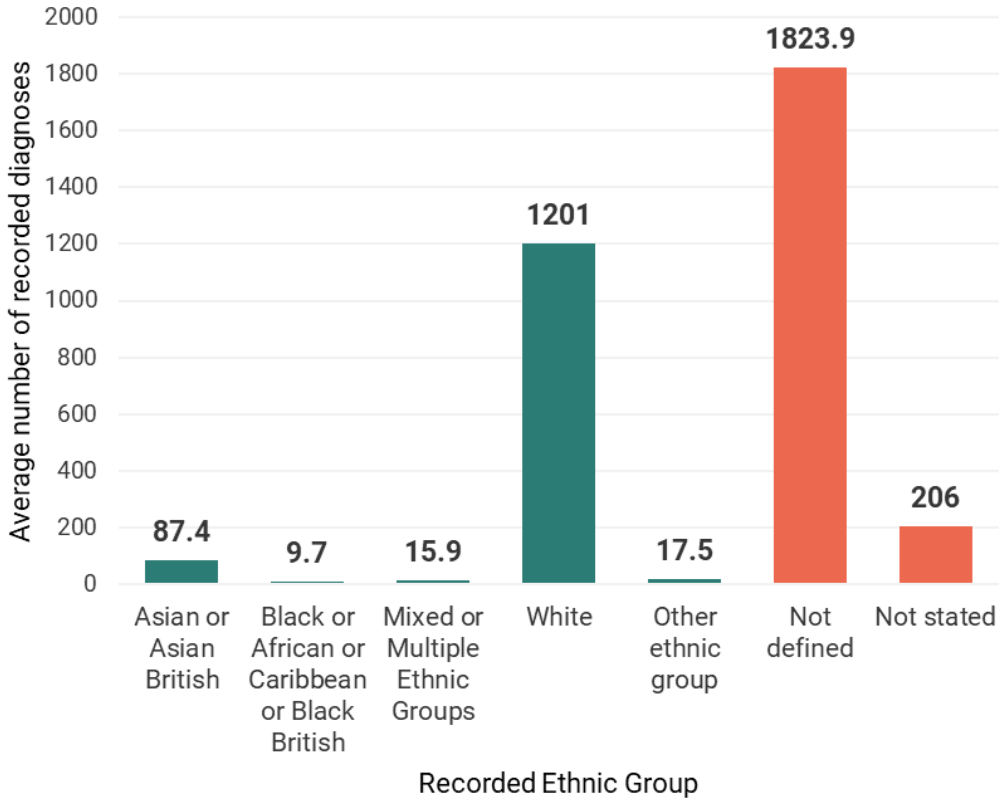


Figure 9 shows differences in prevalence rates per 1,000 of the population between ethnicity groups over time. It shows that prevalence is highest in the White ethnic group, and lowest in the Black ethnic group in all years except 2023, where the Mixed ethnic group is the lowest. Prevalence rates appear low for two main reasons:

Firstly, the numerator (number of diagnoses) is subject to a large issue with missing data, and therefore prevalence rates are underreported within each ethnic group. Without further evidence, we cannot know if there is more underreporting in some groups compared to others.

Secondly, as census population data for sub-ICBs is not available by both age and ethnicity, the denominator is the count of individuals by ethnic group for the entire population (not just the adult population or those over 65). Furthermore, the denominator is fixed for the year 2021. Therefore, prevalence rates in years other than 2021 are subject to additional bias.

The white population estimates of prevalence (4.6 per 1,000 in 2023) are reasonably similar to QOF dementia prevalence (all ages) figures reported by OHID (7 per 1,000 of the total registered population in 2021/22) (Office for National Statistics, 2021). However, for the Black ethnic group, the estimate remains close to zero for most of the study period, while other studies show a higher prevalence and incidence of dementia in the Black population in England (Pham T.M. et al., 2018; Mukadam et al., 2023). This suggests that the missing data issue may be of greater concern for minority ethnic groups compared to the White ethnic group, as it may introduce bias in comparisons across groups. There have been increased incentives to report ethnicity data in primary care in recent

years (Lind, 2021), which is a likely explanation for the sharp uptick in dementia prevalence in later years in Figure 9 rather than a sudden increase in dementia prevalence.

FIGURE 9: GRAPH OF UNADJUSTED DEMENTIA PREVALENCE PER 1,000 OF THE POPULATION, BY ETHNIC GROUP, OVER TIME

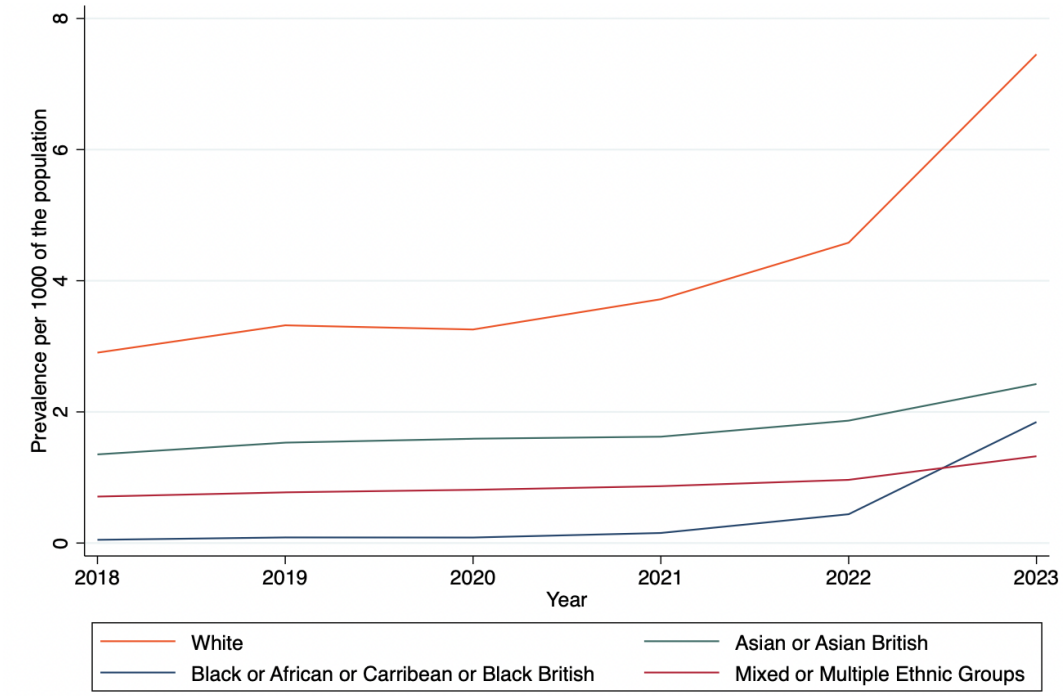
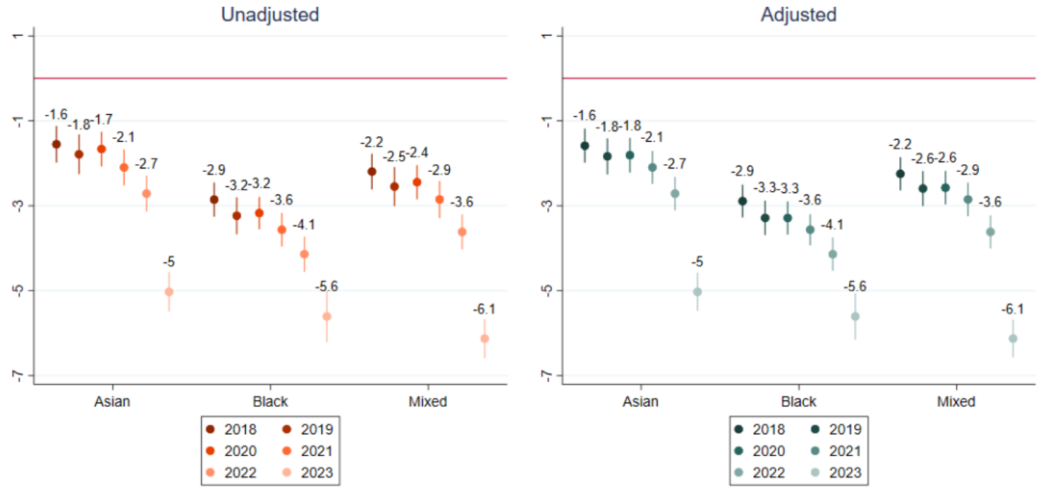


Figure 10 shows, for each ethnic group, in each year, the estimated difference in prevalence rates between the indicated ethnic group and the White ethnic group. For each ethnic group the figure displays the unadjusted differences in prevalence rates in the left-hand graph, and the difference in prevalence rates, adjusted for age, sex and dementia risk factors in the right-hand graph.

The results in Figure 10 suggest that dementia prevalence is lower for the Asian, Black, and Mixed ethnic groups compared to the White ethnic group. This is inconsistent with other studies (Pham T.M. et al., 2018) which finds a higher incidence of diagnosis of diseases that cause dementia in the Black ethnic group compared to Whites (but a lower incidence in Asians compared to Whites).

Including covariates does not affect the size or significance of the differences. This is to be expected, as we could only adjust for dementia risk factors at the sub-ICB level, and these measures are not available separately for each ethnic group at the sub-ICB level. Therefore, risk adjustments are unable to adjust for differences in risk between ethnic groups within a sub-ICB, only differences in risk factors between sub-ICBs. For example, the average age will be the average age in the sub-ICB, not the average age of the different ethnic groups in the sub-ICB.

FIGURE 10: DIFFERENCE IN AVERAGE DEMENTIA PREVALENCE RATES (PER 1000 OF THE POPULATION) BETWEEN EACH MINORITY ETHNIC GROUP, COMPARED TO THE WHITE ETHNIC GROUP



The coefficient estimate is indicated with a circular marker, the vertical lines indicate the 95% confidence interval. The red horizontal line indicates 0. Adjusted concentration indices control for sub-ICB level covariates of the % of registered patients in each age category, the % registered female patients, diabetes prevalence hypertension prevalence, stroke prevalence and obesity prevalence. See Appendix 8 *Table A9 for the full table of* coefficients and confidence intervals.

3.5.3 Is the measure valid?

Summary of validity: There is a high degree of underreporting of ethnicity in the recorded diagnosis of diseases that cause dementia data, and potential bias if this underreporting is more likely in particular ethnic groups. Furthermore, there are issues with the census data used to construct prevalence by ethnic group.

Given the availability of data, this case study presents prevalence rates per 1,000 of the entire population. Even with a better measure of prevalence (for example, prevalence per 1,000 of the adult population or over 30 population), prevalence rates are less informative about inequalities in access and experience of a diagnosis compared to diagnosis rates (which are not published by ethnic group and cannot be estimated with the publicly available data).

There are multiple data quality issues with the data available for this case study.

First, diagnoses of diseases that cause dementia by ethnic group data are severely underreported (most diagnoses are recorded in the 'not defined' group). There is also likely bias due to under-reporting being more concentrated in minority ethnic groups compared to the White ethnic group.

Second, data on the number of individuals in a sub-ICB, by ethnic group, to be able to estimate prevalence, is not regularly published by age. The most relevant measure of dementia prevalence would concentrate prevalence to the affected population, for example over 65s or the adult population. Instead, Census 2021 data on the number of individuals in a sub-ICB by ethnic group are used to estimate prevalence. The issues with using census data to construct prevalence are threefold: (1) data are not available by age, to construct prevalence for the relevant population, (2) the denominator used to estimate prevalence is fixed to the year 2021, across all years of estimating the inequality, and (3), there are discrepancies and differences in how ethnicity data is recorded at the practice level (in the number of diagnoses by ethnic group) and in the census data.

