Regional variation

Increasing access to
a dementia diagnosis

Alzheimer's Society
United Against Dementia

Acknowledgements

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Contents

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'. Grounded in the voices of people affected by dementia, it looked at four stages of NHS England's Dementia Well pathway:

Diagnosing Well   **Supporting Well**   **Living Well**   **Dying Well**
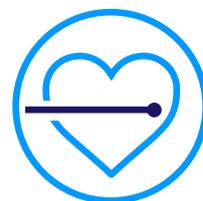
It explored in detail what national guidance and government say people in England should be receiving at each stage, and therefore the care and support they say will enable people to live well with the condition. We benchmarked this against the experiences of people affected by dementia. A key finding of the report was a sense of disjointed, fragmented care.

The report laid the groundwork for deeper explorations into the dementia pathway. As part of a short series of reports into diagnosis, this report seeks to identify and address the reasons behind regional variation of dementia diagnosis rates.

Before COVID-19, England had for some time been achieving the national target of diagnosing two-thirds of people living with dementia. Much of the national drive to increase diagnosis rates therefore focused on reducing regional variation.

This report is based on engagement with commissioners, memory services, our own dementia support services and other health and care professionals involved in dementia diagnosis. We found that how processes are carried out at each step of the diagnostic pathway can significantly disrupt improvements in diagnosis rates. Regional influences such as deprivation and rurality also have a considerable effect. The key challenges are:

Identifying dementia

- how proactive local areas are in case-finding for possible dementia
- how deprivation impacts the identification of dementia, both for people and for services

Referral processes

- how insufficient referral processes impact and delay access to a diagnosis
- how patients' reticence affects their accessing a diagnosis

Diagnosis

- to what extent primary care services are enabled to diagnose dementia
- whether Mild Cognitive Impairment (MCI) is recognised and, where it is, whether these cases are tracked for follow up
- how rurality affects both presentation and access to services for people with dementia

Data and reporting

- how well dementia data is collected and reported

Partnership working

- whether there are systems in place to enable partnership working between all professionals involved in dementia diagnosis.

Though this report concentrates on improving diagnosis rates outside the context of COVID-19, it is important to acknowledge the impact of the pandemic on people and services. COVID-19 has exposed the frailty of our health system and highlighted the role of GPs, memory services and other health professionals in ensuring people living with dementia can access a diagnosis. While each local area will have their own priorities and challenges, we hope this report and its recommendations can provide a framework to improve local diagnosis rates – not only in response to COVID-19, but also as we emerge from it.

It's important to recognise that a diagnosis is not the sole responsibility of any one organisation. The move towards Integrated Care Systems provides an important opportunity for new ways of planning, delivering and commissioning services. It is a chance to understand what works well in local areas and to identify where improvements can be made in diagnostic pathways. Bringing together health and care providers, Integrated Care Systems have a responsibility to address underdiagnosis. The recommendations in this report will help support this.
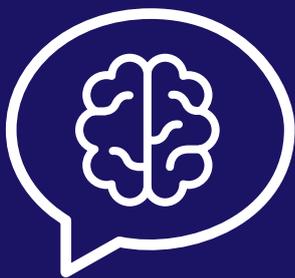
Introduction

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 symptoms that a person experiences will depend on the parts of their brain that are damaged and the underlying cause of their dementia.

The importance of a dementia diagnosis cannot be overstated. It facilitates access to vital care and support that enables people to live well with the condition. Its significance is outlined in the Dementia Statements, which are grounded in human rights law:

'We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live'.[1]

NHS Digital data from May 2021 shows that 434,307 people in England currently have a diagnosis of dementia.[2] However, it is estimated that 678,997 people in England are living with the condition in total. This means that thousands of people are living without a diagnosis, and therefore without the care and support a diagnosis facilitates.

Diagnosis rates background

Over the last decade, there has been a proactive and sustained effort to increase dementia diagnoses. The 2009 National Dementia Strategy emphasised the importance of diagnosing dementia – at the time, a diagnosis was often given late and after a crisis point had been reached.[3]

In 2013, NHS England agreed a national ambition for diagnosis rates, aiming for two-thirds of the estimated number of people with dementia in England to have a diagnosis. This was achieved in November 2015.[4] The focus was then shifted to reducing variation regionally.

There are two important factors when considering diagnosis rates: prevalence and estimation. NHS England calculate dementia diagnosis rates using prevalence rates from the Cognitive Functioning & Ageing Study (CFASII).[5] This study produced prevalence rates of dementia considering the variable factors of age and sex. For example, men aged 70-74 will have a different prevalence rate of dementia compared to men aged 75-79. Women will have a different prevalence rate for these age bands compared to men.

These prevalence rates are applied to GP patient registers to estimate the number of people with dementia. They are cross-referenced with those on the GP register who currently have a diagnosis of dementia. This gives GP practices and Clinical Commissioning Groups (CCG) areas the percentage of all people estimated to be living with dementia in their areas who have a diagnosis.

COVID-19 context

While this report considers systematic and regional challenges outside of the context of COVID-19, it is important to recognise the impact of the pandemic on diagnosis.

Many people who are worried about symptoms of possible dementia will contact their GP. COVID-19 restrictions meant that primary care services had to significantly reduce the number of appointments available or offer remote appointments. As a result, some people were unable to access what is generally the first step in the diagnostic process. The GP-led rollout of the vaccination programme also made it harder for people to see their GP. **All memory services we spoke to reported a reduction of referrals received from primary care during the pandemic.**

In secondary care, many memory services reported closure or part-closure during the pandemic. Some clinicians had been redeployed to other areas of the NHS. Where memory services were operating, some were prioritising urgent or advanced cases of dementia or were not taking on any new diagnostic cases. Some memory services report that they now have significant backlogs in their case list, affecting waiting times.

Services also reported that they were able to offer routine diagnostic appointments during summer 2020, though often remotely. But the fluctuation of infection levels and lockdown restrictions further affected how far memory services were able to diagnose people with dementia.

Our analysis of NHS Digital data shows that in 2020 the average number of monthly:[6]

GP assessments for dementia was	Referrals to memory assessment services was	Memory assessments for dementia was
54% of 2019 levels	**58% of 2019 levels**	**50% of 2019 levels**
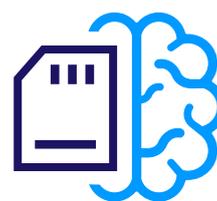
Overall, people's hesitancy to visit services due to concerns about COVID-19, and changes to services' activity and delivery, have contributed to the reduction of diagnosis rates.[7] **Nationally, the impact of the pandemic on diagnosis rates is stark. In just one year, the national diagnosis rate for people aged 65 and over dropped by 6.3 percentage points, from 67.4% in March 2020 to just 61.1% in February 2021.[8] From May 2021, we estimate that over 33,500 diagnoses are needed nationally to get back to pre-pandemic diagnosis levels.[9]**

