

# Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England

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This report was researched and funded by Alzheimer's Society.



All-Party  
Parliamentary Group  
on Dementia



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# Foreword

Dementia diagnosis is the key which unlocks vital care and support for people living with dementia, particularly those who are struggling to manage their symptoms alone. It helps people to understand their condition, and it allows them and their loved ones to start planning for the future.

The All-Party Parliamentary Group on Dementia is acutely aware of the importance of a dementia diagnosis, but we also know that the diagnosis rate in England dropped from 67.6% to 61% during the Covid-19 pandemic. It has not recovered, sitting at around 63.8% today.

Although the national picture is poor, when we dig further into the data, we can see that there is huge regional variation in dementia diagnosis rates. In Stoke-on-Trent, for example, the rate is more than 80%, while in South Hams in Devon it is just over 40%.

Where you live has a massive impact on whether you will get a timely, accurate and high-quality dementia diagnosis. We are united in our view that a postcode lottery for a condition which will affect 1 in 3 of us is not acceptable.

However, during this inquiry, we have been struck by the number of examples of good practice going on in pockets all over the country. Good work is being done and it needs to be scaled up and shared across the NHS – this is the central recommendation of this report. We see this as a key part of the Government's Levelling Up agenda. Health outcomes should not be so disparate between local authorities, and urgent work needs to be done to ensure equitable access to dementia diagnosis.

We have heard a great many powerful, thoughtful and insightful submissions from people right across the dementia sector as part of this inquiry. In particular, we want to thank the 2,300 people who filled out our online survey and shared their story to inform this work. These were all people who either had dementia or had been closely involved with the diagnosis journey of a loved one.

Sadly, just 5% of the 1,400 direct stories were positive. That underlines for us the importance of improving the dementia diagnosis pathway and making it work better for people living with dementia and their loved ones.

The words of people affected by dementia are woven through this report, and they serve as an important reminder that behind the figures and statistics are real people going through extremely trying circumstances. As a Group we have kept this front of mind in our work. This is the first inquiry report we have worked on together as co-chairs and it has been a great pleasure to do so. Together, we thank everyone who has helped shape this inquiry and we look forward to taking our recommendations forward so everyone living with dementia can access a timely, accurate and high-quality dementia diagnosis regardless of where they live.

**Debbie Abrahams MP and  
Baroness Angela Browning,  
co-chairs, APPG on Dementia.**



# List of Acronyms

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**APPG:** All-Party Parliamentary Group

**APG:** All-Party Groups (Northern Ireland Assembly)

**CCGs:** Clinical Commissioning Groups

**CSF:** Cerebrospinal Fluid

**CPGs:** Cross-Party Groups (Welsh Parliament)

**GP:** General Practitioner

**ICS:** Integrated Care System

**OHID:** Office for Health Improvement and Disparities

**PET:** Positron Emission Tomography

**NHS:** National Health Service

**QOF:** Quality and Outcomes Framework

**VCSE:** Voluntary, Community and Social Enterprise Sector

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# Executive Summary

Whether enabling access to medications, support or simply the relief of understanding what is causing the difficulties they are experiencing, 91% of people affected by dementia see clear benefits of getting a diagnosis<sup>1</sup>. Unfortunately, however, the delivery of dementia diagnoses across England has yet to catch up with this, with a current national diagnosis rate of just 63.8%<sup>2</sup>. This means that at the time of writing 257,390 people with dementia are living without an accurate diagnosis and support in England.

Behind these national statistics is significant variation in how quickly and accurately people are being diagnosed with dementia based on where they live in the country. There is a difference of over twenty percentage points in the dementia diagnosis rates between the highest and lowest performing Integrated Care Systems (ICSs) in England at present<sup>3</sup>. This inquiry furthers our understanding of why this is the case by examining how the most deprived and rural communities are particularly adversely affected by this regional disparity.

The inquiry heard from over 2,300 people living with dementia via our survey, oral and written evidence submissions. We also reviewed evidence from academics, health care leaders and clinicians regarding what the current barriers and enablers are to accessing a dementia diagnosis in England's rural and deprived regions. Alongside hearing how a breadth of factors such as limited transport access and reluctance to seek a dementia diagnosis particularly affect these communities, we were also grateful to hear about innovative and effective initiatives to overcome these and level up the dementia diagnosis rate across England. The inquiry's findings show a complex picture in which issues ranging from variation in population health risk and dementia public health understanding, to the geographical spread of brain scans and transport networks all play a part in regional dementia related health disparities.

**91%** of people affected by dementia see clear benefits of getting a diagnosis

The diagnosis rate in England is just **63%**

**257,390** people with dementia living in England without an accurate diagnosis at the time of this report

**20%+** difference between highest and lowest diagnosis rates in ICSs in England

**2,300+** people took part in this inquiry via surveys, and oral and written evidence

The recommendations resulting from the inquiry are therefore ambitious and wide ranging, united by the aim to increase access to a timely and accurate dementia diagnosis for those living in the most rural and deprived regions of England. This will require a commitment from key stakeholders, particularly the Office for Health Improvement and Disparities (OHID), NHS England and ICS leaders to deliver on increasing the detail and quality of dementia data collection and publication, and more importantly translating the subsequent learnings into action. This means targeted public health messaging and the development of dementia diagnosis learning networks within and between ICSs to scale up the examples we have heard in which rural and deprived areas are successfully delivering on dementia diagnosis rates.

It also means taking a whole system approach, including the voluntary community and social enterprise sector, to engage with rural and deprived communities in ways that make sense and are accessible to them.

Unwarranted regional variation in dementia diagnosis rates must be tackled by national and local systems. Otherwise, people living in rural and deprived areas without strong diagnosis pathways and support to access them will continue to be left to cope alone with dementia symptoms and more likely to experience avoidable deterioration in their condition. They will also be disproportionately less able to access new disease-modifying treatments, which are for the first time on the cusp of becoming available<sup>4</sup>.





# Recommendations

Our healthcare system must be inclusive of all who need a diagnosis of dementia, enabling access across every region of England to the advice, care, support and treatment that timely dementia diagnosis can bring. The All-Party Parliamentary Group on Dementia has heard in this inquiry that for too many people in the most deprived and rural regions of England this is not the case as they encounter barriers within their communities and the healthcare system.

Fortunately, we have also heard about areas which have managed to inclusively diagnose those living with dementia in rural and deprived communities. This must be used to inform best practice and delivered at scale so that all who need it can receive a timely and accurate dementia diagnosis.

To achieve this, the Group has developed a series of recommendations across the core themes of dementia diagnosis, data, workforce and public health messaging. Collectively these recommendations outline how dementia pathways can be strengthened to enable access and quality care across all settings, communities and regions in England. While the evidence and recommendations mainly relate to England as informed through the research process, the Group is willing to share findings and work together with equivalent Cross-Party Groups (CPGs) and All-Party Groups (APGs) in the Welsh Parliament and Northern Ireland Assembly to drive change and make dementia a priority in other regions.

## Enabling dementia diagnoses

**1. Each ICS must develop a comprehensive dementia strategy** to enable and support the implementation of the Group's recommendations, driven by an overarching target set by the Government to return and go beyond the national 66.7% dementia diagnosis rate.

**2. All dementia diagnoses must include an accurate subtype.** To end regional inequity of access to advanced diagnostics needed to indicate subtype, such as Positron Emission Tomography (PET) brain scans and cerebrospinal fluid (CSF) the Government must drive emerging research and ultimately timely implementation of blood-based biomarker tests.



## Data

**3. NHS England must continue to review and develop its methods for calculating dementia prevalence and dementia diagnosis rates** based on the evolving evidence base regarding the influence of population health indicators on dementia prevalence. The development of more sophisticated calculations of dementia diagnosis rates along these lines will enable system resources to be deployed in increasingly targeted and effective ways, enhancing accountability for performance and improving care for patients.

**4. A national Dementia Observatory should be created to collate and publish existing data collected across system levels** (i.e. nationally, at ICS and sub-ICS level). This should include the development of additional indicators for the improvement of quality and access to a dementia diagnosis, such as dementia subtype. This intelligence can be used to identify targets for improvement where it is most needed. Regional NHS England leadership has the potential to facilitate this, for example by supporting high-performing diagnosis pathways or practices to scale up across an ICS, and hosting regional learning and improvement networks to share best practice.





## Public Health and messaging



**5. OHID data intelligence regarding the scale and spread of associations between deprivation, rurality and estimated dementia diagnosis rates is translated into action.** Specifically, this should include targeted public health messaging in regions and localities most in need of improving dementia diagnosis rates. Messaging should focus on tackling reluctance to seek a dementia diagnosis in rural and deprived communities, and local health care systems must work with (the Voluntary, Community and Social Enterprise) VCSE sector to bridge the gap between them and the communities they serve.

**6. A broader range of regional and local channels for communication must be utilised to reach those who may be lost to system (i.e. living with dementia and unaware of or unable to access diagnostic services).** ICSs must bring together the communities they serve to enable regional and local relationships to develop, such as between dementia services, primary care networks, local authorities, the VCSE sector and community bodies such as parish councils, farmer's unions and faith networks. By bridging the gaps between communities and health services – whether via person-centred transport planning or dissemination of public health information, health inclusion for people living with dementia in the most rural and deprived areas can improve. Making dementia more of a strategic priority for national and local systems will help to raise awareness of dementia and tackle the stigma of a diagnosis as part of a system-wide approach to increasing national diagnosis rates.

