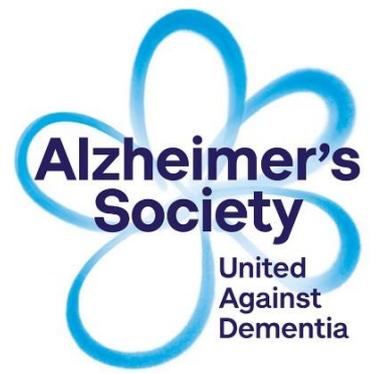


Alzheimer's Society: Increasing access to a dementia diagnosis in Wolverhampton



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This document was created in February 2022 by Alzheimer’s Society as part of a Health Scrutiny Committee meeting for Wolverhampton City Council on dementia diagnosis. If you would like to know more about our regional policy and influencing work please visit: www.alzheimers.org.uk/about-us/policy-and-influencing/local-government.

Executive summary

In 2020, Alzheimer's Society published a report on the dementia pathway, 'From diagnosis to end of life: the lived experiences of dementia care and support'.¹ Based on what people affected by dementia told us about their experiences, the paper looked at four stages of NHS England's Dementia Well pathway. It explored in detail what national guidance says people in England should be receiving at each stage of the pathway. The report laid the groundwork for more detailed work into each part of the pathway.

At the end of October 2021, Alzheimer's Society launched three reports that take a closer look at the Diagnosing Well part of the pathway and how we can increase access to a dementia diagnosis. The three reports look at the challenges and opportunities of reducing regional variation, supporting ethnic minority communities to access a diagnosis, and increasing access to a diagnosis across hospital and care home settings.

Following on from the launch of the diagnosis reports, this paper was written to provide Wolverhampton's Health Scrutiny Committee with an overview of the three reports and how the findings from those reports may relate to Wolverhampton's dementia diagnosis pathway.

Since the start of the Covid-19 pandemic we have seen a significant drop in dementia diagnosis rates across the country. Wolverhampton and the wider Black Country area have also seen a drop in local diagnosis rates. As we pointed out in our diagnosis report on regional variation, people's hesitancy to visit services due to concerns about Covid-19, as well as changes to services' activity and delivery, have contributed to the reduction of diagnosis rates over the course of the pandemic.² However, it's important to highlight that across Wolverhampton and the Black Country we began to see a drop off in the diagnosis rate prior to the pandemic. Between July 2019 and January 2020, we saw a drop of 3.9% for Wolverhampton, as rates dropped from a high of 73.9%.³ As we look to recover from the impact of the pandemic, we are provided with a prime opportunity to address and remove potential barriers to diagnosis that will better enable the people of Wolverhampton to access a dementia diagnosis in the future should they need one.

This paper summarises the community and service level barriers that were found as part of Alzheimer's Society ethnic minority communities report, helping to highlight the difficulties that some communities across the diverse city of Wolverhampton may face. Some barriers include language, stigma and cultural perceptions. The section on regional variation will focus on our findings on deprivation and how deprivation impacts identification of dementia, both for people and services in more deprived areas. The final section on diagnosis will look at the many challenges hospital and care home colleagues face when trying to identify and assess dementia, including the difficulty of distinguishing between dementia and delirium and the impact that can have on making a dementia diagnosis.

¹ Alzheimer's Society. From diagnosis to end of life: The lived experiences of dementia care and support. 2020. <https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life>.

² Alzheimer's Society. Regional variation: Increasing access to a dementia diagnosis, 2021. [regional_variations_increasing_access_to_diagnosis.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/regional-variations-increasing-access-to-diagnosis.pdf)

³ NHS Digital. Recorded dementia diagnosis. 2021. <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses>

Introduction

What is dementia?

Dementia is a progressive neurological condition. It occurs when the brain is damaged by diseases (such as Alzheimer's disease) or by a series of strokes. The symptoms of dementia can include memory loss and difficulties with thinking, problem-solving, language and physical function.

The specific symptoms that someone experiences will depend on the parts of their brain that are damaged and the underlying cause of their dementia. The rate of progression will also vary from person to person.

Dementia in your area

- There are an estimated **3,020 people over 65 living with dementia** in Wolverhampton.⁴
- **4,400 people will be living with dementia** in Wolverhampton by 2030.⁵
- It is predicted that the cost of dementia care in Wolverhampton **will be £211m** by 2030.⁶
- Currently, the annual cost of dementia care in Wolverhampton **is £145m**.⁷
- By 2030, it is estimated that there will be **2,892 of people living with severe dementia** in Wolverhampton.⁸
- Currently there are **14,792 people under the age of 65 with a dementia diagnosis** in England.⁹
- There are around **412 people under the age of 65 with a dementia diagnosis** in the Black Country and West Birmingham.¹⁰

Covid-19 and dementia at a glance

We know that people affected by dementia have been disproportionately impacted by the Covid-19 pandemic.