March 2020 – 67.4%
April 2020 – 65.4%
May 2020 – 64%
June 2020 – 63.5%
July 2020 – 63.2%
August 2020 – 63.1%
September 2020 – 63.0%
Ocotober 2020 – 62.9%
November 2020 – 62.7%
December 2020 – 62.4%
January 2021 – 61.4%
February 2021 – 61.1%
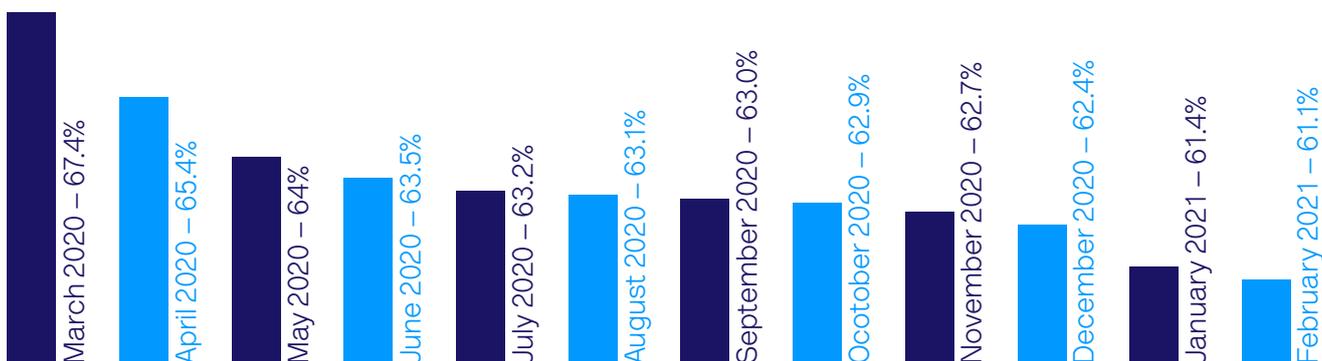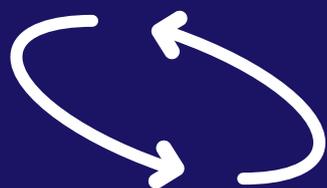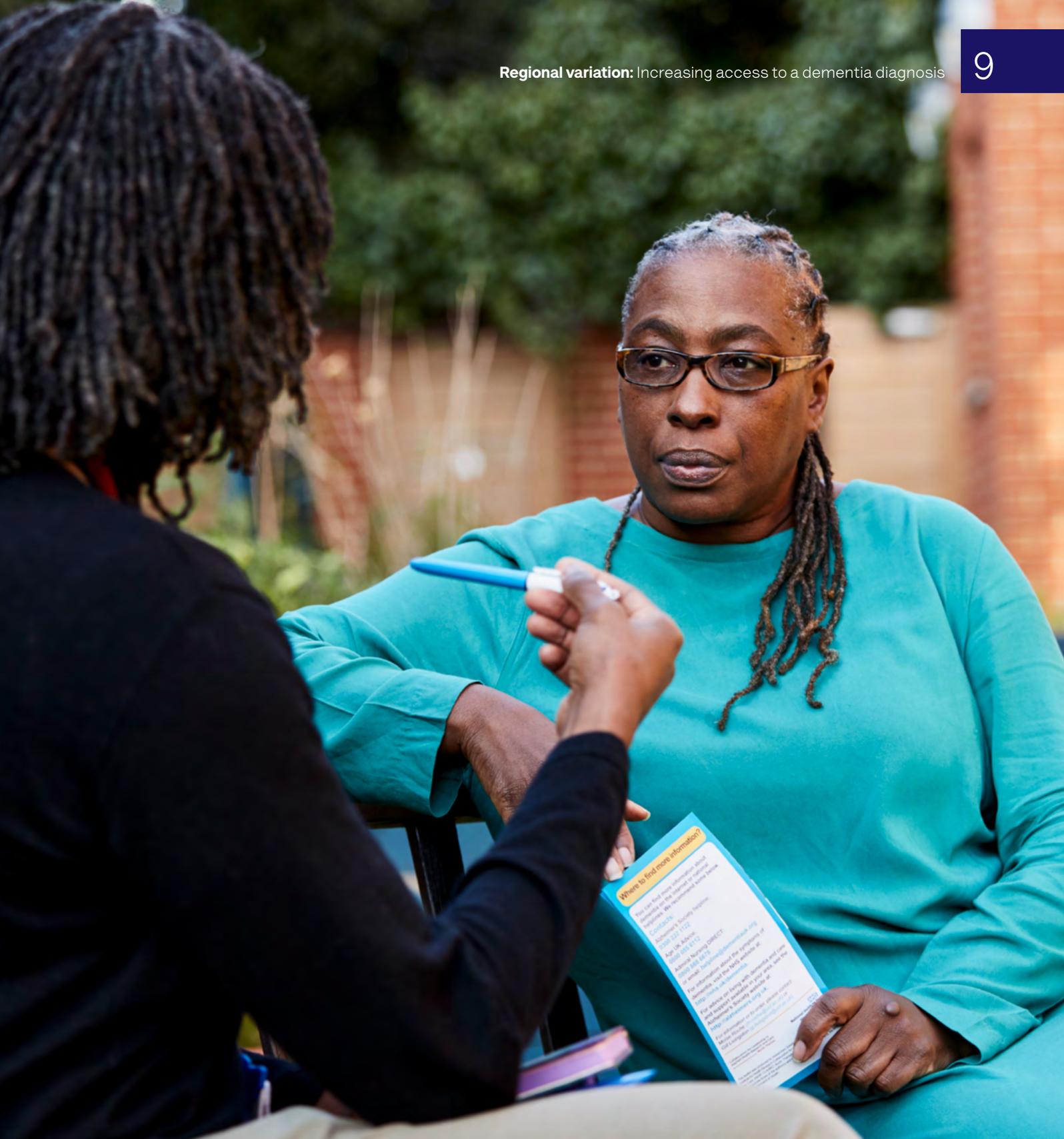
What needs to change?

Some areas in England manage to diagnose more people estimated to have dementia, meaning a post-code lottery for dementia diagnosis. NHS Digital data before COVID-19 in January 2020 shows considerable variation of diagnosis rates across England's CCGs, from 53% to 90.7%.[10]

Dementia is a complex condition, and so the provision of care for people with dementia requires it to be delivered in an integrated way. The move towards Integrated Care Systems provides an opportunity to bring together services and professionals and identify innovative ways in which to increase dementia diagnoses and reduce variation.

Identifying dementia

Integrated Care Systems should:

- ensure that proactive case-finding for dementia is regularly carried out. This can include:
  — using the Dementia Quality Toolkit on GP registers
  — dementia screening for older people newly registered on GP registers
  — dementia screening for clinics serving long-term conditions that are considered risk factors for dementia
- ensure that extra resource is provided to GP practices in areas with high levels of deprivation to support better identification and assessment
- monitor and support the ongoing implementation of NHS Health Checks and ensure that they include the dementia component.

Improving referral pathways

Integrated Care systems should:

- review local diagnostic pathways and identify responsibility for referral protocols for primary care. Secondary care should also be able to access primary care records to support access to clinical information where this is missing in referrals
- drive quality improvements in local referral pathways. This can be achieved by:
  — establishing Single Point of Access and triaging processes
  — establishing feedback channels for referrals between secondary and primary care
  — identifying how secondary care can support primary care to improve diagnosis referral pathways, such as providing an easy-to-access 'advice line' to secondary care or 'Link Workers' to GP practices
  — providing education sessions for GPs
  — auditing referral patterns and working with poorly-performing referral practices to identify educational and service provision needs
  — establishing workforces within primary care to address patient reticence.