## Workforce



**7. Government should ensure the primary care workforce is adequately planned and resourced to enable capacity,** including to engage in continuing professional development on the assessment and benefits of dementia diagnosis. GPs should also be enabled to engage with their primary care networks to maintain awareness of their local referral pathways, and trained to an adequate level to facilitate and undertake dementia diagnosis where appropriate. To support this NHS England should consider incentives, such as reinstatement of the dementia screening Quality and Outcomes Framework (QOF).

**8. Post-diagnostic dementia support services must be available more equitably across England and supported by a named professional to coordinate each individual's dementia journey.** This requires a workforce plan from the Government which is inclusive of allied health professionals and a broader range of non-clinical roles such as social prescribers and dementia advisors. The evidence base for placing a dementia advisor in every primary care practice must be translated into action through each ICSs dementia strategy to increase access to a timely dementia diagnosis and support, particularly in rural and other communities experiencing health disparities. Alternatively, a minimum of one practice advisor (GP or Nurse practitioner) could be appointed per primary care practice to skill up in dementia awareness, assessment and their local dementia pathway,

# Introduction

## Dementia diagnosis: The current picture in England

**“I had to fight for everything to do with my late husband’s dementia.”** Family carer’s experience of obtaining a diagnosis for her husband.<sup>5</sup>

**“The worst part of trying to get a diagnosis is that I was often seen by different doctors each time. Then, when I did see a regular doctor, it had taken up to 5 years to have a scan. Then the doctor had the confirmation of dementia, but kept it on the computer [...] then he retired. When a new doctor was brought in during 2019, I was diagnosed with complex early onset Alzheimer’s dementia. That’s how we know it had been diagnosed in 2017.”** Person with dementia describing the barriers they faced in obtaining their diagnosis.<sup>6</sup>

**“Both parents were diagnosed with mixed dementia. My mum was very unwilling to get help, but it was available. The GP acted quickly when contacted by me, their daughter. The Memory Clinic were excellent. And so helpful.”** Family carer’s experience of obtaining dementia diagnosis and subsequent support for her parents.<sup>7</sup>

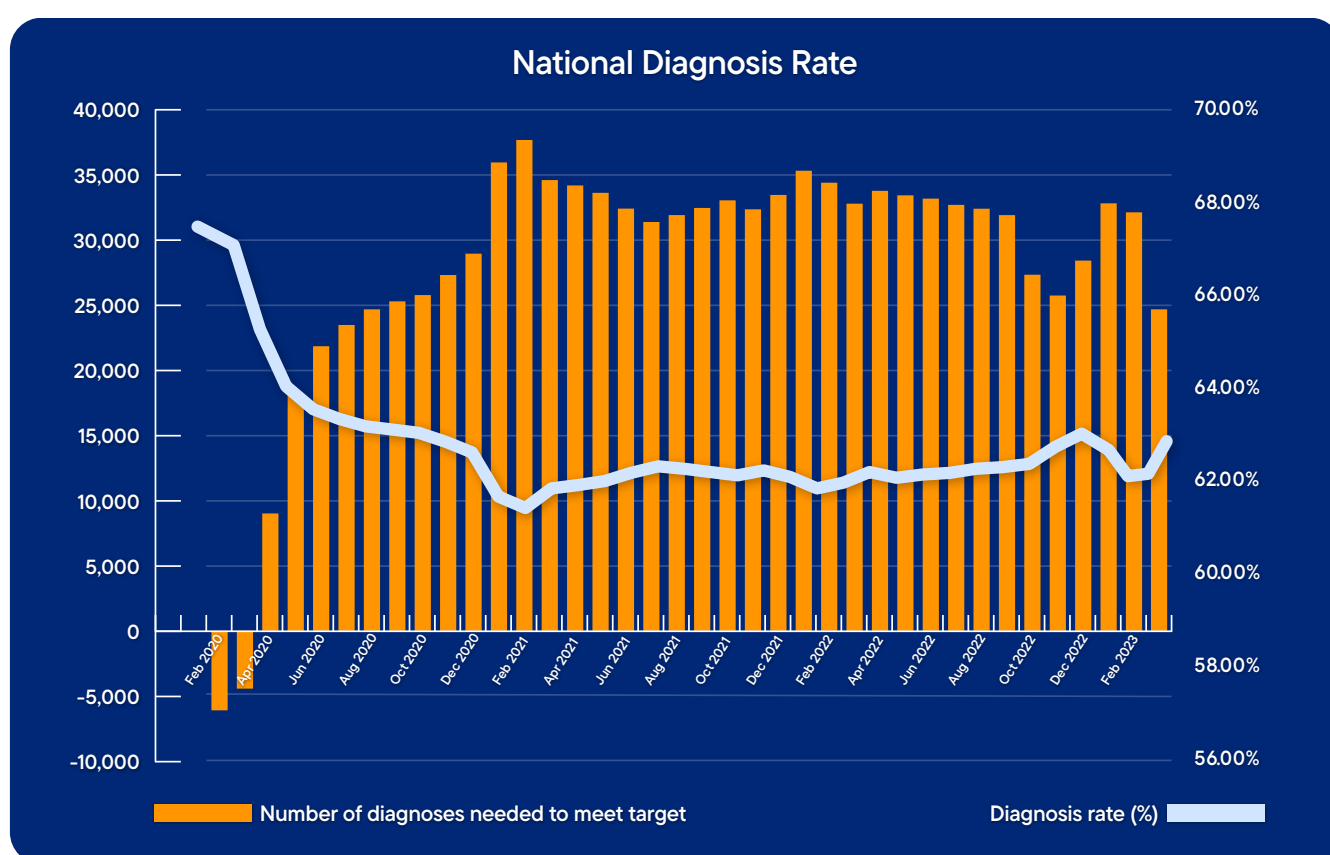
A dementia diagnosis is a fundamental first stage of the dementia pathway.<sup>8</sup> 91% of people affected by dementia see clear benefits of getting a diagnosis, such as access to medications and ongoing support.<sup>9</sup> Missing out on an early and accurate diagnosis can have a significant negative impact, for example limiting access to symptom management interventions, ultimately leading to poorer outcomes and increased health and social care costs.<sup>10</sup> A timely dementia diagnosis is reliant on multiple factors, from public health awareness and the training of health and social care professionals, to recognising the symptoms of dementia and initiating referral. Local healthcare system capacity to assess and diagnose with timeliness and accuracy is also crucial.<sup>11</sup>

This inquiry focuses on understanding the scale of impact of regional health inequalities on access to a dementia diagnosis and developing solutions to reduce their influence. We know from previous research that both population health risk and how dementia care is organised across England affect the experiences, health and wellbeing of people living with dementia and their families.<sup>12</sup>

Alzheimer’s Society has reported on the key system barriers to receiving a dementia diagnosis. In 2022, the Society brought together researchers, clinicians, people living with dementia and decision makers, to form a consensus on the barriers to, and solutions for improving access to a timely and accurate diagnosis of dementia. Barriers identified included workforce capacity, diagnostic pathway design, funding arrangements, public health messaging and regional variation in diagnosis rates.<sup>13</sup>

This inquiry builds on this by taking a whole system view across England, presenting novel health inequalities data and innovative recommendations from key stakeholders working on dementia. By bringing together those living with dementia, researching inequalities in diagnosis, and delivering impactful solutions in their local systems, **this report and its dissemination aims to reduce variation in dementia diagnosis in England and enable everyone to access the support and treatment they need and want to live well with dementia.**

The below graph contextualises the current picture for dementia diagnosis in England<sup>14</sup>. The COVID-19 pandemic caused a significant decline in dementia diagnosis rates - NHS Digital statistics show that the dementia diagnosis rates dropped from 67.6% in January 2020 to 61.1% February 2021, and has only recovered to 63.0% since.<sup>15</sup> This means that at the time of writing 258,489 people with dementia were living in England without an accurate diagnosis, limiting their access to support and care. The diagnostic backlog continues to impact dementia assessment services (commonly called memory assessment services or clinics), as the dementia diagnosis rate has lingered between 61.1% and 63.0% since September 2020.<sup>16,17</sup>



There are several barriers to the recovery of dementia diagnosis rates across the UK, including workforce capacity, poorly designed dementia diagnosis pathways and concerns around funding arrangements.<sup>18</sup> Regional variation underpins all these issues.<sup>19</sup>

The recovery of England's dementia diagnosis rates to 66.7% was added to NHS England's priorities and operational planning guidance 2023/24 for the first time.<sup>20</sup> This indicates that dementia is seen as a priority for the NHS, coming at the same time as the Government's announcement that dementia is one of six priority conditions proposed for inclusion in a Major Conditions Strategy.<sup>21</sup> These frameworks ought to enable and govern restoration of the dementia diagnosis rates, and ultimately lead to a more ambitious national target being set. Building on the success of past dementia strategies for England, setting clear targets for earlier and improved diagnosis alongside workforce planning and investment in diagnostic equipment can help people access the appropriate care and support they need.<sup>22</sup>

## Regional variation in dementia diagnosis rates

There is significant regional variation in dementia diagnosis rates across England. Diagnosis rates vary across ICSs from 73.5% (South Yorkshire), to 53.4% (Herefordshire and Worcestershire).<sup>23</sup> A 2022 report on the topic highlighted that three of the best performing ICSs were in London, and five of the six ICSs with the lowest diagnosis rates were in the South West of England.<sup>24</sup>

In a 2021 report, Alzheimer's Society found that dementia diagnosis rates are influenced by regional factors which can impact processes at each step of the diagnostic pathway.<sup>25</sup> For example, there was significant variation in primary care providers' engagement in dementia case-finding and identification. This includes processes such as proactively reviewing GP registers and offering screening to those at risk, and reducing the incidence of people missing out on a diagnosis due to limited dementia awareness or reluctance to seek help. The report's recommendations were primarily targeted at local healthcare systems, and included proposed improvement of integration across primary and secondary care services involved in dementia diagnosis, and streamlined data sharing and referral processes.