- **45.8% of all care home resident deaths involving Covid-19 were people with dementia** in England and Wales between March 2020 and 2 April 2021.¹¹

⁴ NHS Digital. Recorded dementia diagnoses, December 2021. <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/december-2021>

⁵ Care Policy and Evaluation Centre at the London School of Economics and Political Science. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040. www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

⁶ Ibid

⁷ Ibid

⁸ Ibid

⁹ NHS Digital. Recorded dementia diagnoses, December 2021. <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/december-2021>

¹⁰ Ibid

¹¹ Office for National Statistics. Deaths involving COVID-19 in the care sector, England and Wales. 2021. [Deaths involving COVID-19 in the care sector, England and Wales - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/deaths-involving-covid-19-in-the-care-sector-england-and-wales)

- Dementia and Alzheimer’s disease was the most common pre-existing condition among Covid-19 deaths for care home residents. Between the two waves, there were **19,426 people with dementia who died of Covid-19 in care homes**.¹²
- There were 42,341 care home resident deaths during the pandemic, including 21,677 deaths in the second wave. **This represents 24.3% of all deaths of care home residents**.¹³
- **241 care home residents have died with Covid-19** in Wolverhampton between 20 March 2020 and 2 April 2021.¹⁴
- For people living through the crisis, the effects of social isolation were severe. **46% of people with dementia reported that the pandemic had a negative impact on their mental health**.¹⁵
- During the pandemic, 92 million extra hours have been spent by family and friends caring for loved ones living with dementia. **95% of carers reported that this had had a negative impact on their mental or physical health**.¹⁶

Dementia diagnosis

Why is it important?

Receiving a dementia diagnosis can be life-changing, and often leads to feelings of grief, loss, anger or helplessness. But a diagnosis is essential in supporting people to live well, even in the absence of a cure or drugs to slow the progression. It opens the door to emotional, practical, legal and financial advice and support.

Dementia diagnosis in your area

- **The dementia diagnosis rate for Wolverhampton is 66.6%**, the average for England is 61.8%.¹⁷
- **2,011 people have received a dementia diagnosis** in Wolverhampton.¹⁸
- The national target for **diagnosis rates in England is 66.7%**.¹⁹

¹² Office for National Statistics. Deaths involving COVID-19 in the care sector, England and Wales. 2021. [Deaths involving COVID-19 in the care sector, England and Wales - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk/deaths-involving-covid-19-in-the-care-sector-england-and-wales)

¹³ Ibid

¹⁴ Ibid

¹⁵ Alzheimer’s Society. Worst hit: dementia during coronavirus. 2020.

<https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>

¹⁶ Ibid

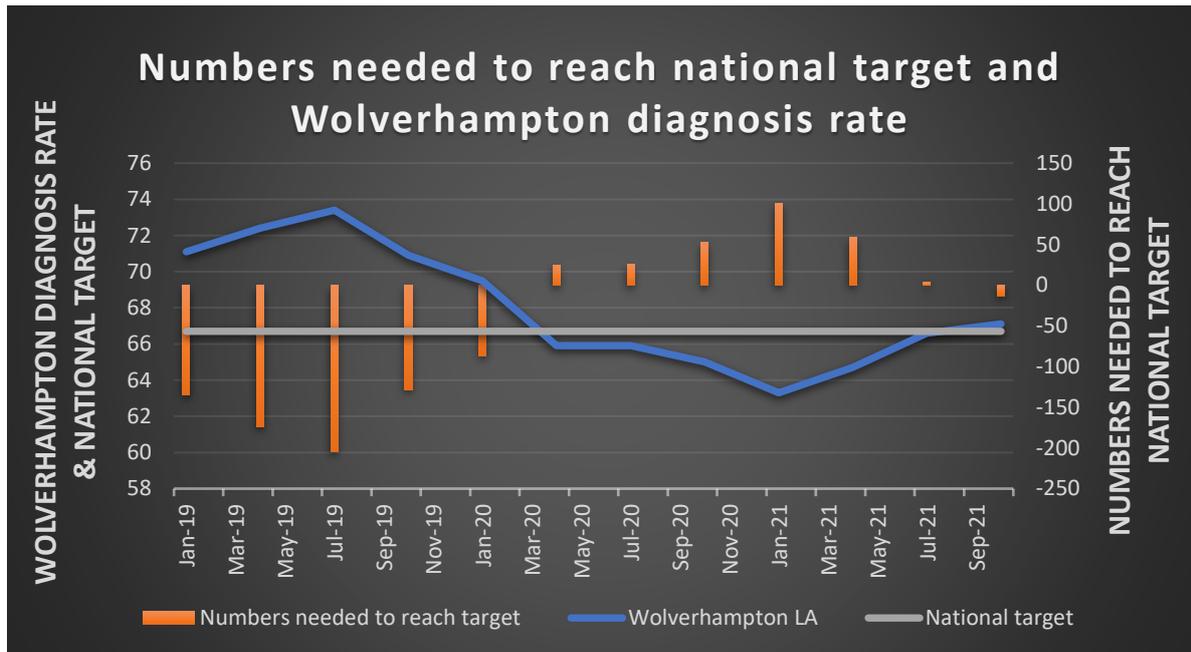
¹⁷ NHS Digital. Recorded dementia diagnoses, December 2021. <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/december-2021>