Increasing access to a diagnosis

Integrated Care Systems should:

- ensure that, where diagnoses are made within secondary care, memory services are commissioned effectively so that they are capable of assessing and diagnosing two-thirds of people living with dementia

- carry out a review to determine how more diagnoses can be made in primary care, especially in cases where specialist memory assessment services are operating at capacity. New primary care-led diagnosis pathways may include:
  - enabling primary care to make more diagnoses in the middle to later stages of dementia. This should include sufficient resource, training and joint working between primary and secondary care
  - establishing secondary care resource within primary care, such as a dedicated memory nurse

- ensure that services recognise MCI and diagnose it where appropriate, and provide a clear pathway to better track and support cases that go on to develop dementia. This should be accompanied by use of neuropsychology assessments and audits of conversion rates

- ensure that there is local agreement over whether follow-up of people diagnosed with MCI is carried out by primary or secondary care

- review the accessibility of diagnostic services, particularly for rural areas. This can include memory service provision within GP surgeries or community 'hubs', or consideration of voluntary transport provision.

Improving data quality and reporting

Integrated Care Systems should:

- ensure consistent dementia coding across primary and secondary care

- ensure that data cleansing exercises are carried out regularly.

Developing better collaboration

Integrated Care systems should:

- establish explicit Dementia Strategy Groups and/or Dementia Steering Groups to improve partnership working and to meet regularly to discuss local diagnostic pathways. This should include commissioners, memory services, the voluntary sector and other health partners involved in dementia diagnosis

- identify practice-level dementia diagnosis rates and investigate low-performing practices, providing additional support and resource.

Identifying dementia

Identification of possible dementia is the first step of the diagnostic process. Many people living with symptoms, or those close to them who notice changes in their cognition or behaviour, usually contact their GP. While GPs should be well-placed to recognise early signs of dementia due to their established relationships with patients,[10] this can vary in practice. One study found that GPs were more likely to under-identify rather than over-identify dementia.[11]

However, many people may be reluctant to visit a healthcare professional with concerns about dementia symptoms. Stigma around the condition,[13] worries about losing their driving licence[14,15] or increased insurance premiums,[16] and fears over how a diagnosis will affect their life more generally[17] deter people from reaching out to health services. This may be more common in rural communities, where dependence on driving is higher compared to urban areas.

Those who live alone may also be less likely to access primary care, as it is less likely for others to be around the person to notice symptoms. GPs have expressed difficulty identifying memory problems among people who live alone.[18] One study suggests that people with dementia living with a long-term partner were around twice as likely to be diagnosed than those in other living arrangements.[19]

The evidence suggests that there are hidden or hard-to-reach people who may be experiencing dementia symptoms and who are reluctant to seek help. One way to address this and to maximise diagnosis rates is for primary care services to proactively find cases in their area.

Case-finding

Proactive case-finding within primary care has already been in place nationally. The Directed Enhanced Service (DES) ran from April 2013 to March 2016 and was a financial incentive for GPs.

It supported a proactive approach to assessing patients at risk of developing dementia and testing them as appropriate. The Dementia Identification Scheme (DIS), another financial incentive scheme, ran from October 2014 to March 2015 and was designed to support and complement the DES.

These pay-for-performance schemes were designed to address the underdiagnosis of dementia. Most GP practices signed up to the DES (98.5%) and a majority signed up to the DIS (76%).[20] These schemes had a positive impact on the national diagnosis rate.[21] Research suggests that practices participating in the DES increased their diagnosis rate by 1.44% more than those that did not participate. The DIS resulted in an increase of 3.59% points.

These schemes together increased registered cases of dementia nationally by an estimated **40,767 people**[22]

However, the schemes left an unintended legacy for primary care professionals.[23] Though they have come to an end, primary care professionals we spoke to suggested that there is a residual view among some GPs that proactive dementia identification exercises are seen as 'extra work', and should continue to be funded as an enhanced service rather than as a core part of the primary care service. **This reluctance is made worse by lack of targeted time and capacity.**

Some of these schemes have since been implemented locally and it is important that commissioners recognise their potential unintended consequences. Despite this, proactive case-finding for dementia should always be carried out by primary care services to identify possible dementia in local areas.

How can local areas improve case-finding for dementia?

Research suggests that data and use of primary care records can be used to identify undiagnosed dementia.[24]

The Dementia Quality Toolkit (DQT) is an effective method of achieving increases in diagnosis rates, considering time and capacity issues at primary care level. It 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. These can include:
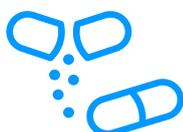
patients who have been prescribed dementia medication

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 a care home.[25]

One commissioner reported that when it began using the DQT, it increased the diagnosis rate of some practices by as much as 25%. This process does not necessarily have to be conducted by a GP but can be completed by other members of the primary care team or by secondary care.

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.

For individuals, this can begin the diagnostic process which will facilitate access to much-needed care and support. For commissioners and service providers, a proactive approach to case-finding will enable a better understanding of dementia prevalence in local areas, which will only improve the planning and delivery of services.

Deprivation

Research suggests that diagnosis rates are associated with deprivation in local populations.[26] Factors include income, employment, health, education and living environment, among others.[27]

In our engagement, of those who identified regional factors affecting local diagnosis rates,

61%
of dementia support workers

64%
of Clinical Commissioning Groups

73%
of memory services

said that deprivation and health inequalities were significant factors.

Challenges identifying dementia

Deprivation may affect how people present to primary care.

One study shows that in areas with higher levels of deprivation, there are likely to be higher morbidity rates for chronic conditions. This may mean that people access primary care more often, and therefore means there are additional opportunities for dementia to be detected in elderly populations.[28]

On the other hand, deprivation may present challenges for identifying dementia. One GP we spoke to suggested that people in areas of high deprivation are likely to have other health conditions. This is a challenge for GPs, because cognitive changes in a person can be overlooked if more urgent health needs are prioritised. This can create a 'hierarchy of disease; where... dementia is... ignored.'[29] Other factors contributing to this may be the patient themselves not noticing these cognitive changes, and the short consultation time at primary care level, where GPs spend an average of just 8-10 minutes with each patient.[30]

Clinicians also reported that in areas of high deprivation, people may have less of a support system and are therefore less likely to have emerging dementia symptoms identified. This can affect the likelihood of them accessing primary care.

GPs add that socioeconomic factors play a role in the recognition of dementia symptoms. People of higher socioeconomic status may have a greater understanding and awareness of dementia symptoms and are therefore more likely to contact their GP.[31] Some memory services we spoke to reported receiving more referrals from affluent practice areas and fewer referrals from deprived areas.

It is important that extra resources to support better identification and assessment of dementia are provided to GP practices in areas with higher levels of deprivation.[32]

Dementia risk factors

The link between dementia and deprivation may positively impact diagnosis rates.

One study found that GP practices in areas with higher levels of deprivation were associated with higher rates of patients diagnosed with dementia.[33] Further research finds that diagnosis rates of dementia were 8% higher in the most deprived fifth of practices, compared to the least deprived.[34]

This supports our own analysis of CCG-level diagnosis rates in January 2020 which showed, where levels of deprivation could be identified, higher levels of deprivation were associated with a higher diagnosis rate.