Prior to the COVID-19 pandemic, England had for some time been achieving the national ambition of diagnosing two-thirds of people living with dementia.<sup>26</sup> Where regions were still struggling to achieve this, conversations with local health care providers, commissioners and clinicians found that, amongst other factors, regional differences in socio-economic deprivation and levels of rurality can affect the identification of dementia as well as presentation and access to dementia services.<sup>27</sup>

Further developing our understanding of regional barriers to diagnosis not only serves to drive up national dementia diagnosis rates, but supports a renewed Government focus on the Levelling Up agenda. The statutory introduction of ICSs across England in July 2022 offers a new framework for Government to address dementia diagnosis rates and regional inequalities in care. It has also created a mechanism to hold local decision-makers accountable for inequities within and between ICSs.

The recently published Hewitt review outlines the mechanisms by which this may be achieved, with a particular focus on local autonomy and collaboration.<sup>28</sup> To tackle the diagnosis challenge, it is imperative that we look beyond the national rate and develop our knowledge and solutions to ensure that diagnosis rates are regionally equitable. This inquiry will build on current anecdotal evidence pointing to the factors associated with regional variation in dementia diagnosis rates, and develop pragmatic recommendations to central Government reduce this variation.

## Rurality

Ageing is the biggest risk factor for dementia, and older people comprise a significant segment of the approximately 10 million people in England who live in rural areas.<sup>29</sup> Rural populations are generally older – 24% of those living in rural areas are over 65, compared to 16% in urban areas.<sup>30</sup> The percentage of the population aged over 85 – the group most likely to need care – is significantly higher in rural areas than in urban areas.<sup>31</sup> Public Health England reported in 2019 that the population aged over 65 years old will grow by around 50% in rural areas by 2039.<sup>32</sup> There are particular challenges to accessing healthcare services in rural areas, including infrastructure limitations such as sparse or unreliable transport links and internet access. In addition, living in rural areas increases the risk of social isolation and loneliness which are known to contribute to the risk of dementia.<sup>33</sup> Future Health's recent analysis of dementia diagnosis rates data for England found an association between above average levels of rural living and rates of dementia under-diagnosis.<sup>34</sup>

The Stride England study has found specific differences in the dementia diagnosis pathway in rural settings.<sup>35</sup> For example, there is increased reliance on GPs rather than dementia specialists, increased likelihood that a person with dementia symptoms will be seen by a GP alone, a reduction in specialist services, and reduced likelihood of referral for dementia diagnosis or treatment. In rural settings GPs are often seen as gatekeepers of both diagnosis and treatment.

As part of Alzheimer's Society's diagnosis consensus events in October 2022, leading dementia clinicians, system leaders and academics reported that rural communities tend to be less likely to encounter public health information and to talk about health issues, and therefore to present to healthcare services.<sup>36</sup> In general, patients in rural areas tend to underuse healthcare services, and usage of services is inversely proportional to the time it takes to travel to them.<sup>37,38</sup>

Consequently, people in rural communities on average access diagnostic services later in the progression of their condition, and are more likely to self-manage symptoms and first access diagnostic services following a crisis.<sup>39</sup>

## Socioeconomic status and dementia diagnosis

The Stride England study has found that there is evidence to suggest that socioeconomic deprivation is associated with barriers to dementia diagnosis.<sup>40</sup> The most deprived areas in England have been found to have higher rates of undiagnosed dementia. It is unclear whether this is a result of differences in the characteristics of this population or the care of this population - mechanisms which are not often mutually exclusive. The King's Fund outline that health inequalities can involve the following types of disparity:

- **health status, for example, life expectancy;**
- **access to care, for example, availability of of given services;**
- **quality and experience of care, for example, levels of patient satisfaction;**
- **behavioural risks to health, for example, smoking rates;**
- **wider determinants of health, for example, quality of housing.**<sup>41</sup>

We know that the risk of getting dementia is clearly linked to health inequalities. The latest evidence indicates that 40% of global dementia cases are potentially attributable to twelve modifiable risk factors including poor diet, smoking and excessive alcohol consumption.<sup>42</sup> Whilst dementia prevention itself aims to reduce dementia inequalities, this inquiry focuses on the inequalities in the process of obtaining a dementia diagnosis and the associated impact.<sup>43</sup>

Deprivation is complex and can include a combination of local factors including income, employment, health, education, and living environment, among others.<sup>44</sup> In a survey conducted by Alzheimer's Society in 2021, 73% of memory services, 64% of Clinical Commissioning Groups (CCGs) and 61% of dementia support workers agreed that deprivation and health inequalities were significant factors contributing to regional variation in diagnosis rates.<sup>45</sup> This finding is also supported by academic research, with the most deprived having higher rates of undiagnosed dementia.<sup>46</sup>

Dementia prevalence may be higher, but detection poorer in more deprived areas.<sup>47</sup> For example, higher education levels in more affluent areas might reduce dementia risk, whilst also increasing the detection rate due to higher socio-economic status improving health literacy and access to healthcare.<sup>48</sup> In addition, increased morbidity for other chronic diseases such as cardiovascular disease, coronary heart disease, and diabetes are found in more deprived areas which may increase dementia risk, but also frequency of presentation in primary care and opportunity for dementia screening.<sup>49,50</sup> It is unclear to what extent these opportunities are currently being missed.

The potential complexity in determining dementia prevalence estimates is not yet reflected in NHS England's calculations to generate dementia diagnosis rates. At present, reported dementia diagnosis rates for England are based on estimated prevalence rates accounting only for the population's age and sex profiles.<sup>51</sup> The intersectionality of population characteristics such as age, sex, socioeconomic status and ethnicity is not accounted for in the current national data sets. This ultimately means that disparities in diagnosis rates may be even greater than they currently appear.

## The need for inquiry

The above overview indicates that we currently have a limited understanding of the scale, mechanisms, and impact of the relationships between rurality, deprivation and regional variation in dementia diagnosis rates. Consequently, there is also a paucity of evidence for potential solutions that might enable a sustained and equitable improvement in dementia diagnosis rates across England, and ultimately access to post-diagnosis dementia care, support, and treatment.

This inquiry set out to:

- **gather novel data to develop what we know about how rurality and deprivation impact variation in dementia diagnosis rates across England.**
- **gather evidence to understand the impact of regional variation in diagnosis rates on people living with dementia.**
- **build on this intelligence by identifying tangible actions which can reduce regional variation.**
- **provide recommendations to central and local Government to support the levelling up and health inequalities agendas.**







# Findings

## Understanding the spread of regional variation in dementia diagnosis rates

**“Services were better when we lived in London as opposed to Lincolnshire – it’s a pure North/South divide”.** Dementia carer.

**“It’s a postcode lottery. I’ve been a carer for two family members - one in Essex and another in Cheshire and had two very different experiences.”** Dementia carer.

## What do population statistics tell us about diagnosis rates, deprivation, and rurality?

We know from routinely published health data that dementia diagnosis rates across England continue to show significant variation.<sup>52</sup> To enable whole-system regional and local improvement, it is important to first understand how regional differences relate to population demographics. In addition, if we can learn more about what variance in dementia diagnosis rates look like at a local level – for example between individual services within the same region – it becomes possible to identify targets and mechanisms for improvement. To this end, the Group has reviewed new analysis provided by the Office for Health Improvement and Disparities (OHID) illuminating the relationships between population demographics, particularly levels of rurality and deprivation and estimated dementia diagnosis rates.

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. In other words, rates of dementia diagnosis are higher in areas of higher deprivation.

Regarding rurality, the data shows a moderately strong association between estimated dementia diagnosis rates and rural/urban classifications, with estimated dementia diagnosis rates generally decreasing as the level of rurality increases. Additional dementia diagnosis rates and demographic data summarised for the Group shows that of the seven areas with the highest diagnosis rates in 2022, all are classified as ‘urban’. Fourteen local authority districts had diagnosis rates of below 50%, and only four of these were classified as non-rural.<sup>53,54</sup>

Whilst these associations between demographics and estimated dementia diagnosis rates are reasonably strong, the OHID data shows that only around 20% to 27% of the variation in the estimated dementia diagnosis rates can be explained by the level of deprivation or rurality. Therefore, other factors must contribute to the remaining variation in diagnosis rates, such as how diagnostic pathways are structured and resourced and how they function. The data also cannot tell us about the intersectionality of characteristics which may be associated with dementia diagnosis rates; for example, ethnicity and gender may interact substantially with rurality and deprivation. Nonetheless, we can develop our understanding of regional variation by looking at the considerable variation within CCGs/sub-ICS areas, not just between.