¹⁸ Ibid

¹⁹ NHS Digital. Dementia diagnosis rate and prescription of antipsychotic medication to people with dementia. 2020. <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/dementia-diagnosis-rate-and-prescription-of-antipsychotic-medication-to-people-with-dementia#:~:text=Since%202012%2C%20the%20NHS%20has,dementia%20to%20be%20formally%20diagnosed.>

- **35 days is the average wait time between a referral and an initial appointment** at a memory clinic in England.²⁰
- **21 to 238 days is the range of time between referral and diagnosis of dementia** in England, meaning that many people wait over six months to receive a diagnosis. Currently the average wait is 13 weeks (91 days).²¹
- **51% of people are diagnosed in the mild/early stages** of their condition in England.²²

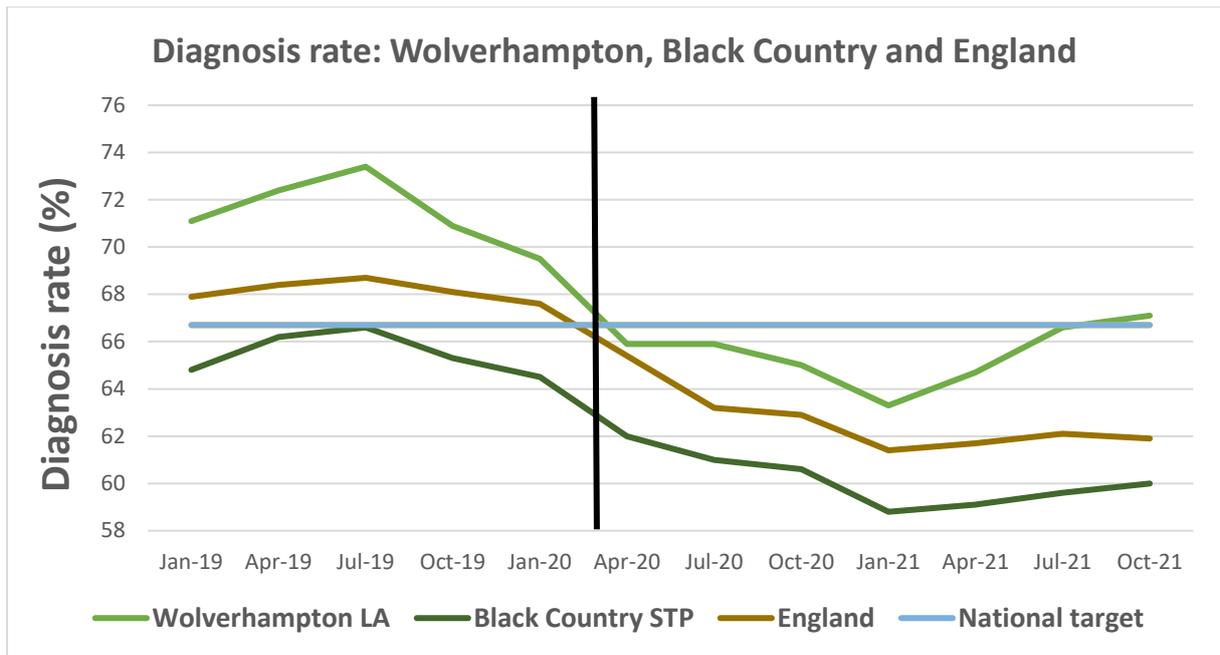
How does Wolverhampton and the wider Black Country, compare to the average for England?



²⁰ Royal College of Psychiatrists. Memory Services National Accreditation Programme Fourth National Report. 2016. https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-publications-fourth-national-report-2015-6.pdf?sfvrsn=2ad61ddf_2

²¹ NHS London Clinical Networks. The 2019 National Memory Service Audit. 2019. [The 2019 national memory service audit \(england.nhs.uk\)](https://www.nhs.uk/clinical-networks/london-clinical-networks/the-2019-national-memory-service-audit/)

²² Royal College of Psychiatrists. Memory Services National Accreditation Programme Fourth National Report. 2016. https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-publications-fourth-national-report-2015-6.pdf?sfvrsn=2ad61ddf_2



(NHS Digital. Recorded dementia diagnosis. 2021. <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses>)

Alzheimer’s Society services in Wolverhampton

We currently offer our Dementia Connect service in Wolverhampton, which operates seven days a week. This service is for people living with dementia, their carers, family and friends. It’s free to use and can be accessed via phone or online.