A partial explanation may be the fact that dementia prevalence may be higher in more deprived areas.[35] This is not reflected in prevalence estimates used by NHS England to generate diagnosis rates – these use prevalence rates from the CFASII, which only takes into account the factors of age and sex.

This higher prevalence may be explained by increased risk factors for dementia in more deprived areas. Local areas should be aware of modifiable risk factors including hypertension, smoking, obesity, physical inactivity, diabetes and excessive alcohol consumption, among others.[36]

How can local areas improve identification of dementia?

Screening processes for clinics serving long-term conditions that are risk factors for dementia may be beneficial. This does not have to be time-intensive – it could involve simply asking people about concerns with their memory or cognition, or using a short cognitive test.

NHS Health Checks – health check-ups for adults in England aged 40 to 74 to spot early signs of conditions[37] – has a specific dementia component. Recent research suggests that new dementia diagnoses were significantly more likely to be identified in those who attended NHS Health Checks than those who did not.[38]

However, take-up of these checks is low – 83.1% of people eligible for a health check between 2013 and 2017 did not attend.[39] **Local areas should monitor and support the ongoing implementation of these checks.**

What is best practice?

South Somerset – Dementia Support Worker and Health Coaches based in GP surgeries

The South Somerset pilot model integrated Dementia Support Workers within GP surgeries, with the aim of increasing the number of people living with dementia who receive a diagnosis. This aligned with the new local dementia diagnosis pathway, which included GPs diagnosing less complex cases of dementia.

Where practices had Health Coaches (Social Prescribing Practitioners), these worked with Dementia Support Workers to review patient lists. They identified people with memory problems or symptoms indicative of dementia, but who were not assigned the code corresponding to dementia.

Where dementia was obvious in some patients, the code was added to their records. Where dementia was suspected, assessment was carried out and, where appropriate, a diagnosis was given. However, it was recognised locally that GPs still required training to carry out more diagnoses at primary care level.

The provision of Dementia Support Workers within practices supported a joined-up approach to dementia diagnosis. The model had a positive impact on the local diagnosis rate and significantly increased referrals into the Dementia Support Worker service. The pilot had been so successful that, before COVID-19, it was due to be rolled out to the rest of the county.

Gnosall Surgery

The Gnosall model for dementia care is a primary care-based service, established in 2006. Patients who are at risk of developing dementia or who are within the early stages are identified through the primary care Quality and Outcomes Framework (QOF) disease database.

Primary care staff look for and identify any changes in cognition or mood in this group of patients. Relevant patients are identified in a number of ways, including:

- observations and knowledge of patients' general health from other GPs at the practice
- concerns raised by family members
- other clinical information such as hospital admissions.

These patients, and any others showing signs of altered cognition or mood, are then referred into the memory service.

The model succeeded in identifying the number of people in their area predicted to have dementia in prevalence modelling, and reduced time to diagnosis.

Doncaster CCG

Practices in Doncaster cross-referenced primary care QOF data against the local mental health trust care records. This was 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 the primary care records accordingly had a positive impact on the local diagnosis rate.

As part of a wider look at local dementia pathways, Doncaster CCG have identified and planned a series of measures to improve identification of dementia at primary care level. These measures include:

- exploring where screening processes can be carried out within current commissioned services other than GP surgeries
- implementing cognitive testing for new patients aged over 65, both within practices and at other clinics for long-term conditions.

Referral processes

A referral to specialist diagnostic services is usually the second step in the diagnostic process. Increases in diagnosis rates are not only due to improvements in recorded diagnoses. Rates can also be increased through systematic improvements in the diagnostic pathway,[40] including aspects such as the referral process.

Inadequate referrals

Memory services have previously reported poor quality and incomplete referrals.[41] Our engagement with memory services shows that this is still an issue today. Many reported significant variation in the content and quality of referral information from primary care.

Incomplete referrals disrupt the diagnostic pathway. They deny secondary care services access to clinical information that would help determine whether the referral is appropriate for the service. Services told us they had to reject referrals and encourage primary care to carry out the necessary clinical investigations, which can delay the diagnostic process.

A review of memory services in the South West in 2013 showed that out of 50 referrals, less than half (48%) had a formal memory test.[42] In another area, up to 25% of referrals were incomplete and required further information.[43] Another review of dementia services in one area found that nearly a third of referrals from GPs had missing information, which required significant administrative time to locate.[44] One memory service we spoke to reported that four in 10 referrals were inadequate or incomplete, requiring the service to contact primary care to complete the required protocols.

However, capacity issues at primary care level may affect adherence to these protocols. Completing referral information can be complex and time-consuming, and can result in several primary care appointments for each individual. Analysis of referral criteria in seven London memory services in 2016 showed considerable variation. Some services required testing in excess of national guidelines and thresholds for incentive payments. One service required physical examinations but no neurological examination. Two had no specific referral criteria.[45]

GPs told us that lack of time to carry out referral protocols was a barrier. Taking blood tests and collecting cognitive history can be a long process. Other health services asking them to do more in terms of referral protocols adds to workload pressure. These pressures can affect primary care's adherence to guidelines.[46]

Concerningly, our support services reported that some referral processes are unnecessarily extended due to disagreement between primary and secondary care over which budgets referral criteria should come from.

How can local areas reduce inadequate referrals?

Standardised approaches to carrying out referral protocols across primary care shortens the diagnostic process.

It identifies patients' suitability for assessment, and supports memory services with information in advance of meeting patients.[47] Local areas should therefore ensure that there is agreement about which protocols primary care should carry out.

Where referrals are incomplete, memory services told us that the ability to access primary care records helps with patient information. This allows services to understand which tests have been completed if this information is missing.

Inappropriate referrals

Inappropriate referrals were a key issue identified by commissioners, memory services and our own support services.

Ensuring there are clear referral pathways in place can help streamline the diagnostic process and avoid inappropriate referrals. This includes defined pathways to dementia diagnosis, such as those for people with learning disabilities, mild cognitive impairment and young-onset dementia.[48,49]

However, it can be unclear how services are commissioned and which services patients should be referred into.[50] For example, a memory service may be commissioned as a standalone service or be part of a wider Older People or Community Mental Health Team. Acceptance criteria, such as whether services accept younger people with dementia or those with significant behavioural issues, can further complicate referral pathways.

Some GPs have expressed a lack of knowledge about how to refer into a particular service.[51] **Our own engagement with clinicians found that improved collaboration and easier methods of communication are needed, and that primary and secondary care should discuss particular cases to establish their suitability for a service.**

Single Point of Access and triaging within secondary care are effective in sorting referrals and optimising timely access to the right services.[52] This is important where services have acceptance criteria such as age, or if services are situated within broader Older People or Community Mental Health Teams. It helps to establish whether a memory-specific service is needed or whether broader neuropsychiatry or neuropsychology services are more appropriate. **Services also told us that having an effective triage process in place allows them to manage the suitability and flow of patients coming into the service.**

How can local areas reduce inappropriate referrals?

Memory services in areas with high diagnosis rates reported receiving few inappropriate referrals, and identified good collaboration between primary and secondary care as a reason for this.