## Variation within sub-ICS regions

OHID's analysis shows that NHS Buckinghamshire CCG had a dementia diagnosis rate in July 2021 of 57.6%. On further examination, the majority of the more rural practices in the region were below the England prevalence rate, yet there were also isolated examples of rural practices that have exceeded the national prevalence rates.<sup>55</sup> The Group heard from Dr Michael Jackson (Program Lead for Neurology and Dementia Intelligence, Office for Health Improvement and Disparities) that this analysis could be used to group primary care (GP) practices by the population characteristics of registered patients, enabling practices with higher rates of recorded dementia prevalence to act as demonstrators of good practice for those serving similar populations but needing improvement.

Intra-regional variation was also evident for primary care practices in what was formerly NHS Knowsley CCG. This CCG was ranked as the most deprived in England, and had an estimated dementia diagnosis rates of 57.5% in the study period (2021). A number of practices in the CCG attained the England prevalence rate. However, controlling for levels of deprivation between practices, comparator practices (i.e. with similar population characteristics but variable diagnosis performance) can be identified and linked up to share learnings.

## How can we use data to improve regional and local diagnosis rates?

In April 2023, OHID released a data tool via the NHS England National Dementia Programme digital platform.<sup>56</sup> This enables local NHS systems to access the estimated dementia diagnosis rates data for their regions and primary care practices in the context of population data on deprivation and rurality.<sup>57</sup> Local system leaders, clinicians involved in the dementia pathway, and other interested parties are encouraged to review this data, and use it to inform and facilitate discussions about the local variations in diagnosis of people with dementia, and identify avenues for improvement where needed.

An initial review of the data available on the platform, which is for all CCGs in July 2021, can also help to identify additional factors contributing to regional variation. For example, some primary care practices show a diagnosed dementia prevalence of more than 40% (i.e. over 40% of all people aged over 65 on their registers have a recorded dementia diagnosis). Further investigation suggests that these practices represent specialist primary care services provided to people living in care homes.

The data also shows that for many places with significantly deprived communities there are outlier practices with very high recorded dementia prevalence. Reaching out to these practices will help us to understand why; for example, whether there are community engagement programmes in these areas, or higher rates of multi-morbidities.

The OHID data enables key stakeholders in the system to develop a much more nuanced understanding of the factors that impact regional variation in dementia diagnosis rates, and points to locally-targeted areas for improvement. The Group heard that rather than being centrally led, this could work via local learning networks, for example with NHS England clinical networks supporting ICSs in their region to collaborate.

Dr Jackson advised for caution, however, in interpreting correlational data, such as the higher diagnosis rates associated with higher levels of deprivation. Our national dementia data systems cannot currently tell us whether, for example, true dementia prevalence is higher in areas with higher levels

of deprivation, or whether detection of cases is simply better. We heard that collection of additional diagnostic data, such as the dementia subtype, would enhance our understanding. This is because some subtypes, such as vascular dementia, are particularly associated with population risk factors.<sup>58</sup>

Whilst rurality and socioeconomic deprivation are important factors, around 75% of dementia diagnosis rates variation is accounted for by other factors. Evidence provided to the Group suggests that this likely includes local variation in the true prevalence of dementia. As outlined above, the dementia diagnosis rates in England are currently calculated by dividing the number of people diagnosed by baseline dementia prevalence. Baseline prevalence is calculated through age and sex profiling of the population, but does not take into account the wider health of the population.

A 2020 Lancet study found that around 40% of dementia cases worldwide might be attributable to twelve potentially modifiable risk factors such as diabetes, obesity, smoking and blood pressure, the prevalence of which also varies by locality.<sup>59</sup> In light of this, review of the current dementia diagnosis rates methodology has become a topic for debate.<sup>60</sup>

The Group heard that applying these population health indicators to estimated dementia diagnosis rates provides a potential mechanism to recalculate the dementia diagnosis rate and assess the performance of a geographical area. Indeed, Future Health Research did just this, and as demonstrated in their analysis, significant changes appear in the dementia diagnosis rate performance of an area when broad population health is considered.<sup>61</sup>

Areas that may appear to be performing well against the government target of 66.7% dementia diagnosis rates may have further room for improvement when population health indicators are applied locally. This is particularly the case where there are notable health inequalities and health outcomes are below the national average, and such metrics could help to target improvement and reduce regional disparities. The Group heard that prevalence is underestimated in regions with higher levels of dementia risk factors. Therefore, areas with seemingly high dementia diagnosis rates may actually benefit from enhanced diagnosis efforts and additional support to improve screening/case finding and access.

Conversely, the Group also heard from members of a strategic dementia group for an ICS region in rural South West England that current dementia diagnosis rates estimates made by NHS Digital may overestimate dementia prevalence in some regions. For example, the ICS region in question has above average levels of 'heart-healthy' older people, which reduces risk for vascular dementia and could mean that the estimated prevalence for the region is higher than actual dementia prevalence in the region. This regional group told us that they have performed below 60% dementia diagnosis rates since 2019, despite efforts to improve, including an increase of 50% in referrals to memory clinics.

Under Future Health's revised model for example, Lancashire and Cumbria ICS has the highest diagnosis performance rate (7.4%) meaning that the region is diagnosing 7.4% more people than expected when compared with the existing NHS data. By comparison North East London ICS has the lowest diagnosis performance rate, of -8.4%, meaning that the region is diagnosing 8.4% fewer people than expected on the existing NHS data. ICSs in the South West: Cornwall, Devon, Herefordshire and Worcestershire, Somerset, Dorset which were in the bottom six for recorded diagnosis all have negative diagnosis performance rates of -2.5%. At local authority level, the new model provides a very different picture for a number of areas, with places such as Manchester, Kingston upon Hull and Southampton falling down the rankings, while others Ryedale, South Staffordshire and West Devon all increase their standing.

## Targeting areas for improvement

In addition to deepening our understanding of population variation in dementia diagnosis rates data, the Group heard from a number of stakeholders about the systemic factors that may be delaying or even preventing the dementia diagnosis process in certain regions or practices. Opportunities clearly exist for primary care practices that share similar registered patient characteristics to learn from each other in relation to good practice, or even to provide dementia services collaboratively through neighborhood primary care networks.

The Group heard that while helpful for context setting, it is important to avoid making generalisations about extremely diverse experiences. For example, people from ethnic minority populations are more likely than their white counterparts to reside in deprived areas.<sup>62</sup> Dr Karan Jutla, Alzheimer's Society Ambassador and Dementia Lead for the University of Wolverhampton, shared data and experiences from Wolverhampton with the Group to exemplify inequity in dementia diagnosis rates. As a city, Wolverhampton was delivering a dementia diagnosis rate of over 70 percent in 2019, however this was much lower for the 35.5% of the community from ethnic minorities.

Researchers found that the South Asian community were not reaching dementia services, but instead seeking help in their communities, for example in faith-based settings. Whilst such inequalities are undeniably present in England, it is also important not to assume that all ethnic minorities live in deprivation. For example, we heard that many South Asian elders who migrated in the mid twentieth century have subsequently moved in large numbers to more affluent areas – though nonetheless continue to have poor access to culturally appropriate health services.

We also heard that on average across Greater Manchester, dementia diagnosis rates are above the national target and improving. However, there is also variation between boroughs in the region. For example, GPs in one of the region's boroughs undertake 80% of diagnosis directly, achieving a higher diagnosis rates than those referring to memory assessment services for diagnosis.

We also heard from the Primary Care Deep End Research Alliance group in the Yorkshire and Humber region regarding clinician experience of variability in the memory service pathways and access to diagnostic tests within the region. To develop their understanding of need, they have developed geospatial data mapping software which allows researchers to map the Sheffield region by ethnic group, deprivation and disease prevalence.<sup>63</sup> The so-called 'Deep End' practices serving areas of higher deprivation experience greater complexity in providing care than GPs in more affluent areas, contributing to poorer access to healthcare services to the communities they serve. The Group heard from this region that as memory service waiting lists have lengthened and primary care resources become even more stretched in the post-pandemic era, inequity has worsened between primary care populations.





# Understanding the regional barriers to dementia diagnosis

Having heard about the scale and spread of regional variation in dementia diagnosis rates, the Group requested evidence on the barriers that may prevent people from accessing a timely dementia diagnosis in rural and/or deprived communities.

During February 2023, the Group surveyed people living with dementia about their experience of accessing a dementia diagnosis across England. We received more than 2100 valid responses, six percent of which came from someone who had a diagnosis of dementia, with the remainder caring for and/or supporting someone to access a dementia diagnosis. Over three quarters of the respondents (78.7%) were inhabitants of urban areas, which is representative of national population data. Using respondents' postcodes to create ten group classifications to reflect the level of associated deprivation, we also had a robust population sample regarding levels of deprivation.<sup>64</sup>

## i. Reluctance to seek a dementia diagnosis

**“I’m reluctant to take up another appointment as I know how badly I will perform and don’t need the embarrassment.”** Survey respondent living with dementia in one of the most deprived regions in England.