Finally, covariates in the adjusted analysis are not able to adjust for differences between ethnic groups, only overall differences (in age, gender, or dementia risk factors) between sub-ICBs. The

reason that the diagnosis rate is preferable to prevalence as a measure of access and experience is that it implicitly adjusts for risk factors which predict dementia (age and gender) in the calculation of the diagnosis rate, and additionally controls for other dementia risk factors (prevalence of other conditions) in the analysis. As risk factor data (age, gender, or prevalence of other conditions) are not available at a granular level by ethnic group, this means the adjusted differences do not capture differences in experience of a diagnosis between the ethnic groups and explainS why it does not have much of an impact on the unadjusted results. The issues with the quality and existence of data in this case study mean that the measure outlined to estimate ethnicity-related inequality in the experience of a diagnosis is inaccurate and should not be used. However, the exercise highlights that improvements are needed in the recording of ethnicity data in dementia, and in primary care data more widely.

3.5.5 Recommendations (across England, Wales, NI)

3.5.5.1 How could the publicly available measure be improved with unpublished, but existing data?

The NHS digital website states that they have data on registered over 65 practice population by ethnicity (to be able to estimate prevalence) but this is not published in the series. If these data were publicly available, it would give a better measure of prevalence than used in this report, which uses 2021 census data as the denominator for prevalence across all annual estimates.

It is worth noting that NHS Digital publish figures on ethnicity as reported in primary and secondary care administrative datasets (NHS Digital, 2023a). These data could also be used for population estimates by ethnic group to estimate the prevalence rate by ethnic group. However, the data collection only began in 2020, so could not have been used to estimate prevalence for the whole time period considered in this study. Furthermore, as it is an administrative recording of ethnicity in healthcare datasets, would also be subject to missing data or underreporting, compared to census data.

3.5.5.2 Are there data which currently do not exist which would improve the measurement of this inequality?

Ethnicity data is sensitive, and it is understandable that patients will not always want this recorded. However, for the full extent of ethnicity-related inequalities in dementia to be measured, so that the problem can be assessed and addressed, this requires better, more complete, data. Data on age, gender, and dementia risk factors, by ethnicity, would have improved the risk-adjusted analysis in this case study.

Using prevalence or diagnosis rate data to capture ethnicity-related inequality, as outlined with the publicly available measures in these case studies, captures elements of both access and experience of a diagnosis. The collection of survey data would allow for a more explicit measurement of inequalities in experience of a diagnosis, distinct from inequalities in access

3.6 Case Study 4: Financial Pressures Faced by Informal Carers

Case Study 4 (CS4) explores financial pressures faced by informal carers versus the general population. We need to identify a measure which captures the degree of financial pressures faced by informal dementia carers, relating to both the direct costs of caring (i.e. the amount spent by carers on care, either resources to provide care themselves, or informal carers paying for formal care) or the indirect costs of caring (i.e. income loss due to reducing work hours or leaving the workforce to provide care).

CS4 key takeaway: More than 40% of the surveyed dementia carers report financial difficulties, and at least one out of five carers report that their employment is negatively affected due to caring.

3.6.1 Relevant evidence about the inequality

Table 18 summarises the evidence we have identified from two sources: relevant results retrieved from the initial literature search (see Appendix 1), and results from an additional targeted search of metrics of financial pressures faced by informal carers (note that the new search was not restricted to England, Wales, and Northern Ireland).

TABLE 18: EVIDENCE FROM THE LITERATURE ON THE MEASUREMENT OF FINANCIAL PRESSURES FACED BY INFORMAL CARERS

Academic Reference	Grey Literature Reference	Health or Health and Social Care Inequalities Observed	How it is Measured/Presented
(Manthorpe J. and Samsi K., 2020)		Negative financial implications from giving up employment for family caregiving, especially for women.	Discussion of literature, **no quantitative metric presented.**
	(Keohane and Petrie, 2019)	Self-funders face a dementia penalty (the average difference between the costs of care faced by people living with dementia versus those with other social care needs).	The average **dementia penalty** for self-funders across England is £761 per annum within residential care and £1,477 in nursing care, this equates to £14.63 and £28.39 per week respectively.
	(Prince et al., 2014)*	Costs of informal care contribute the largest of dementia costs to society in the UK.	The **total cost of dementia to society** in the UK is £26.3 billion. **£11.6 billion is contributed by the work of informal carers** of people with dementia. Costs are estimated based on both the replacement cost (assigns a cost to an hour of informal care equal to the cost of employing a professional carer such as a homecare worker) and the opportunity cost (reflect the value to carers of the activities that they are no longer able to carry out because of their caring commitments)
(Wittenberg R. et al., 2019)* *Updated study of (Prince et al., 2014)*		Costs of informal care contribute the largest of dementia costs to society in the UK.	**Total annualised cost** for people with dementia in England is £24.2 billion at 2015 prices, of which **£10.1 billion is attributed to informal care costs**. The study combines replacement cost and opportunity cost approaches to cost informal care, using data from the MODEM (CFAS II) cohort on the proportion of carer time spent on various caring tasks.

** Additional literature is indicated with an asterisk (*) next to the reference. CFAS: Cognitive Function and Ageing Study.*

In general, studies which provide relevant evidence of the inequalities faced by informal carers, in terms of financial pressures, have aimed to quantify the costs of informal care for individuals with dementia. The study by Keohane and Petrie (2019) illustrates the dementia penalty for a person with

dementia and does not disentangle the amount of this cost burden faced by informal carers. These studies generally take the perspective of the societal costs of informal care and do not specifically focus on the financial pressures faced by the carers themselves.

3.6.2 How can we measure the inequality using publicly available data?

For this case study, we use survey data to evaluate the proportion of informal dementia carers who face financial pressures due to caring.

3.6.2.1 Data - England

The Personal Social Services Survey of Adult Carers in England (SACE) is conducted and published every two years. This survey contains information 'on a number of topics that are considered to be indicative of a balanced life alongside their informal caring role' (NHS Digital, 2022a). The carers surveyed are all informal carers aged 18 or over, caring for another individual aged 18 or over. The informal carers included are reported to have received a form of support from their local authority but as of the 2016/17 survey, include carers who were not assessed or reviewed during the year. The data are for a non-representative sample of carers in England. In the most recent survey, the final sample size was 43,525 (the questionnaire was sent to a random sample of 133,980 informal carers). Survey respondents are not restricted to informal carers of people living with dementia; however, the survey asks individuals to indicate the health conditions for which the person they are caring for possesses. Data is therefore collected that enables for analysis of the survey responses for informal dementia carers to be examined. Data is collected on carers only, and therefore cannot produce comparable estimates of the general population.

3.6.2.2 Method

The two most relevant questions from the survey are questions 15 and 20, which are shown, alongside the associated response options in Table 19.

TABLE 19: QUESTIONS FROM THE PERSONAL SOCIAL SERVICES SURVEY OF ADULT CARERS IN ENGLAND (SACE) THAT ARE MOST RELEVANT FOR DETERMINING THE FINANCIAL DIFFICULTIES EXPERIENCED BY INFORMAL CARERS

Question 15	Question 20
In the last 12 months, has caring caused you any financial difficulties? • No, not at all. • Yes, to some extent. • Yes, a lot.	Thinking about combining paid work and caring, which of the following statements best describes your current situation? • I am not in paid employment because of my caring responsibilities. • I am not in paid employment for other reasons (e.g., retired). • I am in paid employment, and I feel supported by my employer. • I am in paid employment, but I don't feel supported by my employer. • I do not need any support from my employer to combine work and caring. • I am self-employed and I am able to balance my work and caring. • I am self-employed but I am unable to balance my work and caring.

Responses to question 15 enable us to determine the percentage of dementia carers, among survey respondents, who face financial difficulties due to caring. Question 20 allows us to dive deeper into potential losses of productivity by assessing the percentage of informal dementia carers who struggle to combine paid work and caring.

As the survey is only collected every two years, we have used data from the 2016-17, 2018-19 and 2021-22 surveys. Percentages are derived by NHS Digital by weighting the response data with eligible

population figures, to estimate the proportion of the population who hold these views (NHS Digital, 2022a).

The specific research objectives using these survey questions are: (1) evaluate what percentage of carers report facing financial difficulties due to caring, over time, and (2) evaluate what percentage of carers report that their employment is affected by caring.

3.6.2.3 Results

Summary of results: In each year, more than 40% of dementia carers report experiencing financial difficulties in the last 12 months, and at least one in five carers report that their employment is negatively affected by caring (the proportion peaks to more than half in 2021-2022).

Figure 11 and Figure 12 provide the survey results for questions 15 and 20 respectively.

Figure 11 shows relatively little movement in the percentage of informal carers of people living with dementia experiencing financial difficulties since 2016. The percentage of carers reporting some financial difficulties (yes, a lot; yes, to some extent) was:

- 44% in 2016-17;
- 45% in 2018-19; and
- 41% in 2021-22.