One service worked with primary care colleagues and trained them on referral criteria, enabling GPs to recognise their abilities and responsibilities in terms of protocols, reducing inappropriate referrals. **Establishing channels for feedback between primary and secondary care may also support better referral pathways, and is welcomed by GPs.**[53]

Another service we spoke to ran a consultant-based advice line for primary care colleagues, where GPs could discuss potential referrals and their suitability for the memory service. In theory, replicating this would not require a consultant but could be nurse-led, as long as primary care can access a clinician with significant experience and expertise in dementia. Lastly, one memory service provided a 'Link Worker' to local GP practices whose role was to engage and educate GPs to improve referral quality.

It may be beneficial to audit referral patterns if memory services are consistently receiving inappropriate or inadequate referrals. This would help establish where referring clinicians require training and would maximise prompt diagnoses for people with dementia.

Patient reticence

Patient reticence may be a significant barrier to accessing a diagnosis. Our own report on the dementia pathway found that many people with dementia find referral processes confusing and feel daunted about 'what comes next'.[54] **It's important for people concerned about symptoms to recognise that a diagnosis can open doors rather than close them.**

GPs and memory services reported that patients can have fears or concerns about beginning the diagnostic process when they are identified with dementia symptoms. Stigma around the condition may be a factor. Clinicians also felt that memory services in mental health settings or in hospitals may increase stigma and deter people from completing their memory assessments.

Some of our own support services identified this as an issue in their local area. Where people are in denial or are worried about getting a diagnosis, this may affect a GP's decision to complete a referral to memory services.

How can local areas address patient reticence?

We heard positive examples of how services and commissioners sought to address patient reticence.

These included the provision of skilled staff who champion the benefits of a diagnosis and work with those reluctant to be assessed, helping them receive a diagnosis Due to its strong community links the voluntary sector may play an important role here, rather than clinical primary or secondary care staff.[55]

Provision of additional workforces in primary care, with an explicit focus on raising awareness of the benefits of a diagnosis, may be a positive step in addressing this issue.

It is important that all primary care colleagues champion the benefits of a diagnosis.

What is best practice?

Barnsley 'Trio' Memory Assessment and Support Service

Recommissioned in 2016, the Barnsley Memory Assessment and Support Service (MASS) delivers a comprehensive, one-stop service through a hub and spoke model. It is located within the Older Person's Community Mental Health Team, which enables collaborative working.

The model aims to address variation between GP practices in the identification of patients with suspected memory problems, by integrating MASS workforce within Primary Care Networks.

This is achieved by providing a 'trio' service, comprising a band 6 nurse, a band 5 nurse and a band 3 Memory Support Worker who are attached to each practice, building relationships and providing continuity with primary care colleagues. The Memory Support Workers maintain links with dementia champions in each GP practice, while the band 5 nurses maintain a community role in the review and assessment of patients known to the service.

This mix of skills enables the trio to meet patients' complex needs. Primary care colleagues can also ask the trio for advice and to facilitate clinical case discussion. This offers a robust assessment and referral process for those referred into MASS. In some practices, the trio offer a pre-referral assessment clinic.

Individual GP practices report that the service is accessible and quick to react, and that GPs know who to contact for advice or discussion about individual patients.

Wandsworth Memory Assessment Service

Wandsworth Memory Assessment Service, situated in the broader Wandsworth Older People's Community Mental Health Team, has the highest diagnosis rate in South London and the fourth highest in London.

The service has a straightforward referral process for GPs, using a template in the GP's electronic record. This means that patient details and their relevant medical history (such as previous consultations, blood tests or prescriptions) can be filled in automatically.

However, the service has a flexible approach and also accepts emails and letters. The service recognises time and capacity challenges for primary care colleagues where protocols are incomplete. If referrals are not suitable for the Memory Assessment Service (MAS), these are then re-referred to the correct service. If this is not possible, the MAS will let the referrer know and signpost them to an alternative service.

Where referral protocols are not completed by primary care, the MAS is enabled to access the Health Information Exchange – a system that allows them to view some information on GP records, as well as electronic patient records with the local acute hospital and Summary Care Records. This allows the service to build a more coherent picture of referrals where protocols are incomplete.

The service also initiated a new system of managing referrals – a dedicated triage coordinator. A band 6 nurse triages all referrals, with cases of at-risk patients assessed on the same day. The benefit is that patients are assured they are not lost in the system as they are contacted within a short time after referral. It also provides an opportunity to gauge patients' preference for the type of consultation they receive, and whether any special considerations need to be given, such as for patients with sensory impairments. This responsive process is seen to support primary care services' trust in the referral process.

Worcestershire CCG

Worcestershire CCG commissioned a Memory Loss Advisor Pilot, provided by Age UK. This was located within seven GP practices in one locality in Worcestershire for nine months. The role was commissioned to address patient reticence in GP practices with low levels of recorded dementia prevalence.

Where a GP notices a possible cognitive problem with a patient, and the patient is reticent about the assessment process, they are referred to the Advisor. The Advisor works with the patient and their family to improve their awareness of the benefits of a diagnosis, and encourages them to have their memory problem investigated.

This involves developing bonds and building trust with the patient and their family. The Advisor completes a pre-assessment, and would refer either to the local memory service or back to the GP for diagnostic confirmation. This means that in clearer or more advanced cases of dementia, a GP would make a diagnosis, with more complex cases referred on to the local MAS.

In just over a year, the service received 329 referrals. The service was also positively received by service users. Clinicians felt that the pilot provided patients with an appropriate level of care, and practices with necessary support. The visibility of the Adviser at practice level built trust and facilitated good collaboration with practice staff.

The pilot seemed most beneficial at identifying those with young-onset dementia or those hesitant to find out if they had dementia. The pilot allowed for more patient contact than might have been available with just GP involvement. GP practices particularly felt that the service was of value to their patients.

100% of service users felt that:

- they were treated with dignity and respect
- the information and support they received was useful in understanding more about memory loss and its possible causes
- discussions with the Memory Loss Advisor helped them make decisions about the next steps in the diagnostic process.

Camden Memory Service

Camden Memory Service was restructured in 2016. Previously, the quality of referrals from primary care had been mixed. However, promoting the updated service to primary care colleagues increased their awareness of its value, which had a positive impact on the quality of referrals. This relied on many local GP practices' willingness to support the new service model.

Required referral protocols include a recent blood test, medical history, a cognitive test, a description of symptoms and the GP's reason for referral.

Where some referral protocols are not completed, the service has access to some patient information at primary care level through Mental Health Patient Care Records. This includes recent completed medical tests, discharge summaries and medical history.

The new service model also redesigned how referrals are received. Originally, distribution of new referrals required multidisciplinary (MDT) meetings, which was considered inefficient and delayed working through the patient caseload. In the new model, senior clinicians meet weekly and allocate appointments to doctors, with administrative staff booking appointments.

Because all first assessments are conducted by medical staff, diagnoses are given more regularly at the first appointment, where appropriate. This enables more people to be seen with fewer follow-up appointments and quicker access to the post-diagnostic service. As a result, the service has not had a waiting list for the past three years.

Rotherham Memory Service

Rotherham Memory Service is situated in Rotherham, Doncaster and South Humber NHS Foundation Trust's Older People's Mental Health Team. It provides multidisciplinary assessment for the diagnosis of dementia and delivers post-diagnostic counselling, advice and treatment, alongside nurse-prescribing services for patients over the age of 65. In January 2020, NHS Rotherham CCG had a diagnosis rate of 82.6%.[56]

Referral protocols include a 6-CIT (Six-item Cognitive Impairment Test), full blood test screening and a history of the patient's symptoms. While GPs have access to a referral form, the service also accepts letters from primary care that include referral protocols.