The service puts people in touch with a dementia advisor who will listen to their needs and help with all dementia related questions. This includes phone and online support, as well as connecting people to help in their local area, whether that’s signposting them to local support groups or arranging for a face-to-face visit from a dementia advisor. Each service user is then offered a keeping in touch call up to four times a year to ensure people are fully supported along their dementia journey.

As well as our telephone, online and face-to-face support, the team in Wolverhampton also provide a Dementia Café service. Our Dementia Cafés provide a safe and supportive place for people to:

- discuss their own dementia diagnosis, or someone else’s, and think about what it means for the future
- get answers from health professionals and meet and learn from other people in similar situations
- keep active, make new friends and feel more confident.

During the peak of the pandemic our Dementia Cafés moved online to enable the continuation of this vital support service, whilst keeping people safe. As restrictions have lifted the service has moved back to on monthly face-to-face café and weekly virtual cafes,

after the local team found that there has still been a demand for virtual cafés as more people have become accustomed to that method of attendance.

As well as the standard services mentioned above, the local team also provide additional support across the local area via a range of methods. Staff from the local services team have a monthly radio slot on a local Punjabi Radio Station, Gulshan Radio, and offer monthly drop-in session for the South Asian community at the Lashmi Sweet Centre, to try to increase engagement with this community.

Nationally, our online community, 'Talking Point', which enables people affected by dementia to connect with others in a similar situation, as well as the extensive range of resources that are available online via the Alzheimer's Society website, help to provide round the clock support for people affected by dementia.

Referrals into Dementia Connect

Since April 2020, Alzheimer's Society's new Dementia Connect service in Wolverhampton have been receiving referrals into the service. The launch of Dementia Connect in Wolverhampton coincided with the start of the pandemic. Prior to the pandemic the previous service delivered in Wolverhampton by Alzheimer's Society received on average 20-30 referrals a month. From April 2020 to December 2021 the service saw an average of 16 referrals a month. Roughly 40% of referrals over that time have come from memory assessment services (MAS), with just over 9% of referrals coming from GPs. Although Dementia Connect received 26 referrals from GPs in quarter one of 2020/21, referrals from GPs dropped significantly as the pandemic progressed, with Dementia Connect receiving only five more referrals for the remainder of 2020 and 2021. Other referrals were made via NHS secondary care (excluding MAS), self-referral, social services, statutory authorities (excluding social services, voluntary organisations, and internal referral).

Increasing access to a dementia diagnosis

Launched in September 2021, our dementia diagnosis deep dive research followed on from the launch of our pathway report in 2020, 'From diagnosis to end of life: The lived experience of dementia care and support'.²³

The aim of this project was to take a more detailed look at Diagnosing Well, looking at ways to increase access to a dementia diagnosis across three separate themes, producing a report for each theme.

The three reports look at increasing access to a dementia diagnosis with a specific focus on:

- [Ethnic Minority Communities](#) – looking at the barriers communities face when accessing a diagnosis as well as the barriers that exist at service level.
- [Regional Variation](#) – highlighting the challenges and opportunities of reducing regional variation.

²³ Alzheimer's Society. From diagnosis to end of life: The lived experiences of dementia care and support. 2020. <https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life>.

- [Hospitals and Care homes](#) – looking at how areas can increase access to a diagnosis across hospital and care home settings.

Evidence for each of the reports was gathered via a literature review; analysis of datasets, local pathways and policy documents; semi-structured interviews with commissioners, memory service professionals, care home and hospital staff, VSCOs, and people affected by dementia; and surveys.

The three reports were developed outside of the context of Covid-19 but they do reference the pandemic where appropriate throughout.

Although the reports are issue-based, they also contain best practice examples.

Ethnic Minority Communities

In 2013, it was estimated that there are 25,000 people living with dementia in the UK from an ethnic minority background. That number is expected to double by 2026 and go on to increase by 600% by the middle of the century. In comparison, it is projected that there will be a 100% increase in people with dementia across the whole of the UK population in the same time period.

The expected increase amongst ethnic minority communities is partly explained by the fact that people who moved here during periods of higher immigration in the 1950's and 70's are now reaching an age in which dementia is more prevalent. There has also been increased policy focus on boosting access to a timely diagnosis over the last decade, which may have played a part.

However, ethnic minority communities will also see a rise in the number of people with dementia due to an increased risk of developing dementia in comparison to the White British population. For instance, those in Asian and African-Caribbean communities are likely to experience increased vascular risk factors for dementia, such as cardiovascular disease, hypertension and diabetes.

Despite increased prevalence, research suggests that people from an ethnic minority community are less likely to receive a diagnosis or will go on to access one later on in the progression of the disease.