When we asked people living with dementia about their attitude to the diagnostic process, the majority (57%) told us that they had been reluctant to visit a health professional about their symptoms. One carer told us: **“My mum was terrified of dementia, and she avoided the diagnosis until we made her go to the GP,”** whilst another said, **“My dad accompanied mum every time a doctor’s appointment was made, laughing off and subconsciously ‘hiding’ mum’s symptoms.”**

One impact of this reluctance is that 37% of survey respondents agreed that they wished they had gone to the GP sooner to seek help for dementia symptoms. This trend was more marked for those in higher deprivation areas, and we know from previous research that when people receive a dementia diagnosis later in the progression of the condition, they are more likely to have reached a crisis point and have higher care needs.<sup>65</sup>

The small number of survey respondents from the very most rural regions in England (rural hamlets and isolated dwellings in a sparse setting, n = 5) reported qualitatively different diagnosis experiences than those in more urban regions. In addition to increased difficulties travelling to health appointments, there was an even higher level of reluctance to seek a diagnosis, with 80% agreeing that they were reluctant to visit a health professional about their symptoms.

To contextualise this, the Group heard from Ian Sheriff (Alzheimer’s Society Ambassador and Academic Partnership Lead for Dementia at the University of Plymouth) that the divide between urban and rural health and care access in England needs to be addressed as part of the wider levelling up agenda. Evidence provided to the Group highlights that rural populations are generally older and that the farming community in particular experiences high levels of reluctance to seek a dementia diagnosis. This is associated with fear regarding losing one’s driving licence and livelihood if diagnosed. Agricultural workers tend to work for longer into older age than those in other industries and rely on driving to undertake essential activities of daily life in more remote areas.

Whilst driving cessation is not always necessary on diagnosis of dementia, duty to advise the DVLA of the diagnosis and potential risk of removal of a licence are. Consequently, the Group heard about people continuing to work in farming with undiagnosed dementia by using self-management strategies



such as written reminders on the controls of machinery. We were also reminded about the overlap between challenges faced by not just rural communities in accessing dementia diagnosis, but also coastal and remote communities.

The Group also heard about innovative work to develop dementia friendly rural communities and improve access to the healthcare system for this group, which are highlighted later in this report.

## ii. Reluctance to provide a diagnosis

**“The GP thought [a diagnosis] was unnecessary and I had to ask several times to be referred...”**  
Survey respondent living with dementia.

**“It was only once we had moved and used our new GP that things started to move forward.”**  
Survey respondent caring for someone living with dementia.

**“I had to fight my mother’s GP to get a diagnosis.”** Survey respondent caring for someone living with dementia.

Alongside high levels of reluctance to seek a dementia diagnosis, we also heard via the survey that many people seeking access to a dementia diagnosis experienced clinician reluctance to provide or enable this.

Anita, who lives in rural County Durham with young onset dementia told the Group that it took seven years and three strokes for her to get referred from her GP to a memory assessment clinic. Once assessed, she was given a diagnosis of mixed dementia at the age of 51. She reported that the GP had dismissed her symptoms as related to menopause and mental health. Anita was eventually diagnosed with dementia when a brain scan was undertaken following her third stroke.

Anita’s experience highlights both the length of delay people can experience in obtaining a diagnosis they need to access treatment and support for dementia, and the intersection of health inequalities many face. Anita’s gender, age, and the fact that she lives in a rural area all impacted on her diagnosis experience. She told the Group that she felt that being a woman in a rural area particularly affected how seriously she was taken by healthcare professionals. She urges the Government to **“Make dementia a top priority”** and was clear that many such as herself with young onset dementia could continue to be economically active if they had an early diagnosis and subsequent support to manage symptoms.

Further evidence of disparities in the diagnosis of young onset dementia (i.e. before the age of 65) for those living in rural areas was provided to the Group.<sup>66</sup> A lack of awareness of young onset dementia in primary care can be a barrier to a timely diagnosis. The Young Dementia Network advised the Group that GPs may not recognise the change in the person, nor connect the symptoms to dementia, particularly if memory loss is not a presenting symptom early on. Families have noted how important it is to be listened to by the GP regarding the changes in the person, and that language used by health professionals is clear and sensitive to enable timely progression towards diagnosis. Reference to mental health for example may affect people’s willingness to engage in further assessment. In more sparsely populated communities, there is less opportunity to build the necessary knowledge and skills through direct experience of young onset dementia:



**“The GPs openly say there’s little they can do to actually help. Secondly, there is a lack of knowledge [on dementia] and a lack of access to that knowledge. I have taken to investigating and researching for myself how we might maximise quality of living.”** Young Dementia Network member with lived experience, rural southwest England

Similarly, The Lewy Body Society, which represents those living with this rarer type of dementia, told us that **“in our experience, many families are left feeling abandoned in trying to get an accurate diagnosis of Lewy body dementia, especially in rural areas. There is a regional variation of people receiving a correct dementia type diagnosis of Lewy body due to some regions not having specialist knowledge.”**

Finally, the Group heard from Dr Sarah Jane Smith (Reader, Leeds Beckett University) that referrer attitude in primary care can also be affected by a lack of local post-diagnostic dementia support. Known as ‘diagnostic nihilism’, limited treatment and support options can prevent people from even seeking a diagnosis, and likewise clinicians from referring. This can particularly be the case for those presenting with non-Alzheimer’s type dementia which do not have associated medical intervention for symptoms management. This barrier was also evidenced by a strategic ICS dementia group in rural southwest England, who told us that they were aware of **“an inertia to diagnose because of the historic lack of support following diagnosis, something we are working hard to improve despite funding being below what is required.”**

352 of our survey respondents (25.4% of those who provided qualitative comments) supported this concern, telling us about the lack of post-diagnostic care they received. Indeed, one carer told us **“He was diagnosed and discharged at the same time...”** Improvements in post-diagnostic care and support would both help those with a diagnosis, and make clear to clinicians the benefits of diagnosis.

### iii. Difficulties travelling to appointments

Our survey showed that 78% of people affected by dementia who responded were driven to their dementia-related medical appointments by someone else. Reliance on public transport was higher in more deprived areas (8-13% of inhabitants in the most deprived regions reported using public transport to get to appointments, versus 2% in the least deprived). Both these results raise concerns regarding access to a dementia diagnosis for those who live alone and have limited access to either public transport or a social support network.

Again, we heard from Anita that living alone with dementia in rural County Durham means that she faces transport barriers to accessing health and care appointments and support. She told the Group that buses do not serve her local area, and as she lives alone must make her own arrangements, such as costly private taxis, which she may forget to do due to memory problems. Many more people like Anita, and those living in addition with frailty and physical disabilities, may be lost to the healthcare system as they cannot attend the necessary appointments to enable a dementia diagnosis.

**78%** of people with dementia  
rely on someone else to take them  
to medical appointments

The Group also heard from a family dementia carer, Manjit Curtis, who has had the unique experience of caring for members of her family in two different regions in England (Essex and Cheshire). Manjit described significant differences in her cross-regional experience, including poorer public transport in Cheshire in both urban and rural areas. She described how a car was essential to access her family member's appointments in the Northwest, for GPs, community clinics and hospital appointments, particularly for those with mobility needs. In Essex and Greater London however, Manjit and her family were able to use public transport to easily access the services they needed to obtain a dementia diagnosis.

Dementia Carers Count (DCC), a VCSE organisation supporting the emotional and practical needs of family carers, told the Group that in rural areas travel distance to appointments are generally greater, and for some may require travelling hundreds of miles from home. This is particularly the case for the assessment of rarer forms of dementia which may require a level of expertise often only available at national research centres. This can be expensive and present difficulties with carers being able to have time off work to attend appointments with the person seeking a diagnosis. DCC highlighted the importance for many people of attending dementia assessment appointments with a family member to enable a holistic assessment.

Evidence submitted to the inquiry by Roche Diagnostics Limited supported the DCC's concerns by highlighting that there is currently limited access across England to evidence-based medical investigations that may help diagnose suspected Alzheimer's disease. National dementia guidelines recommend that in uncertain cases of dementia where Alzheimer's disease is suspected, or to aid diagnosis of a subtype, the use of an enhanced functional brain scan PET or testing of the cerebrospinal fluid (CSF) should be.<sup>67</sup>

However, only 77% and 44% of memory services have referral pathways to PET scans and CSF testing respectively, whilst only 2.2% of patients were actually referred for specialist diagnostics in 2021.<sup>68</sup> Alongside their limited availability and patient acceptability (the latter regarding CSF testing particularly), these diagnostics are predominantly located within or near research centres with the necessary infrastructure, thereby creating geographical inequity of access.<sup>69</sup> The Group heard that this inequity could ultimately affect access to breakthrough disease-modifying treatments for Alzheimer's disease as their access will be limited to those with an accurate early diagnosis.<sup>70</sup>

Poor infrastructure beyond transport, for example technological barriers to arranging appointments, such as the phasing out of landlines and digital exclusion, present additional barriers in accessing health care systems for people in rural communities.<sup>71</sup>

only **77%** and **44%** of memory services have referral pathways to PET scans and CSF testing

only **2.2%** of patients were referred for specialist diagnostics in 2021

## iv. Delays and gaps within the diagnosis pathway

### Communication

Our survey found that gaps in communication between parts of the healthcare system impacted people's experience of receiving a dementia diagnosis. This includes failure of the healthcare system to actually communicate the dementia diagnosis to the person affected and their carer, and poor communication between services involved in the diagnosis pathway.

**“My mum had dementia, and my sister and I had to chase the assessment and diagnosis as they had lost the original one.”** Survey respondent caring for someone with dementia.