Where referral protocols are not completed, the service will still accept the referral to avoid delaying appointments for patients. At the same time, the service will ask the GP to complete the missing protocol. Additionally, most of the primary care IT systems (90%) are integrated with secondary care systems, so the service can access patient records. Where IT systems are not integrated, the service can still access clinical history such as blood tests and scans.

Previously, the service had discussed referral processes and protocols with primary care colleagues, and trained GPs on what to look for when assessing patients for memory problems. The service reports that it now receives very few inappropriate referrals from primary care colleagues.

Diagnosis

Memory services were introduced in the UK in the 1980s. Their purpose was to receive patients who would not normally be seen by general psychiatry services, which dealt with symptoms that were relatively mild and more responsive to interventions.[57]

The first anti-dementia drugs in 2001 supported the evolution of a national network of memory clinics,[58] perhaps due partly to national guidance recommending that these drugs be prescribed following specialist assessment.

They are considered an effective and efficient way of diagnosing people with dementia.[59,60] Due to changes in commissioning landscapes and local provision, the role of memory services now focuses on providing diagnosis subtypes, as well as access to post-diagnostic provision of therapies and to research.

Dementia is a growing challenge due to increasing prevalence. Local health systems will need to find ways to ensure that people with dementia continue receiving timely diagnoses.

Primary care-led diagnosis

Commissioners and memory services reported mixed views about whether GPs should be making diagnoses. Where GPs took on a more active role, there were concerns within memory services about the capacity and commitment of primary care colleagues to carry out diagnoses. Memory services also told us that where GPs do not want a more active role in diagnosing dementia, this is due to fears of getting the diagnosis wrong or concerns around subtyping.

We found that the professionals enabled to diagnose dementia varied across care settings. There have been longstanding issues with diagnostic responsibility at primary care level.[61] Commissioners in one area told us that referrals to the memory service were continually rejected on the basis that the dementia was 'obvious' or progressed enough for it to be diagnosed within primary care – but primary care were themselves reluctant to provide a diagnosis.

However, it is important to recognise that any clinician with the right skills, confidence and expertise may diagnose dementia.[62] Enabling primary care to carry out more diagnoses, particularly in the middle to later stages of the condition, may be an effective way to ensure that local areas meet demand.

Despite local variation in where diagnoses can be delivered, there are benefits to encouraging health systems to diagnose dementia in primary care more often.

Secondary care capacity

One reason for this is capacity at secondary care level.[63,64] Due to policy drivers for dementia diagnosis, and to the increasing prevalence of dementia, memory services have been expanding to meet demand and will need to continue doing so.[65]

Memory services have had capacity limitations since their creation. Significant increases in referrals have affected waiting lists and the ability to provide follow-up care.[66] The most recent audit of memory services nationally shows that the mean waiting time from referral to diagnosis was 13 weeks, but that it varied among services from three to 34 weeks.[67]

During our engagement, rising waiting times was identified as an issue for services. Many memory services reported that they were operating at capacity, and that the backlog of appointments due to COVID-19 has contributed further to this.

When demand for diagnostic services increases, so do waiting times, leaving more people waiting longer to receive a diagnosis. GPs have reported that a lack of funding and capacity, as well as inadequate clinical and administrative staffing levels, are factors influencing access to a diagnosis.[68]

Other GPs have stated that significant waiting times for memory services would act as a deterrent to referring into the service.[69] For secondary care, many services told us that referrals have been increasing year on year, but that additional funding and resource has not kept up with demand.

One commissioner of a memory service that had long waiting times told us that just 40% of referrals needed a specialist input from a consultant. It was found that some of the other 60% of referrals could either have been diagnosed by primary care, or could have had secondary care support to make a diagnosis in primary care.

Balancing timely diagnoses against complex cases and counteracting stigma

Another reason for diagnosing dementia in primary care is the national drive to diagnose people in much earlier stages of their condition.

Memory services may have a system of prioritisation for case lists. This may affect the speed of diagnoses, because those with more urgent and complex needs are prioritised above those who may be in the earlier stages of their condition.[70] Memory services we spoke to said it was difficult to balance seeing people with urgent needs with providing a timely diagnosis to those with milder symptoms.

There may be further advantages to allowing primary care to take a more active role in diagnosis. For example, there may be stigma attached to mental health services. Positioning diagnosis within primary care, with access to the necessary secondary care expertise, may reduce some people's reluctance to seek a diagnosis.[71,72]

Upskilling primary care

Primary care is already taking on a greater role in the assessment and long-term care of people with dementia.[73]

In many cases, GPs will be the primary clinician coordinating a person's care for the longest period of their journey with dementia. This suggests an existing responsibility for GPs to have core knowledge in the care of older people and those living with dementia.[74]

If GPs are referring into secondary care without the opportunity to diagnose dementia themselves, they are arguably deskilling themselves in the care of people with dementia. In one area, this was a justification for moving to a primary care-led model of diagnosis. 80% of dementia cases had been diagnosed within primary care, which led to extra capacity within secondary care to provide additional post-diagnostic support.[75]

What could primary care-led diagnosis look like?

We heard many positive examples of primary care-led diagnosis happening across the country, mainly where GPs were enabled to diagnose cases of dementia in the middle to later stages, with support from secondary care.

In one model delivering primary care diagnoses, 90% of patients were managed within this setting, with specialist involvement from secondary care. This meant that secondary care could be used to optimum effect in both investigation of complex dementia and delivery of care, due to their increased capacity.[76]

Another area adopted a primary care-led model, in response to low diagnosis rates and high memory service waiting times. A shared care pathway was implemented locally. Initial diagnoses were carried out in primary care, with final diagnosis and medicine initiation carried out by the memory service. As a result, the diagnosis rate increased from 40% to 72% and waiting times to memory services reduced. 95% of referred patients were diagnosed within six weeks.[77]

Provision of secondary care resource within primary care, such as a dedicated memory nurse or similar role, may help ease time and capacity pressures in primary care and improve their ability to make diagnoses. A proactive approach to establishing memory services at primary care level is also commonly recognised as a sign of progress.[78]

However, there is a need to recognise the views of primary care and the challenges they face in diagnosing dementia. GPs we spoke to suggested that it is much easier to refer into a memory service than to carry out the whole diagnostic process themselves, which takes time in a busy setting.

Not all GPs will want to take a lead in dementia diagnosis or feel that it is appropriate – for example because memory services are commissioned to carry out memory assessments and deliver diagnoses. Local areas must therefore consider the enthusiasm and confidence of primary care colleagues when planning any change to diagnostic pathways. **In areas where diagnoses are mainly delivered in secondary care, memory services should be commissioned so that they can diagnose at least two-thirds of all people living with dementia.**

Mild cognitive impairment (MCI)

Mild cognitive impairment (MCI) is a condition in which someone has minor problems with their cognition, such as with memory or thinking.[79] These difficulties are worse than what would normally be expected for a healthy person of their age. However, the symptoms are not severe enough to interfere significantly with daily life, and so are not defined as dementia.