FIGURE 11: PERSONAL SOCIAL SERVICES SURVEY OF ADULT INFORMAL DEMENTIA CARERS QUESTION RELATED TO FINANCIAL DIFFICULTIES

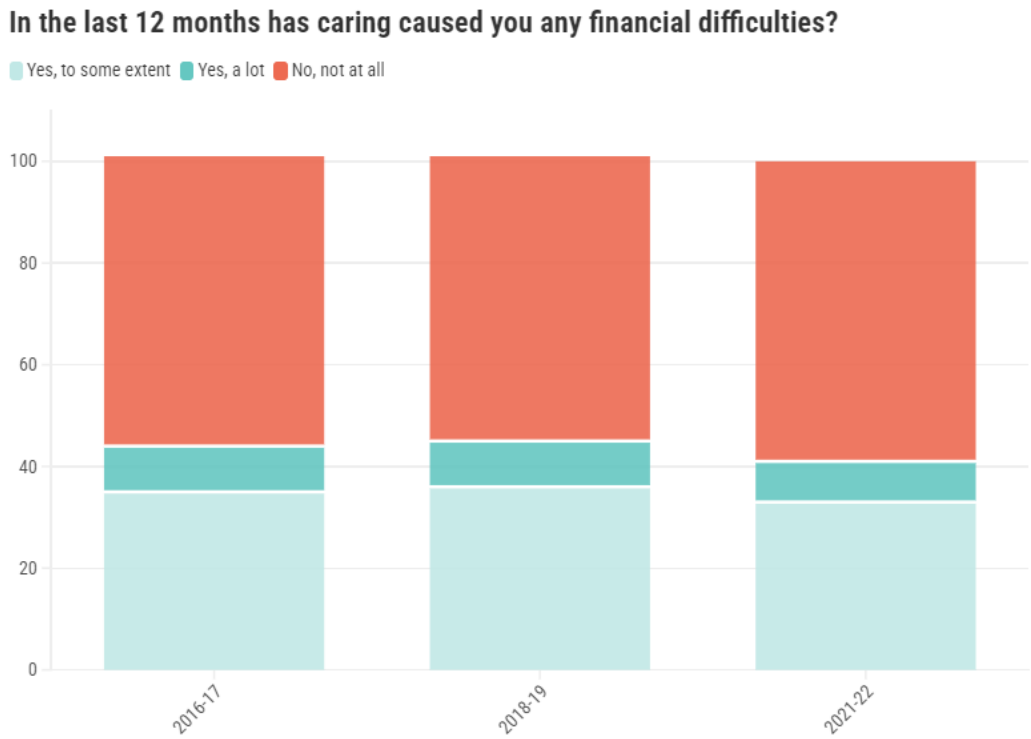
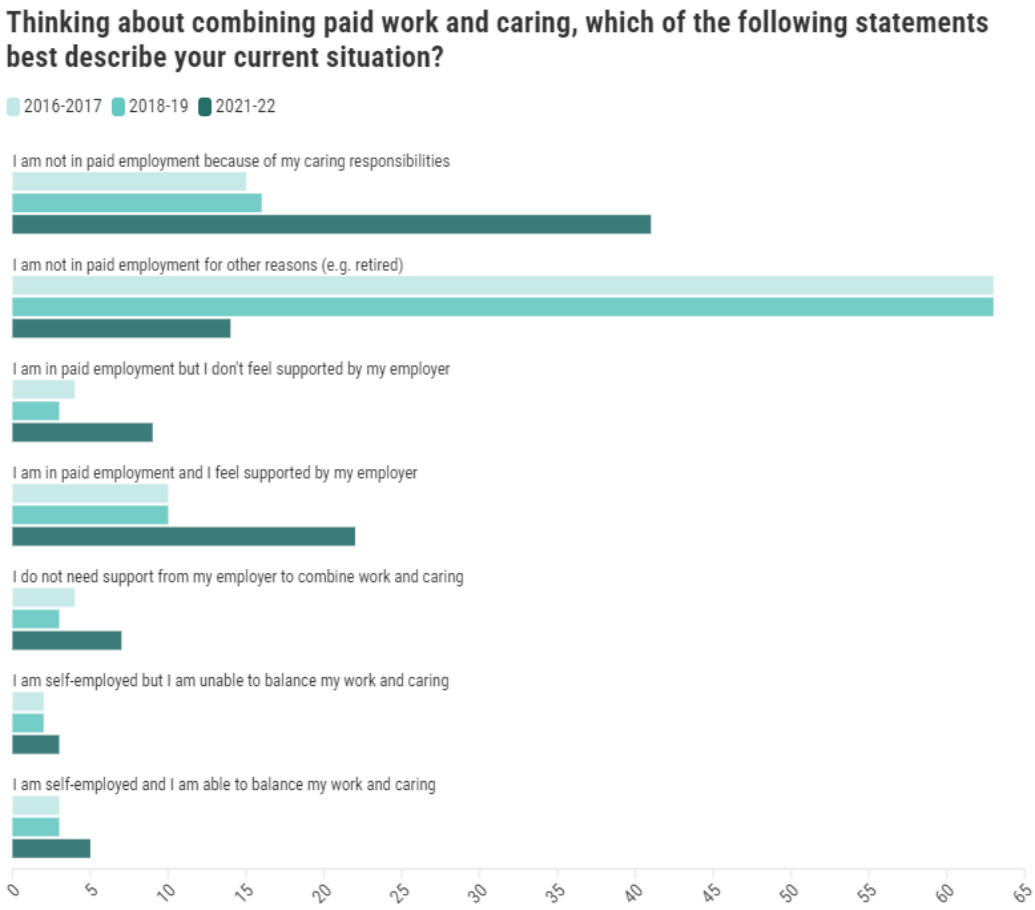


Figure 12 shows that the 2021-22 survey indicates a large increase in the proportion of informal carers who are not in paid work due to their caring responsibilities. This may have been triggered by the increased need for informal carers caused by COVID-19. The percentage of carers reporting that their employment productivity is negatively affected by caring ("I am not in paid employment because of my caring responsibilities"; "I am in paid employment but I don't feel supported by my employer"; "I am self-employed but I am unable to balance my work and caring") was:

- 21% in 2016-17;
- 21% in 2018-19; and
- 53% in 2021-22.

FIGURE 12: PERSONAL SOCIAL SERVICES SURVEY OF ADULT INFORMAL DEMENTIA CARERS QUESTION RELATED TO COMBINING PAID WORK AND CARING



3.6.3 Are the Measures valid?

Summary of validity: The inequality measure provides a basic but useful indication of the financial pressures faced by dementia carers. The inequality measure may be biased by different characteristics of patients who respond to the survey, compared to those who do not.

There are a number of issues with the publicly available data used which make this a crude measure of carer inequalities over time.

The data area non-representative sample of carers in England. Therefore, there is a potential bias in the respondents who opted to respond to the questionnaire, as these carers may be in a less serious financial situation and more able to respond to the survey, and therefore the measure would underestimate the financial pressures faced by carers. The bias could also go the other way as carers in a more serious financial situation may be more inclined to want to report this in the survey, which would lead to an overestimate. The questionnaire is distributed by the council to informal carers. Therefore, the initial sample identified will not include informal carers who are not registered

or known to the council. With individual-level data on carer characteristics, we would be able to adjust for some of these biases.

Data are not available on financial pressures faced by informal carers and the general population, to be able to compare the inequality or give an estimate of how much worse off dementia carers are compared to the general population. However, given that the majority of the general population does not have caring responsibilities, evaluating the financial pressures faced by carers using only data on carers is a reasonable measure of additional financial pressures faced by dementia carers (compared to the average person in the general population with no financial pressures due to caring).

Furthermore, the measures presented are subjective and we do not have data on any changes to income or household income due to caring. However, as the amount of pressure faced by a carer due to changes to their financial situation is an individual and arguably an objective concept, survey data may be an appropriate measure of this inequality.

3.6.5 Recommendations (across England, Wales, NI)

3.6.5.1 How could the publicly available measure be improved with unpublished, but existing data?

Access to more granular data may be made available via an application for the full dataset through the NHS Digital Data Access Request System (DARS) (NHS Digital, 2023c). Access to the individual-level survey data could improve the measure presented here in a number of ways.

We would be able to explore characteristics of the carers, such as job type, or characteristics of the people living with dementia that are being cared for, such as severity, and examine whether this contributes to changing responses to the survey over time. The SACE survey is completed by carers of different long-term conditions, not just dementia, and respondents can select multiple health conditions. Therefore, the individual being cared for may have another co-morbid condition in addition to dementia. With access to more granular data, it would be possible to determine responses for those who have dementia only and compare these to those with co-morbid conditions.

With access to the individual level data, rather than the national average responses, we could also comment on the distribution and variance of the data and provide confidence intervals for the results. Furthermore, granular data would allow evaluation of this inequality by geographical area, to highlight where policy improvements are most needed.

3.6.5.2 Are there data which currently do not exist which would improve the measurement of this inequality?

The individual-level data that is collected by NHS Digital and available upon application could also include more detailed information on the direct costs of caring, for example, the out-of-pocket costs of health and social care needed for the people living with dementia, which is not provided by the NHS. The SACE survey could also collect more detailed data on the income of the individual. To be able to estimate the financial costs experienced by dementia carers in terms of loss of productivity or leaving the workforce, ideally, we would have employment status and income data from before and after the individual became an informal carer.

In general, other data sources which collect useful information on informal carers, such as the British Household Panel Survey (BHPS) or census data (Office for National Statistics, 2021), do not collect data specifically for dementia. The English Longitudinal Survey of Ageing (ELSA) asks respondents

(50 and over) about the informal care that they receive. However, the use of this survey data would approach this inequality from the perspective of the people living with dementia, not the carer.

The number of hours spent caring and employment status can be captured via the Family Resources Survey, which collects data on a representative sample of private households in the UK. However, the survey does not capture the nature of the health condition of the person the informal care is for, and, therefore, dementia-specific information cannot be ascertained. In addition, it does not capture if an individual is unemployed due to their caring responsibilities or whether this is for other reasons.

3.7 Cross-Case Study Comparison with Data in Wales and Northern Ireland

Each case study was carried out using publicly available data in England. In this final section, we compare the availability of data sources in Wales and Northern Ireland.

Diagnosis rates are not publicly available for Wales and Northern Ireland. Furthermore, area-level data on the age and gender composition of the population is not published, which would enable the diagnosis rates to be estimated following the methods provided by NHS Digital (NHS Digital, 2023d). Therefore, expected levels of diagnosis are not able to be determined, which ultimately inhibits the calculation of the access to diagnosis measures presented in CS1 and CS2.

Publicly available dementia data by ethnic group is not available for Wales and Northern Ireland, for either prevalence or diagnosis rates.

Surveys similar to The Personal Social Services Survey of Adult Carers in England (SACE) are not collected in Wales and Northern Ireland. Furthermore, the other measures identified in the literature which quantify the costs of informal care are estimated in England (Wittenberg R. et al., 2019), or estimated using data from England, and inflated to the rest of the UK (Prince et al., 2014)

In Wales, area-level data at the GP practice level on dementia prevalence is available in Wales, alongside information on dementia risk factors (StatsWales, 2022). Index of Multiple Deprivation (IMD) data is available at the LSOA-level (StatsWales, 2019), and rural/urban classification data is also available at the LSOA level (Data Map Wales, 2021). However, data is not available on which LSOA patients at a practice live in and so the IMD or rural classification attributed to the GP practice will be the deprivation level of the neighbourhood (LSOA) the GP practice is in, not the deprivation levels of the LSOAs in which patients in each practice or area live in.

In Northern Ireland, area-level data on dementia prevalence and dementia risk factors is available for Northern Ireland from QOF data (NISRA, 2023), however, this is at a much less granular area-level than for England (local commissioning group or GP federation). IMD data (NISRA, 2017) is available in Northern Ireland and rurality data is also available at the Settlement Development Limit (SDL) level (NISRA, 2017), however again no patient-level LSOA breakdown is available.

4. Discussion

4.1 Literature Review Findings

Our literature review identified many inequalities in the context of dementia. HSCI for people living with dementia were identified at several dementia change points for all three comparators (other people living with dementia, people living with other diseases, and the general population). Therefore, the presence of these unfair and avoidable differences between different groups highlights that there is room for improvement in both access to and experience of health and social care services to improve fairness at all change points. Our literature review also identified that some groups of informal carers also experience both HSCI and HI in comparison to other carers of people living with dementia, carers of people living with other conditions, and the general population. The health inequalities identified in comparison to the general population show that there are unfair and avoidable impacts on the quality of life and well-being of informal carers, which would likely be improved with sufficient support. There are also structural inequalities for informal dementia carers identified for all comparators, suggesting that the current processes in place and the functioning of the health and social care system is not optimal for informal carers.

The inequalities identified in comparison with people with other diseases demonstrate that the experiences of people living with dementia are not just due to the nature of having a disease, but people affected by dementia are also experiencing unfair and avoidable differences in their access to and experience of health and social care. For example, there are no national waiting time targets for dementia diagnosis (Corrado et al., 2022), and there is no global staging scale in dementia – as there is in cancer -, which leads to less targeted and standardised support and healthcare (Semrau M. et al., 2015). These inequalities may be partially reflective of the relatively lower funding of dementia in comparison to many other diseases, such as cancer, which does not reflect the burden of disease on society (Alzheimer's Society, 2014; Luengo-Fernandez, Leal and Gray, 2015).

In addition, the inequalities identified in our literature review for some groups of people living with dementia in comparison to other groups of people living with dementia demonstrate that health and social care for dementia have not advanced enough to support the varying needs of different genders (specifically women), socioeconomic groups, ethnic and cultural groups, age groups, people living with disabilities, people living in rural communities and different dementia types. Many of these inequalities are present during clinical research and development and are then reflected in the access and experiences of people living with dementia. For example, there is a lack of funding for research into rarer forms of dementia (UK Dementia Research Institute, 2022) and people with learning disabilities are often excluded from clinical trials, with any evidence available for these populations being based on small sample sizes and non-blinded study designs (Moran et al., 2013). Large-scale genomics studies of Alzheimer's disease have also largely been conducted in White populations (UK Dementia Research Institute, 2022) and cognitive tests for dementia are also developed and tested primarily in White European and North American populations (Chithiramohan T. et al., 2023). Women are also less likely to be included in clinical trials despite experiencing more drug reactions than men, and dementia has been the leading cause of women in the UK since 2011 (Alzheimer's Research UK, 2022b). Therefore, improvements need to be made to make research and development more inclusive to enable the findings to be translated into practice. This would make health and social care more reflective of the needs of people living with dementia and reduce inequalities.