**“Information was not shared with us, her children. Appointments were made with her and she invariably forgot or did not understand.”** Survey respondent caring for someone with dementia.  
**“Doctors’ surgeries, hospitals, social care professionals, social workers and everyone in between do not talk to one another or share [the] diagnosis.”** Survey respondent caring for someone with dementia.

**“The local consultants could not wait to pass me on to someone/anyone else. There needs to be far greater clarity about who is the key or central coordinator of care.”** Survey respondent living with dementia

We heard via our survey that such communication issues can mean that people living with dementia must proactively manage their own assessment and diagnostic process to receive a dementia diagnosis, raising concerns that those who do not have the cognitive ability or social support to self-advocate may become lost to the system:

**“If Arthur had not had a family around him, he would not have been diagnosed.”** Survey respondent describing caring for someone with dementia.

**“Without the support of myself and family, my 91-year-old mother would have been completely lost in the system.”** Survey respondent describing caring for someone with dementia.

We also heard again from Ian Sheriff that his conversations with GPs in rural regions indicated that the link between GPs and the community teams responsible for dementia diagnosis (memory clinics and community mental health teams) can be poor, with referrals often declined unexpectedly or lost in the system.

Regarding the quality of communication during the diagnostic process, Anita told the Group that she was given the ‘hard facts’ when her diagnosis was delivered, rather than care and support. She spoke about how coming across an Alzheimer’s Society leaflet ‘saved her’ after her initial hopelessness on being presented with information about the likely progression of her condition and attending a dementia cafe in County Durham alongside several elderly men, which was not inclusive to her as a younger woman. Whilst Anita reported she is now well supported by her GP and community mental health team, she advised the Group that having a dementia nurse or support worker, i.e. “a specialist who cared” would better support and guide her through the diagnostic process and beyond. We also heard from 82 survey respondents who made qualitative comments regarding poorly delivered diagnoses:

**“The diagnosis was delivered quite brutally, as the patient’s wife, I hadn’t properly sat down before the consultant had delivered my husband’s diagnosis.”**

**“The initial diagnosis was given over the phone when my husband was alone.”**

**“Diagnosis received at memory clinic – given a piece of paper on which diagnosis was written.”**

We know from previous research that the quality of communication and support during the dementia diagnostic process is important to enable patient and carer and understanding, informed decision-making and person-centred care.<sup>72</sup>





## Knowledge

Dr Karan Jutlla highlighted to the Group that whilst many of the barriers to accessing a dementia diagnosis are universal, these are increased for those from ethnic minority backgrounds. Dr Jutlla described particularly how access to a valid assessment, whether with GPs or memory assessment clinics, can be limited by both language and cultural barriers. These issues were investigated in previous APPG on Dementia and Alzheimer's Society reports on the topic and remain relevant when considering the full complexity of regional variation.<sup>73,74</sup> Alzheimer's Society's research found that people from ethnic minority communities experience an inequity of diagnosis, either receiving one late or not at all with both community and service barriers contributing to this inequity.<sup>75</sup>

The Group received several evidence submissions to the current inquiry which spoke to barriers and solutions for the inclusion of those from minority ethnic backgrounds in the dementia diagnostic process. There was a tendency however to conflate deprivation with ethnicity, and whilst population data does indeed report a robust link between the two factors, this is less well understood in relation to dementia diagnosis.<sup>76</sup> The group therefore recommend that OHID and NHSE develop data collection to examine the intersection between rurality, deprivation and ethnicity and the associations with dementia diagnosis rates. This supports previous recommendations to encourage better demographic data collection to enable commissioners and services to plan and deliver services more appropriate for their populations.<sup>77</sup>

Our survey of people living with dementia found that many experienced a lack of knowledge regarding dementia symptoms in the healthcare workers they encountered in the diagnosis pathway. People told us:

**“The 10 generic dementia questions to answer are not adequate enough, as dementia takes on many forms.”**

**“GPs are not dementia experts.”**

**“I do think it would help if GPs were better trained on dementia – some don't seem to know enough yet dementia is a common occurrence.”**

Knowledge gaps were also reported in relation to the selection of appropriate cognitive diagnostic tools and local referral pathways for further investigation, however there was no clear regional pattern to these findings. Similarly, we also heard from survey respondents that they often were not diagnosed with a dementia subtype:

**“After mum was diagnosed it would have been nice to know what dementia she had, as I never knew there were so many.”**

**“We only got the ‘oh well I suppose we'll say he has Alzheimer's' with no objective tests!”**

**“I subsequently received a different diagnosis on taking part in an Alzheimer's research study when I had a lumbar puncture 18 months later. My diagnosis changed to vascular. More rigorous testing initially would have shown that, wouldn't it?”**

When a generic dementia diagnosis is given rather than a subtype, this can prevent access to timely treatment and support, such as medicines that can control symptoms of rarer subtypes such as dementia with Lewy bodies or healthy lifestyle support to manage vascular dementia.

## System capacity and waiting times

The Group heard from our survey respondents that many people living with dementia never even accessed a memory clinic as part of their diagnostic process, suggesting wide variability in pathways across England.

**“My father has now passed away but he never saw anyone from the memory clinic, we as a family never knew it existed.”**

**“They eventually sent me to a memory clinic which was horrendous. They just asked random current affairs questions from decades ago and said ‘yes, you have dementia and here’s Aricept’ [a drug used to treat symptoms of Alzheimer’s Disease].”**

Our survey found that only 55% of people living with dementia found it straightforward to get a dementia diagnosis, and just 45% were satisfied with the time it took to receive the diagnosis, with a trend towards higher levels of dissatisfaction in those from more deprived areas. One person told us:

**“I would rather have received all the memory assessment services through the GP. The venues were in various quite distant places and we saw many different personnel. Continuity of care is known and proved to be much more effective.”** Person living with dementia in one of the most deprived areas in England.

There was regional variation in some specific aspects of the diagnostic pathway, such as the percentage of respondents who reported that they were referred for a brain scan (typically MRI or CT, ranging from 53 - 54% for NHS North West London, NHS Norfolk & Waveney and NHS Somerset ICSs to 91% for NHS North Central London ICS). Satisfaction with the waiting time to access a brain scan also varied, from 67% in NHS Dorset and NHS Frimley ICSs to 28% to in NHS North West London. Whilst broadly regional patterns regarding satisfaction with the diagnostic process were limited in the data, the scale of dissatisfaction across England indicates that diagnostic pathway improvement remains crucial to increase access and capacity, and action is still needed to implement existing recommendations to enable this.<sup>7a</sup>

Manjit Curtis informed the Group that she noticed a range of differences between Essex and Cheshire. For example, in Cheshire the diagnosis was delivered within 12 weeks from the GP referral, whereas in Essex there was a 20 week wait just to get a brain scan as part of the diagnostic process. Manjit observed that a ‘one-stop-shop’ as per breast cancer clinics would streamline these experiences and minimise waiting times for a dementia diagnosis.

Despite the waiting times, Manjit reported that her family’s experience in Essex post-diagnostically was ‘exemplary’. She described how the memory clinic provided one place for all signposting, including to social care providers when needed. Manjit describes this as acting as a ‘lighthouse’ to show the way to dementia support and care. In contrast, post-diagnostic services felt like ‘a free for all’ in Cheshire, requiring self-management and sourcing their own private care provider. Manjit also described how faith-based community settings in Cheshire enabled dementia diagnosis, drawing on their dementia awareness to sign-post people into the diagnostic pathway. Manjit outlined how her cross-regional experiences have led her to understand that “local ecosystems” of health, care and the VCSE sector must be enabled with sustainable funding to meet their local population need for dementia diagnosis and post-diagnostic care.

Evidence submitted to the Group supports previous findings by Alzheimer’s Society that a range of system issues, including cultural, data flow and funding affect dementia diagnosis rates across England.<sup>79</sup> One strategic dementia group for an ICS with a significant rural population told the Group that in their view these issues present the greatest challenge to their ability to improve diagnosis rates, more so than population factors associated with rurality and deprivation. The Group heard that despite drawing on best practice and population impact to make a business case for an integrated dementia pathway to improve diagnosis rates, only 70% of the required funding was awarded, which will make it difficult to implement the required system improvements.

Finally, as outlined in the recent NHS England report on the topic, general pressure within primary care can cause delays to accessing the diagnostic system.<sup>80</sup> Despite the best efforts of staff, with general practice delivering more than a million appointments every day and half a million more every week than pre-pandemic, 27% of our survey respondents told us that they had not been able to access a GP appointment to discuss their dementia symptoms. This increased to 34% for those in the most deprived areas of England. It’s paramount that primary care services reflect the specific needs and work for people living with dementia. Recommendations have been made to this end in Alzheimer’s Society’s recent reports, for example regarding the provision of a dementia advisor in every primary care network to support and signpost people through the system.<sup>81</sup>

We asked people living with dementia and system experts what support they have encountered or would recommend to enable people to access a dementia diagnosis in rural and/or deprived communities.