Wolverhampton's ethnic minority population is increasing. In 2011, 32% of the population of Wolverhampton were from an ethnic minority community, an increase of 10% from the 2001 census.²⁴ The largest ethnic minority group in Wolverhampton is the Asian community (18%), with the Black community making up 6.9% and those from a Mixed background making up 5.1% of the population.²⁵

²⁴ City of Wolverhampton Council. Wolverhampton City Joint Strategic Needs Assessment. 2017. https://www.wolverhampton.gov.uk/sites/default/files/pdf/Wolverhampton_City.pdf

²⁵ Office for National Statistics. 2011 Census: Key Statistics for Local Authorities in England and Wales. 2011. https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/2011censuskeystatisticsforlocalauthoritiesinenglandandwales/r21ewrtableks201ewladv1_tcm77-290595.xls

With the increased risk of developing dementia amongst ethnic minority communities and research suggesting that people from ethnic minority communities are less likely to receive a diagnosis or will go on to access one later on in the progression of the disease, it will be important for Wolverhampton to assess what – if any – barriers people from ethnic minority communities face when accessing a dementia diagnosis.

Barriers to diagnosis for people from ethnic minority communities

Our report 'Increasing access to a dementia diagnosis within Ethnic Minority Communities', highlighted several barriers that people from ethnic minority communities may face when trying to access a dementia diagnosis. The report sets out the challenges being faced at a community level and at a service level.²⁶

Community level barriers are those that can deter people from ethnic minority communities from accessing a diagnosis and they include:

- **Language** – can result in a lack of access to information about dementia for different communities. Also, an inability to read, write or speak English inhibits access to information for clinicians to support a diagnostic assessment.
- **Stigma and taboo** – although dementia has been and continues to be a stigmatised condition across all groups, the stigma may be more prominent in minority communities. An impact of stigma is that it contributes to low levels of awareness which in turn leads families to ignore or conceal early signs and therefore the opportunity to reach out to formal services. One example of this is that there is no word for dementia in most South Asian languages, and often the words to describe dementia can be derogatory. These derogatory terms can then further entrench the stigma and therefore the lack of awareness of dementia as a medical condition, one which a person can get a diagnosis for and receive appropriate care and support.
- **Cultural perceptions** – cultural perceptions around dementia, health and caregiving, can limit knowledge and awareness of dementia. Caregiving also masks symptoms within families and can deter accessing formal support for symptoms. Families have different roles within different communities – in Asian communities it's generally the view that younger generations care for their elders. Therefore, they don't recognise caregiving as a separate role from that of a son or daughter, but rather it's just an extension of an existing responsibility. Again, this can deter from accessing formal support for symptoms.

Service level barriers are those barriers that may be present in the services being provided as part of the diagnosis process, that may make it difficult for someone from an ethnic minority community to access a diagnosis. Service level barriers may include:

- **A lack of culturally appropriate service provision.** Our report highlighted that generally, it is felt that there is a lack of culturally sensitive and appropriate dementia services, deterring people from these communities from accessing these formal support services.

²⁶ Alzheimer's Society. Ethnic minority communities: Increasing access to a dementia diagnosis, 2021. [ethnic minorities increasing access to diagnosis.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/ethnic-minorities-increasing-access-to-diagnosis.pdf)

- **A lack of culturally appropriate diagnostic tools.** Some cognitive tests can produce biased findings based on ethnicity and language. For instance, some questions rely on a sufficient knowledge of British history, which is likely to be problematic for someone who migrated here.
- **A lack of access to quality interpretation services.** Accessing good quality interpretation services is a challenge. Interpretation is more than the literal translation of words, but more about putting across the service user's view and experience, and we know that many interpreters don't have dementia training.
- **A lack of demographic data to plan services.** This means that commissioners find it difficult to appropriately plan and commission services relative to local demographics.

What can be done to address these issues?

To support communities better it is important to involve community organisations representing these communities in the planning and delivery of dementia services. Not only this, but community link workers should also be provided to deliver an outreach service to communities and raise awareness of dementia.

One example of this is NHS Oldham CCG's BAME Dementia Adviser, which was commissioned to engage with local communities to increase awareness of dementia. The Adviser is proficient in seven South Asian languages and well-versed in religious texts. The service recognises the importance of identifying places to engage with communities, such as mosques, temples and churches, as well as places such as money transfer agencies and cash and carries. The Adviser also works with local GP surgeries and memory services to ensure that local diagnostic pathways are as culturally appropriate as possible.²⁷

At a service level it is important to ensure that areas identify ethnic minority populations and audit referral rates to ensure services are diagnosing the right amount of people. When services fail to be culturally accessible, communities may believe that they will not understand the values, beliefs and language preferences that are important to them. Training for staff on the cultural and religious differences of different communities across Wolverhampton – if not already in place – will help provide a better understanding of the values and beliefs of the different communities' staff may serve.

Access to validated cognitive tests for ethnic minorities as well as access to appropriate interpretation services, will be key to being able to meet the needs of people who may have immigrated here or whose first language may not be English. It may also be worth considering linguistic skill provision when commission services in the future. Slough Memory Assessment Service is an example of where this is already happening, where some staff speak some South Asian languages and there is a protected full-time role for a Punjabi-speaking Assistant Psychologist, created in response to feedback from service users and carers and a review of the needs of the local population.²⁸

Finally, it'll be important for GP practices to adhere to the new demographic data collection requirements, which became a contractual requirement on 1 January 2021. The collection of

²⁷ Alzheimer's Society. Ethnic minority communities: Increasing access to a dementia diagnosis, 2021. [ethnic_minorities_increasing_access_to_diagnosis.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/ethnic-minorities-increasing-access-to-diagnosis.pdf)

²⁸ Ibid

this data will help to provide commissioners of services with a clearer picture of the services needed within an area that meet the needs of the population.