4.2 Literature Review Limitations

There are likely to be inequalities present in the context of dementia beyond those identified in this literature review. A consultation with experts in the field to validate the findings of our literature review through an expert roundtable suggested some inequalities not identified in our literature review. For example, inequalities for people living with dementia who live alone who may face increased financial difficulties and challenges accessing support; inequalities in access to health and social care at all dementia change points (outside of clinical trial settings) for different types of dementia; and inequalities for older informal carers.

Our literature review was conducted as a rapid evidence assessment and not a systematic review of the evidence, so we cannot guarantee that all literature on inequalities in the context of dementia has been captured in our findings. Secondly, a lack of evidence in the literature does not mean that the inequality does not exist. We have tried to approach the not-so-obvious inequalities by implementing a 'bottom-up' search technique (see Appendix 1), but further research is required to assess whether inequalities exist for many people living with dementia and their carers from diagnosis to end of life.

There is a potential risk of double counting some of the inequalities identified in our literature review, as we have not directly considered the intersectionality between identified inequalities. For example, ethnicity may be a proxy for culture (and vice versa), and geography likely overlaps with socioeconomic status. However, we have considered this in our measurement case studies. For example, for CS1 we used a proxy of deprivation in the concentration index to measure inequalities related to socioeconomic status and access to diagnosis. However, for the literature review results, there is a lack of evidence identifying the factor causing the inequality and a paucity of in-depth research exploring the relationship between the inequalities. Therefore, we have listed all inequalities identified in the literature, regardless of any potential relationship between them.

As previously mentioned, we have not considered inequalities relating to the likelihood of developing dementia. However, it may be useful in future research to draw out how having dementia exacerbates existing inequalities.

4.3 Future Challenges

Disease-modifying treatments are under assessment by the National Institute for Health and Care Excellence (NICE) for use in the early stages of Alzheimer's Disease (Donanemab and Lecanemab) (NICE, 2024a; b). Although treatments are on the horizon in the UK, health systems are not prepared. These treatments may be a catalyst for change, but there is a risk that they will increase inequalities among people living with dementia. For example, those who are currently experiencing inequalities in access to diagnosis will also experience inequalities in access to treatments. There are a number of studies which have collected primary data on cohorts with dementia and their carers, such as the MODEM study (Comas-Herrera et al., 2017), IDEAL study (Clare et al., 2014), and Determind (Farina et al., 2020). Data from these studies can provide useful insight on individual characteristics of people in the locations where data are collected. However, the CFAS II study is still used as the key dataset for estimating undiagnosed dementia within a population. This study is used to underlie key dementia research, other than diagnosis rates. For example, the MODEM study aims to understand the potential future impact of dementia by estimating who is likely to develop dementia, the needs of people living with dementia and their informal carers, and the costs of dementia inclusive of modelling the outcome and cost impacts of interventions (including potential future treatments) (Comas-Herrera et al., 2017). However, this study uses CFAS II data as one of the key datasets to underlie their modelling. As discussed in CS1, there are several limitations to this dataset, namely

that the predictions of prevalence extrapolated beyond the geographical areas included in the CFAS II study are based on the age and gender of the population in an area and do not consider other characteristics such as rurality, deprivation, and other dementia risk factors. This limitation may impact the accuracy of predictions made in the MODEM study simulation model (Wittenberg R. et al., 2019), which will be vital to understanding the future challenges of dementia.

4.4 Measurement of Inequalities

Table 20 provides a summary of the case studies. Measures identified vary in the quality and quantity of the data to enable a reliable estimation of the inequality.

TABLE 20: SUMMARY OF CASE STUDIES EXPLORING THE MEASUREMENT OF INEQUALITIES IN DEMENTIA IN ENGLAND

Inequality	Suggested Measure(s)	Measure Outcome	Adequate Measure?	Limitations
Case Study 1: Deprivation-related inequality in access to diagnosis (CS1)	1. Deprivation Gap: Gap in diagnosis rates between the most and least deprived areas. 2. Concentration Index: The extent to which diagnosis rates are distributed disproportionately across less or more deprived areas.	The concentration index, adjusted for differences in dementia risk factors, shows no deprivation-related inequality.	No	- The use of diagnosis rates may overestimate access to diagnosis in more deprived areas and bias the inequality measures. - The inclusion of available dementia risk factor variables confirms this appears to be the case. - Due to data availability, the included covariates may not adequately adjust for dementia risk factors of the population.
Case Study 2: Rurality-related inequality in access to diagnosis (CS2)	1. Rurality Gap: Gap in diagnosis rates between the most and least rural areas. 2. Concentration Index: The extent to which diagnosis rates are distributed disproportionately across less or more rural areas.	Diagnosis rates are lowest for sub-ICBs with patients who live in the most rural areas.	Yes	- The use of diagnosis rates may overestimate access to diagnosis in more rural areas and bias the inequality measures. - We still find that there is lower access to diagnosis in more rural areas after we take account of area-level dementia risk factors. - The direction of the potential bias in the diagnosis rate measure means our results potentially underestimate the true rurality-related inequality; there may be even lower diagnosis rates in more rural areas compared to urban areas.
Case Study 3: Ethnicity and experience of diagnosis (CS3)	Regression analysis to assess differences in the prevalence rates by ethnicity.	Higher estimated prevalence of dementia in White populations compared to other ethnic groups.	No	- Ethnicity data is poorly reported. - Data quality issues arise when combining census data with primary care data to construct dementia prevalence. - Prevalence data is not as informative on differences in experience of diagnosis as other measures, such as diagnosis rates, would be if the data were available.
Case Study 4: Financial Pressures for Informal Carers (CS4)	Survey questions providing: 1. The percentage of carers reporting facing financial difficulties due to caring over time. 2. The percentage of carers reporting that their employment is affected by caring.	In the 2021-22 survey, 41% of carers reported experiencing financial difficulties in the last 12 months. 53% also report that their employment is negatively affected by caring.	Yes	- Use of these survey data may underestimate or overestimate the financial pressures faced by carers, depending on whether carers in more severe financial situations are more or less likely to respond.

Diagnosis rates can be used to measure access to diagnosis and are regularly published in England so they can be tracked going forward. However, as outlined in CS1 and CS2, there are limitations when interpreting diagnosis rates as a measure of access, as the denominator of the diagnosis rate is an estimated value projected based only on the age and gender of the population. Therefore, it ignores the relationship between deprivation or rurality and expected dementia prevalence, leading to potentially upward-biased estimates of the inequalities in both cases.

Furthermore, the data to generate this estimated value has not been updated since 2011. The rurality-related inequality measure still finds that there is lower access to diagnosis in more rural areas even after including sub-ICB level dementia risk factors in the model. However, we find no difference in access to diagnosis between more and less deprived areas after including dementia risk factors. Both measures would be improved with access to individual-level data on dementia risk factors, and individual-level data on both rurality and income deprivation. It is possible to derive individual-level data on rurality and deprivation from published sources. However, we were required to aggregate these data at the sub-ICB level as they could not be linked with publicly available, individual-level measures of access to diagnosis. The case studies outline that there may be more concerns over biased annual estimates for the deprivation measure than for the rurality measure. Objective data and measures, such as administrative waiting time data or severity could be used to capture the more objective aspects of diagnosis, such as health-system-related delay and 'early' diagnosis. However, measuring the point at which it is useful for an individual to investigate symptoms will require access to individual-level survey data on patient experience of a diagnosis, given the subjective nature of this stage.

Results from CS3 seem to indicate a higher estimated prevalence of dementia in White populations of all ages compared to other ethnic groups. This used publicly available data on dementia prevalence in England adjusted for sub-ICB level dementia risk factors. However, ethnicity data is poorly reported and may be more underreported for certain minority ethnic groups. Our result is not consistent with other studies with access to more complete data on ethnicity. Furthermore, prevalence data is not as informative on differences in experience of diagnosis as other measures such as diagnosis rates would be if the data were available. CS1, CS2, and CS3 all consider measures related to dementia prevalence (number of current cases in the population) as opposed to dementia incidence (new cases in the population). Dementia incidence data would improve on the outlined measures in the ability to compare differences in the inequality measure over time, as the inequality measures would better capture access or experience of new dementia cases within a given year, compared to prevalence, which captures historical diagnoses. The use of prevalence and diagnosis rate data in CS1, CS2, and CS3 captures elements of both access and experience. This is because whether an individual with dementia obtains a diagnosis is a function of both access and experience of a diagnosis once they have presented to health services. Survey data on the experiences of an individual's diagnosis of a disease that causes dementia would allow for clearer distinction in measuring these two types of inequalities.

In CS4, the proposed measure is useful to evaluate the size of the inequality within each year, but it is a crude measure and is likely to underestimate the financial pressures faced by carers. This is in part due to likely non-response to the survey by carers in more difficult financial situations with less capacity to take part in the survey. Furthermore, without access to individual-level data to be able to control for characteristics of the respondents or the people living with dementia they care for, this measure cannot reliably make comparisons across years, as the sample is not representative of all informal carers, and we do not have access to enough information on the sample that was interviewed and how they answered.

In summary, two of the four inequality measures give a crude indication of the inequalities using data in England (CS2 and CS4). CS1 is an interesting result, but with concerns over bias and how accurately the measure captures access to the diagnosis given this bias, the results of CS1 should not be interpreted as there is no deprivation inequality in access to diagnosis in England. CS3 illustrates the issues with current data collected on ethnicity in dementia and highlights the importance of better reporting of this data if the inequality is to be properly assessed by each nation going forward.

All the publicly available data used to construct these measures were for England. Although these data may be possible to access for Wales and Northern Ireland, they are not regularly published.

4.5 Our Call for Future Research

Our research has highlighted several gaps in the current literature on inequalities in dementia in England, Wales and Northern Ireland:

- **The quantity and quality of quantitative research on inequalities in the context of dementia needs to increase.**
  The majority of inequalities identified in our literature review ranked low for all three of our quality indicators (publication quantity, publication quality and publisher quality). Without sufficient quantity and quality information on these inequalities in the literature, the ability of policy- and decision-makers to make meaningful changes to reduce them is limited.
- **There is a lack of evidence identifying the factors causing the inequalities.**
  Establishing causality between factors and outcomes is challenging due to many confounding potential determinants. However, improving understanding of the likely cause of the inequality can enable a more targeted approach to tackling it. A mixed-methods approach could aid in filling this gap. Qualitative studies can help identify potential mechanisms that lead to experiences of inequalities, while quantitative analysis can robustly establish the presence of these relationships.
- **There is a paucity of in-depth research exploring the relationship between the inequalities.**
  In general, the literature discussed each inequality in a silo and did not consider any intersectionality between identified inequalities. Therefore, we have necessarily reflected this in our research and included all inequalities identified in our list despite any potential relationships between them. Research exploring the relationship between the inequalities would make it easier to identify the causes of the inequalities identified.
- **Greater knowledge of the health status of people living with dementia is required.**
  Improved understanding of measurements of the health status of people living with dementia, which is challenging due to the difficulties in quantitatively assessing the quality of life and wellbeing of people living with dementia. This would enable researchers to identify the health inequalities related to dementia.
- **Further research is needed on the financial pressures faced by people affected by dementia.**
  More studies are needed to assess the impact of monetary costs on informal carers and people living with dementia. These studies should go beyond identifying the monetary costs of informal care and consider the impacts on wellbeing, such as feeling financial pressure. This would enable a more informed assessment of whether informal carers and people living with dementia are being sufficiently supported.