Of the 2100 people who responded to our survey, 1387 choose to leave qualitative comments relating to their experience of diagnosis. Sadly, only 69 (5%) were entirely positive, with the majority describing their frustrations regarding the barriers to diagnosis outlined above. A number of people living with dementia (n = 84) told us that their access to a dementia diagnosis was enabled by a crisis, for example accessing a brain scan via emergency care or discharge planning:

**“Up until [he was admitted to hospital for a separate condition] it was like ploughing through treacle trying to obtain a diagnosis for dementia.”**

**“Looking back, it is apparent my mother had dementia for years before she was diagnosed in hospital following a fall.”**

**“Following an admission to hospital with a TIA, the dementia diagnosis was made there. Very straightforward and well done.”**

Unfortunately, accessing a dementia diagnosis at a later stage in the disease progression or during a crisis can worsen outcomes via missed opportunities for symptom management, improved wellbeing and future planning.<sup>82</sup> 42 of our survey respondents circumnavigated these difficulties by paying for brain scans, private diagnosis, or participating in dementia research trials.



# Understanding the regional enablers to dementia diagnosis

## Examples, enablers and innovations

Dr Sarah Jane Smith shared her current research with the Group, which looks at improving the experience of dementia diagnosis and post-diagnostic support. In addition to producing a best practice guide, her team conducted a national survey of memory assessment services in England in Wales, resulting in fifteen good practice case studies across the dementia pathway.<sup>83</sup> These particularly focus on innovations where services have developed to meet the needs of local community, rather than application of uniform models of delivery such as assessment, diagnosis and discharge back to a GP.

Dr Smith described how presence of a clear post-diagnostic support pathway encourages people to seek and pursue a diagnosis. This is particularly important for suspected subtypes of dementia such as vascular dementia which do not currently have recommended medical treatment, but for which symptoms can be managed with psychosocial interventions such as cognitive stimulation therapy to support maintenance of functional skills and wellbeing.<sup>84</sup> The Group heard from Dr Smith about two specific examples of good practice to improve access to the dementia pathway for diagnosis.



## Improving access to dementia diagnosis in a deprived region

This innovative approach took place in a community in England with high levels of socio-economic deprivation and low dementia diagnosis rates.

- The memory assessment service collaborated with the local Alzheimer's Society Dementia Advisors to design and deliver community 'brain health' sessions.
- This involved setting up drop-in sessions in community locations such as supermarkets, libraries and garden centres.
- In addition to providing verbal and written dementia awareness information, a quick symptom checklist was offered and completed with attendees, who were encouraged to take this to their GP to access the formal diagnostic pathway.<sup>85</sup>

## Improving access to a dementia diagnosis in a rural region

This memory assessment service covers a large and very rural area in one of the largest counties in Wales.<sup>86</sup> It sits within a community mental health team, led by a consultant psychiatrist alongside a dementia nurse who coordinates the assessment and post diagnostic support with part-time support from community psychiatric nurses in the wider team. The features which enable inclusion of those living in rural regions include:

- There is no central office location. Services are delivered via a range of existing community clinic locations and home working.
- The service aims to deliver a personalised approach, providing home visits and ongoing individual follow-up as needed.
- Patients are referred to the service from primary care. Referrals of suspected dementia are screened by the dementia nurse who makes initial contact and does a pre-screen assessment, checking bloods, heart rate and ensuring that a brain scan has been requested.
- Patient need and preference determines whether memory assessments are conducted via home visits or at one of several locations in the community that can be accessed by the service.
- Patients with a diagnosis are offered immediate post diagnostic support within the service and also referred onto appropriate community connectors and services in the VCSE sector, depending on patient preference and need.

Dr Smith advised that her research group plan to share best practice across the dementia system to enable service improvement locally, regionally, and nationally in England and Wales.<sup>87</sup> It is important that there are good networks at each level to enable effective sharing of good practice, and that the examples can be sufficiently tailored to meet local need. The Group heard that the Dementia Programme at NHS England can enable this via their existing case studies hub, online and regional

clinical networks, as can the Royal College of Psychiatrists via their Memory Services National Accreditation Programme member network.<sup>88,89</sup> Good examples of dementia diagnostic pathways and innovations need to both have evidence that they work, and either be embedded easily in diverse local systems, or adapted to meet local need. We heard how some examples easily translate into practice, whereas others may form the basis of a business case to be made locally to commissioners.

Shared learning between services is also indicated by OHID's analysis of the spread of dementia diagnosis rates variation within regions. As outlined earlier in this report, this data enables similar populations to be matched (e.g. by level of rurality and deprivation), and lower performing primary care practices within them to improve via learning from higher performers.

## A whole system approach to health inclusion in areas of high deprivation

- Inspired by the Deep End Scotland, the Deep End GP Yorkshire and The Humber collaboration was initiated in 2015.<sup>90,91</sup> So called 'Deep End' primary care practices experience greater complexity in providing care than GPs in more affluent areas, ultimately contributing to poorer access to healthcare services.<sup>92</sup>
- As memory service waiting lists have lengthened and primary care resources become even more stretched in the post-pandemic era, the Group heard that these complexities continue to increase and worsen inequity between primary care populations' access to a dementia diagnosis.
- We heard that in general GPs are lacking up-to-date knowledge and awareness of the benefits to patients of dementia assessment, diagnosis and the support services available in their locality. Deep End GPs have less time available for relevant professional development on this topic due to the additional pressures of their setting.
- Working with primary care researchers, the Deep End practices across Yorkshire and Humber can access a geospatial mapping tool (PriD3) to quantify referrals at a practice-level, explore demographic factors which may contribute and use maps to visually demonstrate this data.<sup>93</sup> The tool can link local levels of deprivation with dementia prevalence, and cross reference this with ethnicity to identify areas for improvement. Local primary care sites can use the data to contact patients whose background and health needs are relevant to a project, for example to work with a local community to co-produce accessible assessment tools.
- The Deep End collaboration aims to provide sustainable leadership and development for improving health inclusion in the region. This is important as the Group heard that previous 'parachute' projects often come and gather intelligence, and at best provide a short-term intervention with limited funding.
- The Group also heard that a Dementia Collaboration is being built in Yorkshire and the Humber between NHS, academic and VCSE institutions to further strengthen efforts to combine resources, reach and cohesion and to avoid silo working in efforts to improve services. One example is The Sheffield Council People Keeping Well (social prescribing) initiative which supports people while they are awaiting diagnosis via local wellbeing and social initiatives.<sup>94</sup> However variability in localities can be a challenge for the public and for GPs to maintain awareness of what is currently available to support families affected by dementia. These initiatives address intersectional needs on a local basis.

## Enabling a timely diagnosis for young onset dementia

The Young Dementia Network told the Group about an exemplary service model which works well for the person, family, professionals and the local NHS system within one of the most deprived areas of Yorkshire.

The Young Onset Dementia Service for Doncaster (Rotherham, Doncaster and South Humber NHS Foundation Trust) is long established, having been commissioned to reduce the cost of hospital admissions and multiple consultations for this group in the region. The service accepts referrals directly from GPs, neurology and psychiatry, requiring patient history and brain scans to accompany the referral.

Each person referred has an allocated nurse contact to provide continuity through the diagnostic process and beyond. Generally, a home assessment, multi-disciplinary discussion followed by a home visit to discuss the diagnosis and treatment/care plans is provided.

The service aims to deliver both a timely and accurate dementia diagnosis. The service has generally managed to achieve a 6-week referral to diagnosis target – though at the time of writing we heard that this may now be affected by system delays to scan access and reporting.

In response to the significant barriers to dementia diagnosis experienced by people in rural communities, research and pilot initiatives shared with the group provide evidence for the potential for improvement. Much of this work has been led by Ian Sheriff, Alzheimer's Society ambassador and academic, in collaboration with rural communities in England. See below for a summary of this work.

## Enabling dementia diagnosis in rural communities

- Plymouth University faculty of health have been carrying out a four-year research programme evaluating the feasibility and impact of placing dementia advisors in GP practices. The sites include predominantly South Asian communities in Manchester and rural communities in Devon.
- The development of dementia-friendly rural communities has involved a high level of involvement with key stakeholders, notably via parish councils providing a central community resource to develop dementia awareness, reduce stigma and signpost people into the dementia pathway. Within this agenda, dementia advisors have sat on councils, and a written guide has produced making recommendations targeted to this audience.<sup>95</sup> The Group heard that robust local dementia alliances are now forming in the rural regions that have engaged, with significant influence in their communities.
- The Group heard that there have also been examples of engagement of the broader farming community network in dementia support. For example, young farmers have volunteered to support those with dementia symptoms affecting their work to undertake necessary tasks. This work also serves to reduce stigma in the community, ultimately improving access to services as willingness to seek help increases.
- To raise dementia diagnosis rates in Cornwall the DiADeM protocol (Diagnosis of Advanced Dementia Mandate in Care Homes) is in place, aiming to improve rates of diagnosis of dementia for people living with advanced dementia in a care home setting.<sup>96</sup> In addition to improving dementia diagnosis rates, this can enable those in care homes to access person centred care to meet the specific support needs of dementia, such as communication, behavioural and at end of life.



## Strategic enablers

Richard Sloggett (Founder and Programme Director of Future Health) described the whole system need to improve secondary prevention of dementia - i.e. screening, early diagnosis and interventions at the earliest stages of cognitive decline before symptoms cause disability. The Group heard that to change practice across the system however, dementia needs to be made a national priority by government.

This has been the case previously, particularly with the advent of the then 'Prime Minister's challenge on dementia 2020' launched in 2015.<sup>97</sup> This policy enabled the implementation of strategy focusing on a broad range of improvements, towards ambitions including improved public awareness of dementia and "In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be 6 weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia". This was supported by incentives for case finding, namely the establishment and maintenance of a register of patients with dementia in the Quality and Outcomes Framework (QOF). The QOF is a voluntary annual reward and incentive programme for all GP practices in England, which has ceased to include dementia diagnosis targets since the pandemic.