Regional Variation

As part of our paper 'Regional Variation: Increasing access to a dementia diagnosis' we highlighted two main regional challenges that have an impact on dementia diagnosis rates. They are deprivation and rurality.²⁹

Deprivation

According to 'The English Indices of Deprivation 2019', Wolverhampton has become relatively less deprived.³⁰ Despite this Wolverhampton was ranked as the twenty first most deprived area of England out of 152 upper tier local authorities.³¹ We found as part of our work on regional variation of dementia diagnosis that in areas of higher deprivation there may be a higher prevalence of dementia, given vascular risk factors for dementia.

Deprivation factors may also impact how a person presents to primary care. For instance, in areas of higher deprivation people may have less of a support system around them and therefore less likely to have emerging dementia symptoms identified. There are also challenges for GPs; people will likely have co- or multi-morbidities in areas of higher deprivation, which is a challenge for GPs since more pressing or urgent health needs can be prioritised over slight cognitive changes at primary care appointments.

How can local areas improve identification of dementia?

Simply asking people about concerns with their memory or cognition as part of a screening process for clinics that serve long-term conditions which are risk factors for dementia may be beneficial. Using a short cognitive test as part of this screening process may be another option.

We would encourage areas to continue to support and monitor NHS Health Checks to increase the likelihood of identifying signs of dementia. NHS Health Checks are check-ups for adults aged 40-74 in England, to spot early signs of conditions. This check has a dementia specific component.

From 2018/19 to 2019/20, Wolverhampton saw the number of people invited for an NHS Health Check per year increase from 11,336 (16.3% of those eligible in 2018/19) to 13,674 (19.3% of those eligible in 2019/20). In comparison the West Midlands as a whole invited

²⁹ Alzheimer's Society. Regional variation: Increasing access to a dementia diagnosis, 2021.

[regional_variations_increasing_access_to_diagnosis.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/resources/reports/regional-variations-increasing-access-to-diagnosis.pdf)

³⁰ Ministry of Housing, Communities and Local Government. The English Indices of Deprivation Statistical release – main findings. 2019.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/835115/loD2019_Statistical_Release.pdf

³¹ Ministry of Housing, Communities and Local Government. The English Indices of Deprivation File 11: Upper-tier local authority summaries. 2019.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/834001/File_11_-_loD2019_Local_Authority_District_Summaries_upper-tier_.xlsx

21% of those eligible in 2019/20 and 17.7% of those eligible across England were invited in 2019/20. Wolverhampton saw just over half of those invited in 2019/20 take up the offer of an NHS Health Check, which is a better take up rate than the West Midlands (36.6%) and England (43.7%) over the same period.³²

As well as continuing to push NHS Health Checks, it is also important to provide extra resources to better support GP surgeries in areas of higher deprivation. This extra resource may help where a GP is presented with multiple health conditions that are of concern, hopefully avoiding the need to prioritise more pressing or urgent health needs over slight cognitive concerns. Proactive case finding within primary care should also be carried out to help identify possible dementia in local areas. Research suggests that reviewing local data and primary care records can help areas identify undiagnosed dementia.³³ This can be achieved using the Dementia Quality Toolkit (DQT). The DQT runs a series of reports on GP registers to identify patients who may have dementia but are not recorded as having it, or to identify those at risk of developing dementia. This can include:

- Patients who have been prescribed dementia medication.
- Patients who have a code in their record that may suggest dementia.
- Patients who have been coded with delirium in hospital.
- Patients who live in care homes.³⁴

Local areas should recognise that a lack of awareness of dementia as a condition will mean that people are less willing to contact services regarding their symptoms. It is essential that local areas adopt a proactive approach to case-finding and running the DQT on local GP registers is a way to do this.

Good practice examples

In South Somerset, a pilot model integrated Dementia Support Workers within GP surgeries to help increase the number of people receiving a dementia diagnosis. Where practices had Health Coaches, they worked with Dementia Support Workers to review patients lists, identifying people with memory problems or symptoms indicative of dementia, but who were not assigned the code corresponding to dementia.