- Greater consensus around the stages along the 'time to diagnosis'
  There needs to be greater consensus in the dementia literature on what stages define the 'time to diagnosis' to enable future data and research to measure elements of the dementia diagnosis pathway (for example, patient-related or health system-related delays) accurately. There are also unclear and contrasting definitions of a 'timely' diagnosis in the literature. This understanding is particularly important in light of the new disease-modifying treatments requiring a diagnosis at an early stage.

4.6 Our Call for Improved Data

Better data collection, reporting, and publishing in the context of dementia could improve ways to measure and track inequalities.

Our research highlights that key areas for improvement are:

- Updating and enhancing the methods to calculate dementia prevalence estimates.
  Diagnosis rates (which are regularly published in England) use estimated prevalence based on outdated CFAS II survey data that is only based on data from three cities. The application of more recent prevalence studies for different geographical areas of the UK (or individual data) could improve the accuracy of the diagnosis rate measure. Furthermore, only the age and sex-specific dementia prevalence rates within an area are used to estimate the prevalence. Individual-level risk factors and the demographics of the area should also be collected and used to estimate area-level dementia prevalence.
- Removing the disparities in data collected and published across England, Wales and Northern Ireland.
  Data is not available in Wales and Northern Ireland to calculate any of the measures from our four case studies. There is insufficient data on diagnosis rates and ethnicity of people living with dementia, and there is no evidence exploring the financial difficulties of carers.
- Beginning data collection on the stages along the time to diagnosis pathway.
  None of the data identified can assess the nuanced stages along the time to diagnosis. This is in part due to a lack of consensus around the definition of the elements that make up the dementia diagnosis pathway. For example, survey data would be a more informative source of information on the point at which it is useful for an individual to investigate symptoms, as cannot be fully captured in administrative datasets such as waiting times. A measure of health system delay would be an informative measure of access to diagnosis. NHS England has waiting time standards for cancer diagnosis and care (for example, 75% of people should have cancer ruled out or a diagnosis within 28 days, and 85% should receive treatment within two months of an urgent referral (Lowes, 2023)). This means that these data are consistently collected and published. However, the recommendation from the Alzheimer's Society that an individual should wait no longer than 12 weeks from initial GP referral to receiving their diagnosis (Alzheimer's Society, 2014) has not been formally adopted by NHS England.

5. Conclusion

Many inequalities have been identified in the literature at all dementia change points for both people living with dementia and their informal carers. This demonstrates that there are significant improvements that can be made to remove unfair and avoidable differences in access to and experience of health and social care services for people affected by dementia. The literature review also highlighted many gaps in research that need to be filled to improve our understanding of inequalities in dementia and allow for these to be effectively tackled. These gaps include the need to increase the quantity and quality of research on inequalities in dementia, and exploring the factors causing inequalities in dementia, the relationships between inequalities, and the health impacts of dementia. More research on the financial pressures faced by people affected by dementia could also be beneficial.

Our case studies have highlighted the need to develop robust measures for a set of priority inequalities in dementia, to show the need to intervene and provide tools to assess changes over time. For the inequalities explored in our case studies, the key next steps are: updating and enhancing the methods used to calculate dementia prevalence estimates; removing the disparities in data that is collected and published in England versus Wales and Northern Ireland; and collecting data related to the concept of time to diagnosis.

Appendix

Appendix Contents:

Appendix 1: Academic Literature Searches

Technical note:

In our description of search terms, a "*" is included to indicate that there are multiple relevant characters at the end of the word. For example, inequal* will ensure that titles and abstracts, including inequality or inequalities, will be identified. A "$" is used to dictate where there may be a space or other character included between the words. For example, well$being will ensure results including well-being or wellbeing are captured. The phrase adjX is used to describe that the two words need to appear close to each other, where X is the maximum number of words that can be between the two search terms. For example, carer adj5 dementia would mean that the title and/or abstract must include the words carer and dementia with no more than five words in between, such as carer of someone living with dementia.

Search 1:

Our first search focused on papers that directly refer to inequalities (or related terms) and dementia. (Note: we conducted preliminary searches including alternative terms to describe common sub-types of dementia such as Alzheimer's disease, dementia with Lewy bodies, frontotemporal dementia or vascular dementia, but they did not generate additional search results.)

	Search Command
	inequal* OR inequit* OR equit* OR equality OR fair OR unfair
AND	
	dementia
AND	
	England OR Wales OR Northern Ireland OR UK OR United Kingdom

Search term as entered into the search bar: ((inequal* or inequit* or equit* or equality or fair or unfair) and dementia and (England or Wales or Northern Ireland or UK or united kingdom)).ti,ab

Search 2:

In our second search, we dropped the terms specifically related to inequalities and include terms that describe the intermediate outcomes being considered in this research: patient access to and experience of diagnosis, care and treatment. In this search, we also included the term Alzheimer's as preliminary searches showed that this would retrieve additional research papers.

	Search Command
	(access OR experience) AND (diagnos* OR care OR treatment OR home OR hospital OR support OR 'end of life')
AND	
	dementia OR "Alzheimer's"
AND	
	England OR Wales OR Northern Ireland OR UK OR United Kingdom

Search term as entered into the search bar: (((access or experience) adj3 (diagnos* or care or treatment or home or hospital or support or "end of life")) and (dementia or "Alzheimer's") and (England or Wales or Northern Ireland or UK or united kingdom)).ti,ab.

Search 3:

In our third search, we sought to identify literature discussing inequalities experienced by informal carers of people with dementia, where informal carers refer to informal carers. Including Alzheimer's in this search produced additional search results.

Search Command	
AND AND	inequal* OR inequit* OR equit* OR equality OR fair OR unfair OR differences ((informal OR unpaid OR family OR relative) and (care* OR care$giver)) adj5 (dementia OR "Alzheimer's") England OR Wales OR Northern Ireland OR UK OR United Kingdom

Search term as entered into the search bar: ((inequal* or inequit* or equit* or equality or fair or unfair or differences) and (((informal or unpaid or family or relative) and (care* or care$giver)) adj5 (dementia or "Alzheimer's")) and (England or Wales or Northern Ireland or UK or United Kingdom)).ti,ab.

Search 4:

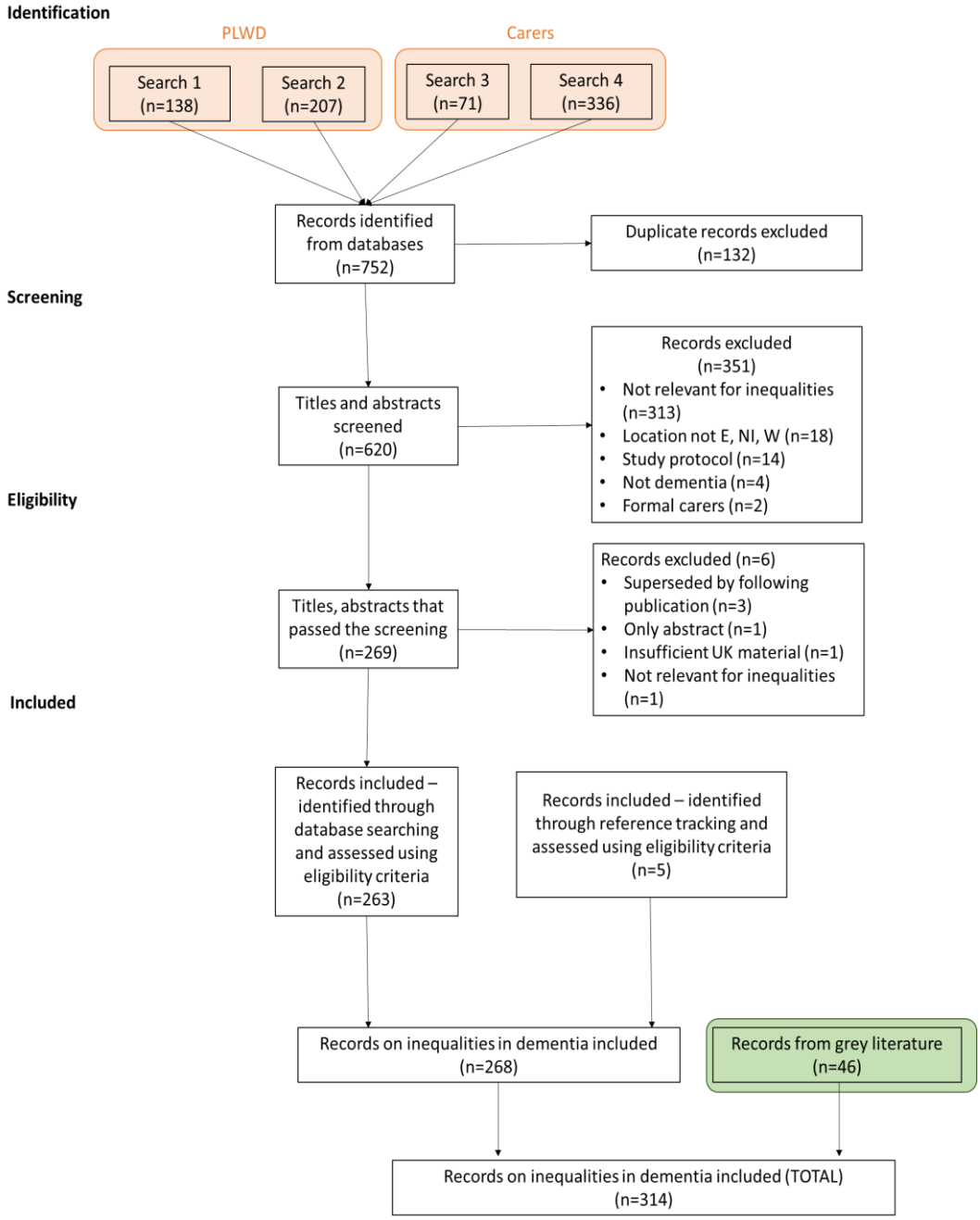
In our fourth and final academic literature search, we sought to identify factors relating to the health and well-being of carers. Including Alzheimer's in this search produced additional search results.

Search Command	
AND AND	health OR well$being OR quality$of$life OR life expectancy OR burden ((informal OR unpaid OR family OR relative) and (care* OR care$giver)) adj5 (dementia OR "Alzheimer's") England OR Wales OR Northern Ireland OR UK OR United Kingdom

Search term as entered into the search bar: ((qualityoflife or life expectancy or health or well$being or burden) and (((informal or unpaid or family or relative) and (care* or care$giver)) adj5 (dementia or "Alzheimer's")) and (England or Wales or Northern Ireland or UK or United Kingdom)).ti,ab.

Appendix 2: PRISMA Diagram

This PRISMA diagram shows the number of papers identified through our academic and grey literature searches.