Richard Sloggett outlined to the Group that dementia is now less of a national priority than it was 5 - 10 years ago, which means that ICSs have limited incentives for its diagnosis and management. Whilst it is encouraging to hear that many local dementia services are improving organically as a result of engagement with the communities they serve and networks of best practice, the Group were also advised that the government's anticipated Major Conditions Strategy should have at least one national marker for dementia to act as a steer for those areas which have not yet made dementia a priority amongst competing demands.<sup>98</sup> This need not be prescriptive about how any target(s) might be achieved. Broadly, the analysis outlined by Richard Sloggett for the Group suggests that improved data intelligence, reintroduction of incentives and improved operational capacity will be necessary to enable equity and improvement in regional variation in dementia diagnosis rates.

Some strategic enablers for reducing regional variation in dementia diagnosis rates sit outside of the health system's remit however, for example transportation and lack of social support. By making dementia a priority for ICSs, there is an opportunity for dementia to offer an exemplar of integration across the health, care and VCSE sectors regionally and locally. The Group heard of an example of just this, outlined below.

### Making dementia a priority at ICS level

A five-point plan sets out to improve the lives of Surrey and Sussex residents with dementia and their families.

The five-year dementia strategy, which includes direct input from people living with dementia and their carers, sets out how the county council and the wider Surrey Heartlands Health and Care Partnership, along with Frimley Health and Care Integrated Care System, will work with other organisations to support people with dementia, their families and carers to obtain a diagnosis, maintain their independence and enjoy a good quality of life.<sup>99</sup>

The new joint health and social care dementia strategy will include raising awareness of dementia, preventative actions people can take, 'diagnosing well' by making sure people have equal access to dementia care, the dementia diagnosis rate and assessing inequalities and gaps within and across the region's diagnosis systems.







# Conclusion

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Throughout the research process, it was clear that service-users regularly experience delays and inequalities in accessing a timely and accurate diagnosis which must be addressed to support the provision of quality post-diagnosis care and independent living. A timely and accurate diagnosis requires seamless access to primary care settings, an effective referral to specialist assessment services, and identification of a subtype to facilitate quality post-diagnosis planning, guidance and support. Each stage of the diagnosis pathway must be person-centred to meet individual needs and be informed by co-production with those with lived experience.

Diagnosis rates need to improve if the healthcare system is to meet the challenges presented by the growth in the prevalence of dementia within an ageing population, the key barriers to which include regional variation in the availability and quality of diagnosis services, a lack of awareness of the benefits of receiving a diagnosis, a societal stigma around dementia, and a lack of an effective multi-disciplinary approach between different healthcare settings preventing the sharing of information and effective referral.

Unwarranted regional variation in dementia diagnosis rates must be tackled as a priority by national and local systems to improve access to a timely and accurate diagnosis. People living in rural and deprived areas without strong diagnosis pathways and support to access them will continue to be left to cope alone with dementia symptoms and may be likely to experience avoidable crises and deterioration in their condition. They will also be disproportionately less able to access new disease-modifying treatments, which are for the first time on the cusp of becoming available.

It is important for Government and local system leaders need to act now to tackle the key barriers to diagnosis and lay the necessary foundations to equalise access to an accurate and timely dementia diagnosis across England, so that all who need it can benefit from the innovations in treatment, person centred care and VCSE support which offer more hope than ever for living well with dementia.

This report's data and lived experience insights, combined with recommended actions ranging from targeted public health messaging, development of local learning networks and national dementia policy markers has the potential to truly respond to the plea of those living with dementia who contributed to this inquiry and improve the diagnosis pathway as an integral part of a collective mission to 'Make dementia a top priority'.<sup>100</sup>

## Methodology

The Group produced a call for evidence in February 2023, comprised of a call for written evidence designed for professionals and academics working on dementia, and a survey designed for the public. 15 written submissions were received, and 2361 survey responses. Just over 2100 responses were valid for inclusion in the analysis – the validity criterion was a full postcode located in England. Responses were removed from the analysis for having either an incomplete or incorrect postcode, or having a postcode located outside of England.

Alongside the call for evidence, the Group held three oral evidence sessions in March 2023 which heard evidence from 10 witnesses. Recordings of these sessions are hosted on the Group's webpage on Alzheimer's Society's website.<sup>101</sup>

Each survey response was associated with a rurality and a deprivation figure. Postcodes were mapped to lower-layer super output areas (LSOAs) using the Office for National Statistics' Postcode Directory.<sup>102</sup>



All LSOAs have a Rural Urban Classification which is assigned using data from the census, current classifications relate to the findings of the 2011 census.<sup>103</sup> There are 10 classifications: 6 rural and 4 urban, ranging from Rural hamlets and isolated dwellings in a sparse setting to Urban major conurbation.

Deprivation statistics come from the then-Ministry of Housing, Communities & Local Government which published the English indices of deprivation in 2019.<sup>104</sup> The index is a compound measurement of deprivation based on 7 indicators including income, education and crime. All LSOAs were sorted sequentially by the index and received a rank – 1 being the most deprived LSOA in England, and 32,844 the least deprived.

The Group conducted statistical analyses based on the rurality and deprivation scores of all valid responses to the survey. For ease of use, the 6 rural and 4 urban classifications were bucketed into 1 rural and 1 urban label for some calculations. Responses were bucketed into deciles by deprivation for some calculations.

1387 pieces of qualitative data were received via the survey. Each was coded with a single tag based on the primary theme of the comment. These tags were analysed via constant comparison analysis to reveal the major themes which are presented in this report.

In May 2023 the Innovation team at Alzheimer's Society delivered a workshop at the Society's annual conference entitled 'A Rural Dilemma: Dementia Diagnosis in Non-Urban Environments'. Having been briefed on the aims of the APPG by the project team, the innovation team designed an interactive activity to co-create insights and solutions to overcome the barriers to accessing a dementia diagnosis in England's most rural regions. The team were particularly interested in hearing how we might share best practice in dementia diagnosis to deliver the greatest impact in rural settings. 139 people completed an online survey on this topic ahead of the event, and 33 participants took part in the event at the conference. This included health and care professionals, academics and people living with dementia. Isolation and related transport problems was named as the single biggest barrier to inclusion in the diagnostic process for people living in rural areas. Subsequently, one of the key recommendations made by participants to overcome barriers to access in rural areas was relatively simple and cost-effective – namely to increase the visibility of existing tools (such as diagnostic checklists) and think broadly and locally about the channels and methods used to do so.



## Acknowledgements

The Group would like to thank Alzheimer's Society, who provide the Secretariat for the Group and who have been instrumental in bringing this report to fruition. In particular, the Group would like to thank the project team: Lewis Scott, Tessa Fulton, George Parish-Wallace and Alex Osborne.

The Group would like to thank the thousands of people who responded to our online survey to share their experiences and stories – they were instrumental to the development of this report.

The Group would also like to thank the following people who gave oral and written evidence to the inquiry:

### Oral evidence:

Manjit Curtis, former carer and Trustee, Wetherby in Support of the Elderly  
 Jonathan Fox, Public Affairs Manager, Roche Diagnostics  
 Anita Goundry, who lives with dementia  
 Barış Güç, Senior Data Scientist, Roche  
 Dr Ashton Harper, Head of Medical Affairs (UK & Ireland), Roche Diagnostics  
 Michael Jackson, Program Lead for Neurology and Dementia Intelligence, Office for Health Improvement and Disparities, Department for Health and Social Care  
 Dr Karan Jutlla, Dementia Lead, University of Wolverhampton  
 Ian Sherriff BEM, Academic Partnership Lead, University of Plymouth  
 Richard Sloggett, Founder and Programme Director, Future Health  
 Dr Sarah Jane Smith, Reader in the School of Health, Leeds Beckett University

### Written evidence:

Dr Daniel Blackburn, Senior Lecturer, University of Sheffield  
 David Crabtree RMN  
 Dementia Carers Count  
 Dementia United, Greater Manchester Integrated Care Partnership  
 Michael Jackson, Program Lead for Neurology and Dementia Intelligence, Office for Health Improvement and Disparities, Department for Health and Social Care  
 Parkinson's UK  
 Roche Diagnostics  
 Dr Sarah Jane Smith, Reader in the School of Health, Leeds Beckett University  
 The Lewy Body Society  
 We Care Group  
 Young Dementia Network (Dementia UK)

The inquiry also took evidence from a number of people affected by dementia and practitioners who wished to remain anonymous.

# Footnotes

If you would like to find out more about this report or inquiry, please contact [appgondementia@alzheimers.org.uk](mailto:appgondementia@alzheimers.org.uk)

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The All-Party Parliamentary Group (APPG) on Dementia is a group of cross-party parliamentarians with an interest in dementia. It was created to build support for dementia as a publicly stated health and social care priority, in order to meet one of the greatest challenges presented by our ageing population.

The APPG prides itself on remaining at the forefront of debates on the future of dementia care and services. Over the past decade, we have run Parliamentary inquiries into key issues affecting people with dementia, their families and carers.

**October 2023**

Alzheimer's Society provide the Secretariat for the APPG on Dementia.

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Together we are help & hope  
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Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity number 296645.