In Doncaster, practices cross-referenced primary care data against the local mental health trust care records to identify cases where people were recorded as having a dementia diagnosis in secondary care but where this was not recorded in primary care. Updating primary care records accordingly had a positive impact on local dementia diagnosis rates.³⁵

³² Public Health England. NHS Health Check. 2020. [NHS Health Check - OHID \(phe.org.uk\)](https://www.phe.org.uk)

³³ Alzheimer's Society. Regional variation: Increasing access to a dementia diagnosis, 2021. [regional variations increasing access to diagnosis.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk)

³⁴ Ibid

³⁵ Ibid

Hospitals and care homes

The final paper from our series looks at 'Hospitals and care homes: Increasing access to a dementia diagnosis'.³⁶ The aim was to look at what impacted access to a dementia diagnosis across these settings. The report highlights the key challenges that exist in identifying, assessing and diagnosing dementia in hospitals and care homes.

Hospitals

In hospitals we heard of difficulties distinguishing between dementia and delirium. As we know delirium commonly affects older people, and the symptoms can be similar to dementia, which makes it difficult to assess for dementia. Not only this, but older people are likely to have comorbidities and therefore may have multiple pathologies within a hospital admission. It's important to remember that a clinician's primary responsibility is to treat the reason for admission, and therefore a dementia assessment may be secondary in their priorities. Integrating dementia assessment pathways alongside common reasons for admission for older people such as stroke and falls may improve the likelihood of assessment.

Lack of staff time, skill and confidence was also identified as a barrier. Ensuring staff have enough training could help to reduce this barrier. Another option could be to provide explicit hospital teams to assess dementia.

Clinicians reported struggling to access clinical information to support an assessment, so it is important that IT systems are integrated, as well as ensuring family members are involved in the assessment process. Having family members present can support the assessment process by detailing any history of symptoms or recent behaviour.

Complicating the discharge process was also a factor. Ideally, hospitals are best avoided for people with dementia, and a stay in hospital is sometimes associated with adverse outcomes.³⁷ However, we found that some clinicians may be deterred from carrying out dementia assessment as they fear it would complicate the discharge process and unnecessarily extend the time a person spends in hospital. There is a need to ensure the discharge process is not a barrier to assessment.

Finally, research and engagement with professionals suggest the biggest challenge is the lack of assessment post-discharge. We heard from clinicians that they have identified and assessed a person with dementia in hospital, referred them for memory assessment, and then seen the same patient back in with an acute admission some months later still without a diagnosis.

There were a series of reasons for this.

- Firstly, GPs reported disjointed information within discharge letters which makes it difficult and time-consuming to piece together little bits of information to support an onward referral.

³⁶ Alzheimer's Society. Hospitals and care homes: Increasing access to a dementia diagnosis, 2021. https://www.alzheimers.org.uk/sites/default/files/2021-09/hospitals_and_care_homes_increasing_access_to_diagnosis.pdf

³⁷ Fogg, C et al (2018). Hospital outcomes of older people with cognitive impairment: An integrative review, *International Journal of Geriatric Psychiatry* 33(9): 1177-1197.

- Secondly, it's best practice to have a 'period of stability' after an acute admission, in order to allow any potential delirium to subside and therefore undertake a more appropriate assessment of dementia. This period should be three months. However, this increases the chance of people falling off the diagnostic pathway. Where patients are more advanced in their condition or do not have a support network around them, it can be difficult to facilitate access back into the diagnostic pathway.³⁸

Having a dedicated team or workforce to provide follow-up and facilitate access back to assessment areas may reduce instances of this. This service could be delivered by a community or district nurse, or a social prescriber.

Care homes

In care homes we heard of the need to improve access to and availability of training for staff. We heard that many care homes have difficulty accessing GP services for dementia assessment, so a process whereby primary care review all new care home admissions may increase identification of dementia.

We know that GPs can diagnose dementia in a care home setting using the DIADEM tool, however, commissioners reported that there is a low level of awareness of the tool amongst primary care professionals, so there is a need to promote this amongst primary care colleagues.

Finally, both care homes and GPs said accessing patient information was challenging. GPs reported that the diagnostic assessment can be time-consuming and they struggled to access patient information from care homes, or that information wasn't up to date in care home records. So there is a need to ensure all care home records are up to date.

Prevention and Pre-diagnostic support

Over the course of the pandemic, we saw a steady decline in dementia diagnosis rates. Across England rates dropped from 67.6% in February 2020 to 63.2% in July. Over the same period, the diagnosis rate in Wolverhampton dropped from 69.9% in February 2020 to 65.9% in July 2020, hitting the lowest point in January 2021 at 63.3%.³⁹ Overall, hesitancy to visit services due to concerns about Covid-19, and changes to Memory Assessment Services and Primary Care, have contributed to the reduction of diagnosis rates.⁴⁰

The impact of this is that more people have been unable to access the benefits that a diagnosis can bring. Without a diagnosis and the post-diagnostic support that should come after, people affected by dementia risk missing out on essential care and treatment. This

³⁸ Alzheimer's Society. Hospitals and care homes: Increasing access to a dementia diagnosis, 2021.

https://www.alzheimers.org.uk/sites/default/files/2021-09/hospitals_and_care_homes_increasing_access_to_diagnosis.pdf

³⁹ NHS Digital. Dementia: 65+ Estimated Diagnosis Rate: Purpose. [Online] 2020.