Appendix 3: Full Literature Results for people living with dementia

TABLE A1: HEALTH AND SOCIAL CARE INEQUALITIES IDENTIFIED FOR PEOPLE LIVING WITH DEMENTIA COMPARED TO OTHER PEOPLE LIVING WITH DEMENTIA

Dementia Change Point(s)	Access or Experience?	Inequality Group	Health and Social Care Inequalities	Publication Quantity	Publication Quality	Publisher Quality	Academic Reference	Grey Literature Reference
Diagnosis to end of life	Access	Geography	Overall, service provision and funding varies across England, Wales and Northern Ireland					(Arblaster and Brennan, 2022; Dementia Voice Team, Alzheimer's Society, 2022)
Diagnosis	Access	Gender	Men with dementia are less likely to be diagnosed than women. As a result, men are less likely to receive access to carer support, appropriate healthcare and treatment, an alternative home, and end of life care				(Manthorpe and Samsi, 2020)	
		Technology	Exclusion to wearable devices to detect preclinical dementia				(Wilson S. et al., 2022)	
		Culture	BAME people living with dementia are less likely to have access to timely diagnosis and present later for assessment than White British people living with dementia				(Dodd E. et al., 2022; Baghirathan S. et al., 2020; Chithiramohan T. et al., 2023)	(Hopson, 2023; Arblaster, 2021; Dementia UK, 2020; Race Equality Foundation, 2022; Watt, Raymond and Rachet-Jacquet, 2022; Jeraj and Butt, 2018)
		Geography	Less access to timely diagnosis in rural areas compared to non-rural areas, resulting in a higher average diagnosis age					(Slogget, 2022; Arblaster, 2021)
Diagnosis	Access	Geography	Geographical variation in the delivery of memory assessment services					(Arblaster, 2021)

		Disabilities	People living with dementia with learning disabilities face increased barriers to accessing diagnostic services					(Beresford-Webb et al., 2021; Zeilinger, Stiehl and Weber, 2013)
		Socio-economic	Less access to timely diagnosis in deprived areas					(Arblaster, 2021)
	Access and Experience	Geography	Lower than expected diagnosis in areas where there are notable health inequalities and where health outcomes are below the national average					(Slogget, 2022)
	Experience	Geography	Access to diagnostic equipment is not equitably distributed across the country					(Slogget, 2022)
		Age	Young people living with dementia can face challenges receiving a diagnosis					(Dementia UK, 2020)
		Culture/ Ethnicity	BAME people living with dementia were less likely to receive a cognitive assessment than White British people living with dementia				(Dodd E. et al., 2022)	
			Lower diagnosis rate for Asian, Black and other ethnic minority groups people living with dementia, compared to White people living with dementia				(Chithiramohan T. et al., 2023; Pham T.M. et al., 2018)	(Fenton, 2016)
		Disabilities	Methods used for diagnosis are not appropriate for people with learning disabilities					(Zeilinger, Stiehl and Weber, 2013; Beresford-Webb et al., 2021)
			A deaf person living with dementia is less likely to be diagnosed with dementia				(Young, Ferguson-Coleman and Keady, 2016)	
Adjusting to living with dementia	Experience	Age	Young people living with dementia face increased challenges in living their usual daily life, due to challenges associated with continuing employment					(Dementia UK, 2020; Dementia Voice Team,

								Alzheimer's Society, 2022)
Adjusting to living with dementia Carer support	Access	Culture	BAME people living with dementia are less likely to access the support services when compared to the White dementia patients				(Chithiramohan T. et al., 2023)	(Jeraj and Butt, 2018)
		Geography	Variation in the availability and consistency of services (including social care and community-based services) in different postcodes				(Giebel C. et al., 2021b)	
	Experience	Age	Community and residential care services and mental health strategies may not be suitable to the requirements of people with young-onset dementia				_(Rabanal L.I. et al., 2018)	(Dementia Voice Team, Alzheimer's Society, 2022)
			People living with young-onset dementia face increased ongoing financial insecurity				(Mayrhofer A.M. et al., 2021)	
Healthcare and Treatment	Access	Disabilities	Not enough support to enable access to healthcare and treatment for those living with disabilities (e.g., deaf people living with dementia, people with learning disabilities)				(Ferguson-Coleman, Keady and Young, 2014; Louch et al., 2021; Oliver, 2017; Lesch et al., 2019)	(Arblaster, 2021; National Institute for Health and Care Excellence, 2018)
			Treatments may not be suitable to people living with dementia with learning disabilities due to weak study designs and the limited inclusion of people with learning disabilities in clinical trials				(Hanney et al., 2012; Mohan, Carpenter and Bennett, 2009; Moran et al., 2013; Sheehan, Ali and Hassiotis, 2014; Strydom et al., 2016; MacDonald and Summers, 2020)	
	Access	Ethnicity	Compared to White ethnic groups, Asian people were less likely to be prescribed anti-dementia drugs when				(Jones M.E. et al., 2020)	

Healthcare and Treatment			they were potentially indicated, and more likely to be prescribed Anticholinergics					
			Ethnic minorities are underrepresented in clinical trials for dementia					(UK Dementia Research Institute, 2022)
		Gender	Women with dementia received less primary, preventative healthcare than men with dementia				(Cooper C. et al., 2017; Manthorpe and Samsi, 2020)	
			Women are overlooked in dementia research (including clinical trials), which could lead to ineffective treatment and outcomes					(Alzheimer's Research UK, 2022a; UK Dementia Research Institute, 2022)
		Dementia Type	Rarer forms of dementia are under-recognised and under-researched compared to more common forms					(UK Dementia Research Institute, 2022)
	Experience	Gender	Women with dementia were more likely to be taking psychotropic medication than men with dementia				(Cooper C. et al., 2017; Manthorpe and Samsi, 2020	
		Geography	Inconsistent hospital care quality across UK and different hospitals				(Handley M., Bunn F., and Goodman C., 2019)	
		Gender, ethnicity, socio-economic and geography	Several groups (including men, people from White ethnicity groups and people from more deprived and rural areas) have a greater likelihood of A&E attendances and emergency and elective hospital admissions				(Watson J. et al., 2022)	
Carer Support	Access	Socio-economic	People from lower socioeconomic statuses (men with dementia and those from non-White and multi-ethnic backgrounds) have less access to post-diagnostic care				(James T. et al., 2023; Giebel C. and Heath B., 2023; Giebel C. et al., 2021a, 2023)	(Health Economics Research Group, OHE and RAND Europe, 2008)

Carer Support	Access	Socio-economic	People from lower SES face challenges in getting to locations to receive appropriate post-diagnostic care				(James T. et al., 2023)	
		Geography	Eligibility criteria for publicly funded care vary considerably across England due to the discretionary power of local authorities				(Wittenberg R. et al., 2019)	
	Experience	Ethnicity	People living with dementia from ethnic minorities face difficulties accessing care delivered by a person with the same ethnic/cultural background meaning that people living with dementia experienced services that were not culturally appropriate (e.g., home care workers did not speak the same language as the care recipient or could not prepare culturally appropriate meals), preventing higher levels of engagement with services				(Herat-Gunaratne R. et al., 2020)	
		Structural	People living with dementia at home are at increased risk of malnutrition compared to those in an alternative home				(Mole L. et al., 2019)	
Alternative home	Access	Technology	Decreased access to technologies that have the potential to enhance care and safety for some people living with dementia				(Hall A. et al., 2019)	
End of life	Experience	Disabilities	People living with dementia with learning disabilities face additional barriers to accessing appropriate end of life care				(Hunt et al., 2020; Watchman, 2005)	(Watchman, 2017)

TABLE A2: HEALTH AND SOCIAL CARE INEQUALITIES IDENTIFIED FOR PEOPLE LIVING WITH DEMENTIA COMPARED TO THE GENERAL POPULATION

Dementia Change Point(s)	Access or Experience?	Inequality Group	Health and Social Care Inequalities	Publication Quantity	Publication Quality	Publisher Quality	Academic Reference	Grey Literature Reference
Diagnosis through to end of life	Experience	Structural	There is a lack of properly trained dementia healthcare workers					(NHS, 2019)
Diagnosis through to End of Life (due to NICE's recommendation of a palliative care approach)	Access	Communication, Consent and Decision Making	Few people with dementia have an advance care plan (ACP) in place when they move into a care home				(Dening K.H. and Aldridge Z., 2021; Moore K.J. et al., 2020; Manthorpe and Goodwin, 2019)	(NHS England, 2018)
	Experience	Communication, Consent and Decision Making	Decreased choice and control leads to worse experiences of care for people living with dementia that may not align with their preferences				(Manthorpe and Goodwin, 2019; Moore K.J. et al., 2020; Dening K.H. et al., 2016)	(NHS England, 2018)
Adjusting to living with dementia	Access	Structural	Augmentative and alternative communication likely to be underprovided				(Creer S. et al., 2016)	
			People living with dementia often have to stop activities they enjoy					(Royal Town Planning Institute, 2020)
	Experience	Structural	Inequalities for people living with dementia faced by their experience of the built environment (housing and other local environments)					(Daly and Allen, 2016)
		Environment	Lack of support and 'reasonable adjustments' for workers with dementia on issues around work performance and job retention, often leading to unemployment				(Egdell, Stavert and Mcgregor, 2018; Chaplin R. and Davidson I., 2016)	(Fenton, 2016)
Adjusting to living with dementia,	Experience	Communication, Consent and Decision Making	Difficulty for people living with dementia without cognitive capacity to adhere to COVID-19 restrictions				(Giebel C. et al., 2021a)	

Healthcare and Treatment								
Healthcare and Treatment	Access	Structural	People living with dementia are less likely to get diabetes checks or cataract surgery					(National Institute for Health and Care Research, 2016)
			Difficulties accessing primary care dental services				(Burke S. et al., 2017)	
			People living with dementia experience less access to interventions, such as COVID-19 treatments, treatments for age-related muscular degeneration, pain management for fractured neck of femur and oral anticoagulant (OAC) for nonvalvular atrial fibrillation (NVAF)				(Narhi F. et al., 2022; Keenan, Goldacre and Goldacre, 2014; Sampson, 2010; Ajabnoor A.M. et al., 2022; Sampson et al., 2006)	
			Difficulties physically accessing cancer treatments and navigating services, appointments and information				(Surr C. et al., 2021)	
			People living with dementia receive less primary, preventative healthcare than people without dementia				(Cooper C. et al., 2017)	
		Communi-cation, Consent and Decision Making	People living with dementia are often excluded from clinical trials				(Shepherd V., Wood F., and Hood K., 2023)	(APPG on Medical Research, 2023)
	Experience	Structural	People living with dementia when admitted to hospital for an unrelated reason can see their condition deteriorate rapidly					(Dementia UK, 2020)
			People living with dementia can be disproportionately affected by care environments in hospitals which can impact the patient experience and receival of treatment					(Waller, Masterson and Finn, 2013; The King's Fund,

								2014; NHS England, 2015)
Healthcare and Treatment	Experience	Structural	The standard approach for treating cancer is not suitable for people living with dementia				(Price M.L. et al., 2022; Farrington et al., 2023; Ashley L. et al., 2021)	
		Gender	Women with dementia who have other long-term health conditions see medical practitioners less frequently and have fewer hospital stays than women with long-term health conditions but no dementia				(Manthorpe and Samsi, 2020)	
		Culture	Dementia Patients have less attention paid to the spiritual needs and religious background				(Sampson et al., 2006)	
Healthcare and Treatment Alternative Home	Experience	Structural	Comorbid conditions in people living with dementia in care homes are not always as well-managed as in those people without dementia, which leads to a higher number of hospital admissions				(Dening K.H. and Aldridge Z., 2021)	
			Experiences of quality, appropriate care by secondary care providers				(Richardson A. et al., 2019; Lamahewa et al., 2018; Hutchings et al., 2010)	(Dementia Voice Team, Alzheimer's Society, 2022)
Carer Support	Gender	Gender	Women with dementia who have other long-term health conditions are more likely to have moved to residential care (i.e., they receive less support at home) than women with long-term health conditions but no dementia				(Manthorpe and Samsi, 2020)	
	Access	Structural	Unmet need in social care support during the initial stages of lockdown during the COVID-19 pandemic				(Hanna K. et al., 2022)	
Alternative home	Experience	Structural	People living with dementia in care homes are not receiving the best standard of medicines management and administration				(De Witt Jansen B., Parsons C., and Hughes C., 2013; Alsulami N., Hughes C.M., and Barry H.E., 2023)	(Daly and Allen, 2016)