However, there are links between MCI and dementia. As with dementia, incidence of MCI increases with age.[80] It is thought that total prevalence of MCI in the UK is between 12% and 18%.[81] Research suggests that around 16% of people with MCI will go on to develop dementia,[82] with others suggesting this may be as high as 20%.[83] MCI is therefore a significant predictor of dementia.[84]

Diagnosing MCI

Given the prevalence of MCI and its relationship to dementia, it is important that diagnoses of MCI are given.

The most recent national audit of memory services found that 17% of people over 65 were diagnosed with MCI, but this varied across services, ranging from 0% to 47% per service.[85]

We heard differing opinions from clinicians about the appropriateness of MCI diagnoses. Some feel it is beneficial as an initial diagnosis,[86] while others see it causing unnecessary anxiety. However, it is important for commissioners recognise that any person has a right to a diagnosis, and to ensure that MCI diagnoses are delivered locally.

It may be beneficial for memory services to audit conversion rates from MCI to dementia. This may allow further understanding into MCI as a risk factor for dementia, which will help determine which patients are most in need of follow-up.[87]

Tracking and follow-up of MCI

When MCI diagnoses are given, they should be recorded and monitored. This ensures that people who go on to develop dementia are provided with as timely a diagnosis as possible.

Research suggests that neuropsychological testing can be useful in diagnosing MCI and tracking cognitive symptoms.[88] Services may benefit from using this tool to understand who is likely to develop dementia.[89] **We heard it is good practice that people with MCI diagnoses are assigned a code and have cognitive tests repeated at regular intervals, such as every six or 12 months.**

If MCI is not diagnosed and coded, it may be harder to track people who are at risk of developing dementia.[90] GPs told us about other benefits of diagnosing and coding MCI, particularly in cases where a person accesses other health services such as hospitals. It increases access to patient information to support clinical decision making. Memory services also identified MCI diagnoses as an effective opportunity to promote healthy living, to reduce instances of people with MCI developing dementia.

Our engagement with GPs, commissioners and memory services found significant variation in whether MCI diagnoses are given. There was also variation in who carries out the tracking and follow-up of people given MCI diagnoses, and to what extent. Some memory services expressed frustration at commissioners who were reluctant to admit the importance of MCI diagnoses and tracking in supporting better identification of dementia.

GPs, commissioners and memory services also had varied views about whether follow-up should be carried out in primary or secondary care. Issues included capacity and how memory services are commissioned. Some are commissioned as diagnostic services only, which may create pressure to discharge patients once a diagnosis is given. This makes it harder for secondary care to track patients who go on to develop dementia. Memory services also highlighted that the number of people with MCI who would need to be retested may further reduces services' capacity.

On the other hand, memory services had reservations about primary care being responsible for follow-up. MCI is not listed in the QOF as an indicator of dementia, so primary care may not regularly review patients diagnosed with MCI to identify signs of possible dementia. Other concerns were raised about the ability of primary care to carry out effective neuropsychological testing, given the expertise needed to detect changes in cognition using this method.

Commissioners should recognise the impact of tracking these cases. It would likely increase the services' caseloads, so it is important to consider whether tracking is carried out in primary or secondary care.

Rurality

In our engagement, of those who identified regional factors affecting local diagnosis rates, 74% of dementia support workers, 55% of CCGs and 55% of memory services identified rural and urban geographies as significant factors. Rurality may affect diagnosis rates in several ways, which presents challenges for both commissioners and memory services.

Prevalence of dementia in rural communities

Prevalence of dementia may be higher in rural communities.[91] Rural populations are generally older — 24% of those living in rural areas are over 65, compared to 16% in urban areas.[92]

The number of people aged 65 and over increased by 37% in rural areas between 2001 and 2015.[93] 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.[94]

One study suggests that there are higher rates of cognitive decline and impairment in rural areas.[95] Loneliness is a particular issue for rural areas with higher proportions of older residents. Loneliness is a risk factor for dementia[96] — one study suggests that it may increase risk by as much as 40%.[97]

Identifying symptoms in rural communities

Commissioners we spoke to suggested that people in rural communities, such as farming communities, access diagnostic services later in the progression of their condition.

This may be because those in rural communities are more likely to be self-reliant and have a family support network around them. This means that some people live with symptoms and only access diagnostic services following a crisis.

Our support services found that in rural communities there are fewer social activities or groups to attend, or that they are less accessible. This may mean there are fewer opportunities for people outside of a person's immediate family support network to identify symptoms.

Accessing services in rural communities

Lack of access to services among rural communities may also be a barrier to dementia diagnosis.

Patients in rural areas tend to underuse healthcare services,[98] and use of services negatively correlates with the time it takes to travel to them.[99] People living in rural communities may find it harder to access to services involved in diagnosis, such as GP practices or memory services.[100]

41% of people living in rural areas do not have access to their nearest hospital within an hour's travel by public transport or walking, compared to just 6% of users living in urban areas.[101] This is particularly important if memory services are located in hospital. Rurality can play a role in patients' hesitancy to access a diagnosis, particularly due to concerns about losing driving licences and a lack of public transport.[102]

Older people – the group most likely to have dementia – are more likely to experience health and care problems and to need to access health services. As a result, there is a higher demand on services in rural areas.[103] Research suggests that getting a diagnosis of dementia, particularly in the early stages of the condition, in rural areas is challenging.[104]

Our own analysis of local diagnosis rates in January 2020 showed that, where area classifications of CCGs could be identified, CCGs in urban areas had a higher diagnosis rate. Those situated in rural areas tended to have a lower diagnosis rate.

This may be because access to services is easier in urban areas compared to rural areas. As noted, rural populations tend to be older, and research has found that fewer patients are diagnosed with dementia in practices with larger proportions of elderly patients.[105]

One commissioning group found that diagnosis rates of practices were:[106]

57.8%
in mainly rural areas

70.3%
in urban areas

Ensuring accessibility to memory services and assessment is part of national guidance. Services should cater to the needs of those less likely to access health and care services.[107]

How can local areas improve access to a diagnosis for rural communities?

Commissioners should recognise challenges for rural communities when designing dementia services.[108]

In meeting these challenges, the role of primary care may be considered, as its role is greater in rural communities where access to specialist services is reduced.[109] There are positive examples of proactive approaches to delivering dementia diagnoses in the community within primary care.[110,111] Other local service provision can include carrying out more home assessments.[112]

Memory services covering large rural areas told us that they delivered services within community hubs or GP practices. Provision of voluntary transport schemes is another approach to improving access to clinical appointments for people living in rural areas.[113]

What is best practice?

Mid Essex CCG - The Community Dementia Pilot Project

The Community Dementia Pilot Project, based on the Danbury pilot, covers 12 GP surgeries in mid-Essex. It is made up of an Advanced Nurse Practitioner (ANP) and Healthcare Assistant (HCA), who work flexibly across GP surgeries to support primary care diagnosis.

When patients access a GP surgery with concerns about cognitive or memory issues, the HCA will visit them, carrying out screening blood tests as well as a cognitive and functional assessment. Patient information is reported back to GP, who decides whether to refer into the ANP service or to secondary care specialists. This is decided according to a 'tier' system, where clear or advanced cases of dementia are diagnosed in primary care (Tier 1), and more complex cases are referred to secondary care (Tier 2).