<https://digital.nhs.uk/data-and-information/national-indicator-library/dementia-65-estimated-diagnosisrate#purpose>

⁴⁰ Alzheimer's Society. Regional variation: Increasing access to a dementia diagnosis, 2021.

[regional_variations_increasing_access_to_diagnosis.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf)

also means that people face an extended period of fear and uncertainty of unexplained symptoms. As systems work to reduce the backlogs in diagnosis that we now face, prevention and risk reduction, as well as pre-diagnosis support for those showing signs of dementia, will be key.

Recent research from the Lancet Commission showed that there are 12 modifiable risk factors for dementia which account for up to 40% of dementia cases globally which, in theory, could be prevented or at least delayed.⁴¹ By including dementia alongside cancer and heart disease in healthy living messaging, Wolverhampton can raise public awareness that what is good for the heart is also good for the head. It will also be important for Wolverhampton to continue to support the ongoing implementation of NHS Health Checks, as mentioned in the Deprivation section earlier in the paper.

To support those waiting for an assessment, Wolverhampton may want to create information resources that will help to prepare each individual and their family for the diagnosis process. The Dementia Change Action Network (DCAN) have been working with NHS England to try to understand the experiences of people who are waiting for a memory assessment. As part of the project DCAN has run several focus groups, online surveys and virtual forums to gather information from people about the needs they had during this time, the support they received and the support they would have liked to receive. The information gathered as part of this piece of work was collated into a briefing and a new guide to 'Living well while waiting for a memory assessment' was created from the findings of this project.⁴²

Post diagnostic support

Once a diagnosis has been made, the post-diagnostic support that follows is vital to help people come to terms with their diagnosis and help them to manage their condition. In our report, 'From diagnosis to end of life', we highlighted some benchmarks that areas should use to assess what care people are receiving at the 'supporting well' part of the pathway.⁴³ Offering oral and written information to the person and their family is a good starting point. This information should help to explain in more detail what to expect, what their rights are, and what support services are available locally.

While information can help to support some people in the initial stages, more proactive person-centred support in the form of a care coordinator can help people affected by dementia navigate the complex health and social care system. Because of the progressive and unpredictable nature of dementia, people will often encounter a range of services and health and social care professionals. This can often lead to the care a person receives

⁴¹ Livingston, G. et al (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*. 396(10248):413-446. [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext).

⁴² Dementia Change Action Network. Pre-Memory Assessment. 2021. <https://dcan.org.uk/projects/prediagnosis/>

⁴³ Alzheimer's Society. From diagnosis to end of life: The lived experiences of dementia care and support. 2020. <https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life>.

feeling disjointed. Identification of a care coordinator must happen towards the beginning of the pathway, either by a memory clinic or by primary care during a follow-up appointment.

Under NICE guidance, everyone diagnosed with dementia should have access to a named health or social care professional. This person is responsible for coordinating their care from the point of diagnosis to the end of life.⁴⁴ During the early stages of the condition, this may involve signposting to services. In later stages, it may involve coordinating all aspects of the person's health and social care.⁴⁵

Dementia advisors may undertake some elements of care coordination for people living with dementia. They may also provide additional and valuable post-diagnostic support services. However, we know that access to dementia adviser services can be patchy. As part of the work on our report, 'From diagnosis to end of life', we heard that where dementia advisers are integrated within primary care or specialist diagnostic services, the number of service users being recruited to the service at point of diagnosis increased. We also heard that automatic referral to a local dementia advisor service with an 'opt out' system can also work well.⁴⁶ In Wolverhampton, we saw a reduction in referrals into the local Dementia Connect service during the pandemic. We recommend that the reasons for this reduction in referrals are investigated to explore what would support GPs to refer into the service in order to ensure everyone is able to receive good quality post diagnostic support.

Recommendations

To improve dementia diagnosis, we would recommend the following is carried out in Wolverhampton:

- An assessment is carried out across Wolverhampton to identify possible barriers to diagnosis for ethnic minority communities.
- An assessment is carried out within more deprived areas of the city to determine whether there are barriers due to deprivation and to identify what additional support GP surgeries may need in those areas.
- An assessment of the reasons for the drop in referrals to the Dementia Connect services from GPs during the pandemic.
- Consider the provision of dedicated community link workers to improve awareness and understanding of dementia and access to services in ethnic minority communities, if this is not already available.
- Where there are currently high waiting time for a diagnosis, Wolverhampton should ensure that those waiting for a diagnosis are able to access support when needed, so that they can proactively begin to prepare for the assessment and the future.

⁴⁴ National Institute for Health and Care Excellence. Quality statement 4: Coordinating care. 2019.

www.nice.org.uk/guidance/qs184/chapter/Quality-statement-4-Coordinating-care

⁴⁵ Alzheimer's Society. From diagnosis to end of life: The lived experiences of dementia care and support. 2020.

<https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life>.

⁴⁶ Ibid