End of Life	Experience	Structural	Sub-optimal care is provided to people dying in the end stages of dementia					(Robinson et al., 2005; Smith C. and Newbury G., 2019)	(NHS England, 2018)

TABLE A3: HEALTH AND SOCIAL CARE INEQUALITIES IDENTIFIED FOR PEOPLE LIVING WITH DEMENTIA COMPARED TO OTHER PEOPLE LIVING WITH OTHER DISEASES

Dementia Change Point(s)	Access or Experience?	Inequality Group	Health and Social Care Inequalities	Publication Quantity	Publication Quality	Publisher Quality	Academic Reference	Grey Literature Reference
Diagnosis to End of Life	Access	Structural	Lack of strategies and frameworks to enable local services to deliver dementia services.					(Department of Health, 2009)
Diagnosis	Access	Structural	There is evidence of a substantial number of people with symptoms of dementia who are undiagnosed at any given time in England					(Slogget, 2022)
			People living with dementia are less likely to seek diagnosis for dementia compared to other conditions					(Hopson, 2023)
			There is no global staging scale - as there is in cancer - leading to less targeted and standardised support and healthcare				(Semrau M. et al., 2015)	
			Less access to early diagnosis				(Iliffe S., Manthorpe J., and Eden A., 2003)	
			Less research output to support improved diagnosis					(UK Government, 2015, 2022; NHS, 2019; Hopson, 2023)
	Experience	Structural	Delays to diagnosis					(Corrado et al., 2022; UK Government, 2015)

			There is a lack of national waiting time standards for dementia					(Corrado et al., 2022)
Adjusting to living with dementia Healthcare and Treatment Carer Support	Access	Structural	Gaps in services available following diagnosis				(Bennett H.Q. et al., 2018)	(Dementia Voice Team, Alzheimer's Society, 2022; NHS Digital, 2023d; UK Government, 2022)
			Lack of guidance on support for people living with dementia post diagnosis, reducing the opportunities for people living with dementia to access to quality care					(Royal College of Psychiatrists, 2018; Health and Social Care Northern Ireland, 2023; Arblaster and Brennan, 2022; Dementia Voice Team, Alzheimer's Society, 2022)
Healthcare and Treatment	Access	Structural	Less research output to support treatments					(UK Government, 2015, 2022; NHS, 2019; Hopson, 2023)
			The absence of societal costs in cost effectiveness analysis (CEA) means no inclusion of caregiver burden or explicit consideration of health inequalities, and so the full impact of treatments for people living with dementia is not accounted for. This puts them at a disadvantage compared to treatments for other diseases that do not depend so heavily on carers or face such large inequalities				(Torres L. et al., 2022)	(National Institute for Health and Care Excellence, 2021)

			Fragmented services make accessing healthcare challenging					(Arblaster and Brennan, 2022)
Healthcare and Treatment	Access	Structural	Less experience of dementia appropriate care					(UK Government, 2015)
Healthcare and Treatment Carer support	Access	Structural	People living with dementia are less likely to seek healthcare and carer support due to stigma				(Bennett H.Q. et al., 2018)	(Dementia Voice Team, Alzheimer's Society, 2022)
Carer Support	Access	Structural	People living with dementia experience higher financial burden (indirectly less access/utilisation of care)					(Keohane and Petrie, 2019)
			Low access to formal carers providing quality, experienced care					(Dementia UK, 2020)
	Experience	Insufficient Investments/ Public Funding	Reductions in social care funding have a larger impact on people living with dementia in comparison to other diseases				(Wittenberg R. et al., 2019)	
End of Life	Access	Communi-cation, Consent and Decision Making	People living with dementia are significantly less likely to have an advance care plan (ACP) compared to those with cancer				(Moore K.J. et al., 2020; Sampson, 2010)	

TABLE A4: INEQUALITIES IDENTIFIED FOR INFORMAL CARERS OF PEOPLE LIVING WITH DEMENTIA COMPARED TO CARERS OF OTHER PEOPLE LIVING WITH DEMENTIA

Inequality Group	Health and Social Care Inequalities	Publication Quantity	Publication Quality	Publisher Quality	Academic Reference	Grey Literature Reference
Gender	More carers for people with dementia are women, increasing the burden placed on women compared to men				(Manthorpe and Samsi, 2020)	(Alzheimer's Research UK, 2022b; Fenton, 2016)
	Female carers of people living with dementia are less supported and report overall higher levels of stress, burden and depression compared to male carers				(Manthorpe and Samsi, 2020; Sutcliffe C.L. et al., 2016)	(Fenton, 2016)
	Women are more likely to combine caregiver roles (such as caring for a family and someone living with dementia)				(Egdell V., 2012)	
Dementia Stage	Carer burden is higher for carers of people living with dementia who require more supervision				(Sutcliffe C.L. et al., 2016; Bremer P. et al., 2015)	
Type of Dementia	Carers of rare types of dementia are not provided the support that is appropriate for the person they care for					(The King's Fund, 2023)
Co-morbidities	Higher carer burden for carers of people living with both cancer and dementia				(Price M.L. et al., 2022)	
Structural	Arts-based programs improve carer's well-being, but they are not available to all people living with dementia and their carers				(Windle G. et al., 2020)	
Socioeconomic	Carers of people living with dementia who lived in higher area deprivation (lower IMD decile) were associated with a greater decline in quality of life following the COVID-19 pandemic				(Hicks B. et al., 2022)	
Age	Older carers are at greater risk of negative effects (poorer mental and physical health outcomes)				(Oliveira D., Sousa L., and Aubeeluck A., 2020; Egdell V., 2012)	
	Carers of working age can have their careers, finances and quality of life impacted					(Dementia UK, 2020)

TABLE A5: INEQUALITIES IDENTIFIED FOR INFORMAL CARERS OF PEOPLE LIVING WITH DEMENTIA COMPARED TO THE GENERAL POPULATION

Inequality Group	Health and Social Care Inequalities	Publication Quantity	Publication Quality	Publisher Quality	Academic Reference	Grey Literature Reference
Gender	More informal carers for people with dementia are women				(Manthorpe and Samsi, 2020)	
Finances	Financial pressures as a result of needing to fund care to meet complex needs and/or leaving work to provide informal care				(Manthorpe and Samsi, 2020)	(Keohane and Petrie, 2019)
Health and Well-being	Carers are more likely to experience negative emotions and mental health problems such as depression and anxiety disorders compared to the general population. Ultimately, this can impact their ability to continue to provide care				(Manthorpe and Samsi, 2020; Lacey, McMunn and Webb, 2018; Hall L. and Skelton D.A., 2012; Egdell V., 2012; Botsford, Clarke and Gibb, 2011)	(Dementia UK, 2020; Fenton, 2016; Daly and Allen, 2016)
	Loneliness of carers during the period of lockdown				(Hanna K. et al., 2022)	
	Carers of people living with dementia experience a huge burden as they have to make decisions on access and continuation of treatment on behalf of people living with dementia				(Hutchings et al., 2010)	
	Few people with dementia have an advance care plan in place when they move into a care home, placing additional burden on carers				(Cooper C. et al., 2017; Manthorpe and Goodwin, 2019)	
	For most family carers, the pandemic led to a significant decrease in carer's mental health and well-being				(Daley S. et al., 2022)	
	Lack of expertise in managing physical conditions in a specialist dementia unit adds burden and additional responsibilities to the carer, resulting in high levels of stress				(Hynes C. et al., 2022)	
Health and Well-being	Carers often feel isolated and unsupported, lacking a reliable first point of contact for advice when confronted with challenging decisions to make				(Hynes C. et al., 2022; Egdell V., 2012)	(Arblaster and Brennan, 2022; Fenton, 2016; Daly and Allen, 2016)
	Abuse from individuals they are caring for increases carer burden and anxiety				(Cooper C. et al., 2008)	

Inequality Group	Health and Social Care Inequalities	Publication Quantity	Publication Quality	Publisher Quality	Academic Reference	Grey Literature Reference
	Being an informal carer was associated with increased adiposity (excess body fat) amongst UK men and women. Caring is particularly negatively associated with adiposity when occurring during non-normative life stages, such as early adulthood, and when high-intensity				(Lacey, McMunn and Webb, 2018)	
	Carers experience reduced sleep, impacting their quality of life and ability to continue to provide care				(Kinnunen et al., 2018; Richardson et al., 2021)	
Structural	Systems are not currently designed to involve family carers in decision-making, and healthcare professionals reported not routinely involving carers in appointments or decision-making processes				(Bhatt J. et al., 2022)	

TABLE A6: INEQUALITIES IDENTIFIED FOR INFORMAL CARERS OF PEOPLE LIVING WITH DEMENTIA COMPARED TO CARERS OF PEOPLE LIVING WITH OTHER DISEASES

Inequality Group	Health and Social Care Inequalities	Publication Quantity	Publication Quality	Publisher Quality	Academic Reference	Grey Literature Reference
Structural	Lack of preparedness for end of life				(Lamahewa et al., 2018)	
	Challenges associated with planning for future care				(Giebel C. and Heath B., 2023)	
	Difficulties obtaining a diagnosis make it difficult for carers to seek support both from practitioners and social/informal networks (statutory or voluntary services)				(Egdell V., 2012)	
	The requirement for informal care to help people living with dementia means that primary carers usually have no training, preparation and very little support in their role					(Dementia UK, 2020)
Well-being	Higher numbers of tasks they need to provide support with compared to other conditions, increasing stress				(Egdell V., 2012)	

Appendix 4: Diagnosis Rate

Diagnosis rate data in England are published monthly at the sub-ICB level by NHS Digital as part of the Primary Care Dementia Data series (previously the Recorded Dementia Diagnosis series) (NHS Digital, 2023d, 2022b). We use annual diagnosis rate data (recorded in April of each year).

The number of persons estimated to have dementia (the denominator of the diagnosis rate) is calculated by NHS Digital and is based on the age- and sex- specific prevalence rates of the Cognitive Function and Ageing Study II (Matthews et al., 2013; CFAS, 2023). Further detail on how the diagnosis rate measure is calculated by NHS Digital is included in the NHS Digital methodology of indicators (see NHS Digital, 2023). However, it is important to note that changes have been made to the data collection procedures for the diagnosis rate in England, meaning that data from May 2023 is no longer directly comparable to previous data.

Appendix 5: Sub-ICB-level Deprivation Measure

We use the percentage of patients living in the most deprived Lower Layer Super Output Area (LSOA) as a sub-ICB level measure of deprivation. The percentage of patients living in the most deprived LSOA is created from three main sources, as follows. Firstly, data is available on the LSOA of patients registered at a GP practice in England (NHS Digital, 2023b). Secondly, the GP practice data on these patients and their LSOAs can be mapped to the sub-ICB for each practice (NHS Digital, 2023d). Thirdly, the deprivation deciles from English Indices of Multiple Deprivation (IMD) 2019 data (DLUHC, 2019) can then be linked to the LSOAs of these patients, to quantify the level of deprivation that the patients in a sub-ICB are living in. From this, we created a measure of deprivation at the sub-ICB level which is equal to the percentage of patients living in the most deprived IMD decile of LSOAs.

Appendix 6: Sub-ICB-level Rurality Measure

The rurality variable is created in a similar way to the deprivation measure, using data from three main sources, as follows. Firstly, data is available on the LSOA of patients registered at a GP practice in England (NHS Digital, 2023b). Secondly, the GP practice data on these patients and their LSOAs can be mapped to the sub-ICB for each practice (NHS Digital, 2023d). Thirdly, we can link 2011 rural/urban classification data, which determines whether an LSOA is rural or urban (ONS, 2011). With these data, we create a continuous measure of rurality that demonstrates the percentage of registered patients in the sub-ICB that live in a rural LSOA.

Appendix 7: Deprivation Concentration Index Estimation Method

We estimated the deprivation concentration index using an Ordinary Least Squares (OLS) regression, following methods outlined in (O'Donnell et al., 2007):

$$2\sigma_r^2\left(\frac{d_i}{\mu_d}\right) = \alpha + \beta r_i + \sum_i \delta_j x_{ji} + \varepsilon_i$$

Where i is a sub-ICB. r is the fractional rank of the deprivation measure (the relative position of how deprived the sub-ICB is), therefore $2\sigma_r^2$ is equal to 2 times the variance of the fractional rank. d_i is the diagnosis rate, μ_d is the average diagnosis rate across all sub-ICBs x_j are the risk-adjustment variables. The OLS estimate of β is an estimate of the indirectly standardised concentration index.

Appendix 8: Full Detail of Coefficients and Confidence Intervals in Case Studies 1, 2 and 3

TABLE A7: DEPRIVATION CONCENTRATION INDICES OVER TIME (REGRESSION COEFFICIENTS)

Year	2018	2019	2020	2021	2022	2023
Concentration index (unadjusted)	0.021 [0.013, 0.029]	0.019 [0.011, 0.027]	0.022 [0.014, 0.030]	0.026 [0.016, 0.036]	0.022 [0.013, 0.032]	0.026 [0.015, 0.036]
Concentration index (adjusted)	0.006 [-0.005, 0.018]	0.008 [-0.004, 0.020]	0.013 [-0.000, 0.027]	0.006 [-0.010, 0.023]	0.010 [-0.004, 0.024]	0.004 [-0.012, 0.021]

95% confidence intervals are included below the concentration indices, in brackets. Adjusted concentration indices control for rurality, diabetes prevalence, hypertension prevalence, stroke prevalence and obesity prevalence.

TABLE A8: RURALITY CONCENTRATION INDICES, OVER TIME (REGRESSION COEFFICIENTS)

Year	2018	2019	2020	2021	2022	2023
Concentration index (unadjusted)	-0.028 [-0.036, -0.020]	-0.029 [-0.037, -0.021]	-0.018 [-0.026, -0.010]	-0.029 [-0.039, -0.019]	-0.029 [-0.038, -0.020]	-0.030 [-0.040, -0.020]
Concentration index (adjusted)	-0.028 [-0.040, -0.017]	-0.027 [-0.038, -0.016]	-0.011 [-0.022, -0.000]	-0.023 [-0.036, -0.011]	-0.026 [-0.039, -0.013]	-0.031 [-0.045, -0.017]

95% confidence intervals are included below the concentration indices. Adjusted concentration indices control for deprivation, diabetes prevalence hypertension prevalence, stroke prevalence, obesity prevalence and depression prevalence.

TABLE A9: DIFFERENCE IN AVERAGE DEMENTIA PREVALENCE RATES (PER 1000 OF THE POPULATION) BETWEEN EACH MINORITY ETHNIC GROUPS, COMPARED TO THE WHITE ETHNIC GROUP

Ethnic group	Difference in group means, compared to the White ethnic group	2018	2019	2020	2021	2022	2023
Asian or Asian British	Unadjusted	-1.55 [-1.98, -1.12]	-1.79 [-2.26, -1.32]	-1.67 [-2.07, -1.26]	-2.10 [-2.52, -1.68]	-2.71 [-3.14, -2.29]	-5.03 [-5.49, -4.56]
	Adjusted	-1.59 [-1.99, -1.18]	-1.84 [-2.26, -1.41]	-1.81 [-2.22, -1.40]	-2.10 [-2.48, -1.71]	-2.71 [-3.11, -2.32]	-5.03 [-5.48, -4.58]
Black or African or Caribbean or Black British	Unadjusted	-2.85 [-3.26, -2.45]	-3.23 [-3.67, -2.80]	-3.17 [-3.55, -2.79]	-3.56 [-3.96, -3.17]	-4.14 [-4.56, -3.72]	-5.61 [-6.21, -5.00]
	Adjusted	-2.89 [-3.28, -2.51]	-3.29 [-3.69, -2.88]	-3.29 [-3.68, -2.90]	-3.56 [-3.93, -3.20]	-4.14 [-4.53, -3.75]	-5.61 [-6.15, -5.06]
Mixed or Multiple Ethnic Groups	Unadjusted	-2.19 [-2.61, -1.78]	-2.55 [-3.01, -2.09]	-2.44 [-2.85, -2.04]	-2.85 [-3.29, -2.41]	-3.62 [-4.03, -3.21]	-6.13 [-6.59, -5.67]
	Adjusted	-2.25 [-2.64, -1.86]	-2.59 [-3.01, -2.18]	-2.57 [-2.97, -2.18]	-2.85 [-3.24, -2.46]	-3.62 [-4.00, -3.23]	-6.13 [-6.57, -5.68]

95% confidence intervals are included below the concentration indices, Adjusted concentration indices control for sub-ICB level covariates of the % of registered patients in each age category, the % registered female patients, deprivation, diabetes prevalence hypertension prevalence, stroke prevalence, obesity prevalence and depression prevalence.

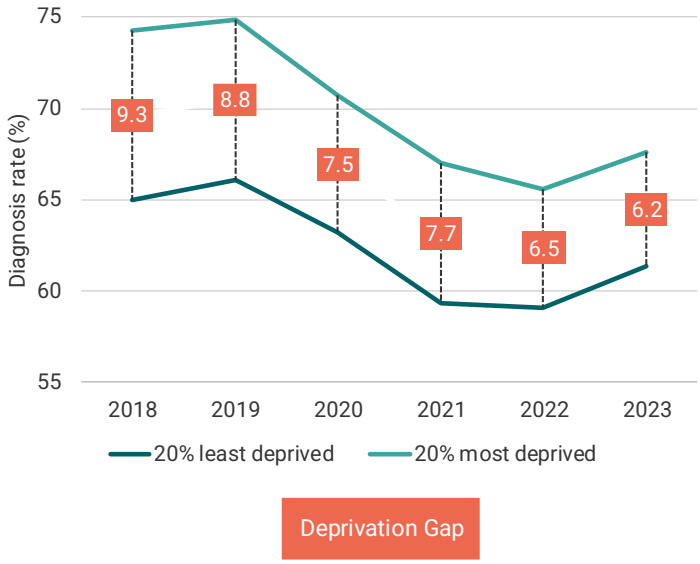
Appendix 9: Deprivation-Related Inequality Analysis using the Income Deprivation Index

Results 1: Deprivation gap

Figure A1 plots the average diagnosis in the 20% most deprived sub-ICBs and the 20% least deprived sub-ICBs between 2018 and 2023, and the deprivation gap (the difference between the two groups) using the alternative income deprivation index. The figure shows that, on average, diagnosis rates are higher in the most deprived sub-ICBs.

A rurality gap of 6.2 indicates that diagnosis rates are 6.2 percentage points higher in the most deprived group, compared to the least deprived group. Figure A1: Average diagnosis rates in the 20% most and least deprived groupsshows consistent results with the main analysis in Case Study 1. The diagnosis rate deprivation gap has fluctuated over time, however, there has been a general decrease in this measure.

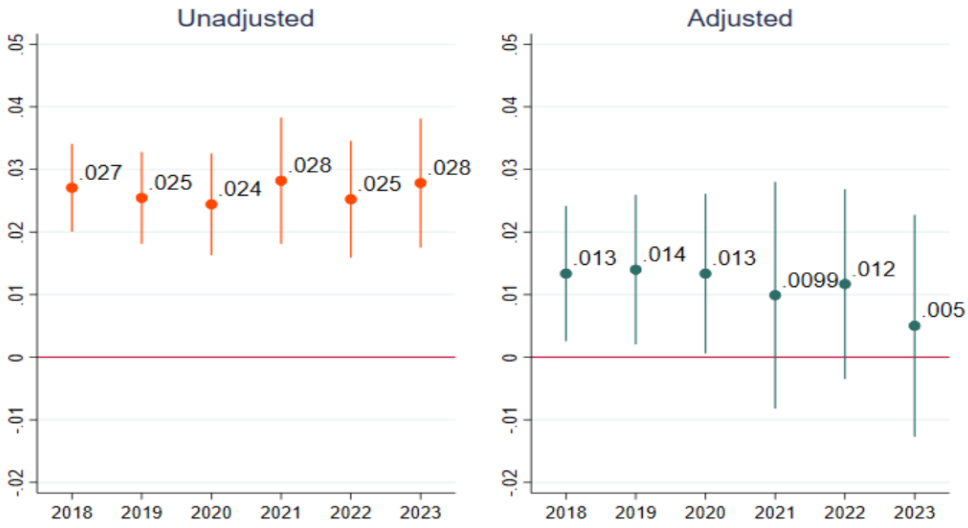
FIGURE A1: AVERAGE DIAGNOSIS RATES IN THE 20% MOST AND LEAST DEPRIVED GROUPS



Results 2: Concentration Index

Figure A2: CONCENTRATION INDICES OVER TIME (REGRESSION COEFFICIENTS) also shows consistent results with the main analysis, in terms of the size, direction and statistical significance of the estimated concentration index.

FIGURE A2: CONCENTRATION INDICES OVER TIME (REGRESSION COEFFICIENTS)



Appendix 10: Rurality Concentration Index Estimation Method

We estimated the rurality concentration index using an Ordinary Least Squares regression, following methods outlined in (O'Donnell et al., 2007):

$$2\sigma_r^2\left(\frac{d_i}{\mu_d}\right) = \alpha + \beta r_i + \sum_i \delta_j x_{ji} + \varepsilon_i$$

Where i is a sub-ICB. r is the fractional rank of the rurality measure (the relative position of how rural the sub-ICB is), therefore $2\sigma_r^2$ is equal to 2 times the variance of the fractional rank. d_i is the diagnosis rate, μ_d is the average diagnosis rate across all sub-ICBs x_j are the risk-adjustment variables. The OLS estimate of β is an estimate of the indirectly standardised concentration index.

Appendix 11: Ethnicity Regression Analysis

We used OLS regression analysis to estimate the differences in prevalence rates between ethnic groups, calculated for each year, separately, following:

$$\begin{aligned} DementiaPrevalence_{ig}{}^{t} &= \beta_0{}^{t} + \beta_1 BlackEthnicGroup_{ig}{}^{t} + \beta_2 AsianEthnicGroup_{ig}{}^{t} \\ &+ \beta_3 MixedEthnicGroup_{ig}{}^{t} + \boldsymbol{\gamma Covariates}_{i}{}^{t} \end{aligned}$$

Where, the subscript i indicates the sub-ICB, g indicates the ethnic group, and t indicates the year of the data used in that regression. $BlackEthnicGroup$ is a binary variable equal to 1 for the Black ethnic group, and 0 otherwise. $AsianEthnicGroup$ is a binary variable equal to 1 for the Asian ethnic group, and 0 otherwise. $MixedEthnicGroup$ is a binary variable equal to 1 for the Mixed ethnic group, and 0 otherwise. Included covariates ($\boldsymbol{Covariates}$) are dementia risk factors (diabetes, hypertension, stroke and obesity prevalence in the previous year), age and gender at the sub-ICB level. Each regression is carried out separately, for each year of data.

The important details to note from the regression equation above, is that β_1 gives the difference in prevalence between the Black ethnic group compared to the White ethnic group. β_2 gives the difference in prevalence between the Black ethnic group compared to the White ethnic group. β_3 gives the difference in prevalence between the Black ethnic group compared to the White ethnic group. Excluding the covariates from the regression produces the unadjusted estimates, and including the covariates produces the adjusted estimates.

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