Those referred into the ANP service receive psychometric, medical and psychosocial assessments. Patients choose whether this is done at a practice or at home. Once assessments are complete, the ANP will review the results with the GP and decide whether a diagnosis is appropriate.

The ANP has extensive training in dementia diagnosis. Where possible, they will identify a subtype with the support of the GP. Neuroimaging is offered during the initial assessment, if appropriate. The ANP will then disclose the diagnosis to the patient in a separate appointment.

There are several benefits to the service. Both the ANP and GP have access to the same IT system, including patient information that would support an assessment. It is also considered a more cost-effective approach to diagnosis than referring all people suspected with dementia into secondary care, since it reduces the memory service case list.

The pilot has a two-triage system. HCA assessments are reviewed by the GP, who then refers to the ANP. The ANP carries out further assessments and either delivers a diagnosis or refers to secondary care specialists. Secondary care services benefit from the more robust assessment process by receiving more appropriate referrals.

GPs participating in the pilot also reported that it saved them time, as there is additional clinical resource to carry out dementia assessments, which can involve several primary care appointments.

Bury CCG

In 2015, Bury CCG carried out a pathway redevelopment. It supported the assessment, diagnosis and management of people with 'non-complex' cognitive impairment or dementia within primary care, without referral to the local MAS (Memory Assessment Service). Through collaborative working with the MAS, primary care clinicians were enabled to diagnose most of these patients. This included carrying out and recording initial assessments and diagnostic tests. Primary care clinicians were expected to manage their patients along the whole pathway in the same way as with other long-term conditions.

Where a diagnosis is uncertain – such as with dementias other than Alzheimer's disease or vascular dementia – people are referred to the local MAS. Practices can contact the MAS to discuss potential complex cases.

The new pathway aimed to reduce the number of referrals to the MAS, provide a timelier and more accurate diagnosis of dementia, improve the local diagnosis rate, and enable the MAS to focus its resources and skills on more complex cases.

While the prevalence of dementia in Bury is the 14th highest in England, the new pathway enabled the area to diagnose 86% of people over 65 expected to have dementia in June 2016 – up from 56% in March 2014. The pathway also reduced the number of referrals to the MAS by 40%, reduced the time taken by the MAS to assess new referrals by 20%, and reduced the time taken by the MAS to diagnose new referrals by 41%.

The model supports collaboration between MAS consultants and GPs, which is important to support more primary care diagnoses. It is thought that around 80% of diagnoses in Bury can now be carried out within primary care.

Salford Memory Assessment and Treatment Service

At Salford Memory Assessment and Treatment Service, a 'one-stop' model is used for most of the initial assessments. A nurse, a support worker and a senior clinician – usually a consultant – will review and decide on next steps in collaboration with the patient. Where a patient meets the MCI criteria, the service is commissioned to review all MCI diagnoses for up to two years, with annual reviews also carried out during this period.

When MCI diagnoses are given, the relevant code is provided to the GP, stated clearly in correspondence with primary care and with the patient themselves. Additionally, the service identifies MCI diagnoses as an opportunity to promote healthy living. Interventions are recommended, and MCI diagnosis information packs are provided, as well as a review of medication. The service also reviews social prescribing using local community-based groups.

When MCI diagnoses are given, patients are offered a review to check whether their cognitive impairment has increased on an annual basis. The service will repeat assessments including the Addenbrookes Cognitive Examination (ACE) III. Patient needs will be reviewed, and the service will establish whether they would benefit from further investigation should concerns around dementia emerge. Should memory difficulties not change, and the patient continues to be independent, it would be appropriate to discharge them following discussion with the patient at the end of the monitoring period. If cognitive impairment changes following discharge, Salford MATS would review the circumstances again following referral from primary care.

Data and reporting

Data is essential in dementia care. Regular and robust collection and reporting of dementia diagnosis data highlights the prevalence of dementia in local areas. It allows commissioners, services and professionals to make informed choices about how to plan and deliver their services for the populations they serve, as well as driving performance improvements.

In the absence of a cure for dementia, robust collection and reporting of diagnosis data is needed to ensure that as many people as possible are supported by timely and accurate clinical decisions. This can facilitate access to vital care and support to enable them to live well with dementia.

Aligning data coding across primary and secondary care

During our engagement, some commissioners and memory services reported a disconnect between data coding in secondary and primary care. It is important that there are standard practices for information sharing.

Some cases of dementia that are diagnosed in secondary care are not coded appropriately in primary care records. As a result, dementia cases are missed out of data reporting, and local dementia prevalence is underrepresented.

Commissioners in some areas with low diagnosis rates identified this as a particular frustration. Some areas may be achieving diagnosis targets but are missed from official data reporting. A lack of compatibility between IT systems was cited as a reason for this – for example, in one area with a low diagnosis rate, the memory service used one IT system and primary care used another.

Another reason was a lack of local agreement on coding. **It is important that primary and secondary care use the same coding, as well as individual GP practices.**[114] We heard examples of GP practices using different coding systems, leading to the underrepresentation of dementia in official reporting.

Where diagnoses are made within secondary care and there is a lack of compatibility between IT systems, we heard it is good practice to ensure that letters and other forms of communication to primary care include the appropriate code for the person's type of dementia. During our engagement, we found this was common practice in areas with a high diagnosis rate.

Data cleansing

Where record-keeping systems and processes are not aligned between secondary and primary care, cases may be underrepresented in official reporting. Regular reviews to 'clean up' data within primary care may improve diagnosis rates.[115]

One study suggests that cleaning up dementia coding at practice level can increase identification rates by up to 8.8%.[116] The study involved GP practices carrying out data cleansing exercises which took under five hours to complete, on average.

The DQT provides one way of achieving this aim. Where it can be used with GP systems, it can identify patients who have dementia but who are not coded appropriately within the practice.[117] This can include those assigned local codes which are not used for QOF reporting, or identifying those who are on dementia medication without an appropriately-coded diagnosis.

Commissioners reported significant increases in local diagnosis rates after initiating these activities. While it is important that these exercises are conducted regularly, the capacity of primary care to carry them out should be considered.

What is best practice?

Camden Memory Service

Camden Memory Service employed a social worker for around three months to support identification of dementia in the local area and to increase diagnosis rates. This involved identifying irregularities in diagnosis coding between primary and secondary care.

Coding in local GP practice registers was cross-referenced against that of the memory service to ensure that all local diagnoses were captured in data reporting. For those that did not match — for example, where a diagnosis was recorded in primary care but not in secondary care — the service worked to identify and code these appropriately.

An additional benefit of the service was its engagement with primary care colleagues. The worker attended primary care team meetings, which was an opportunity to promote awareness of the memory service.

Overall, this supported the memory service to diagnose most people living with dementia in Camden — NHS Camden CCG had a diagnosis rate of 90.7% in January 2020.[118]

Partnership working

In our engagement, of those who identified factors positively affecting local diagnosis rates,

67%
of CCGs

79%
of memory services

identified partnership working as a significant factor.

While systematic improvements in the diagnostic pathway and mitigation of regional influences can both affect local diagnosis rates, it is crucial that all services involved in diagnosis work effectively together. Opportunities for commissioners, memory services, the voluntary sector and local authorities to come together, identify emerging issues, and share information and best practice, can help local areas to understand and improve their diagnostic pathways.

Commissioners reported that good communication and collaboration between all services and professionals involved in the diagnosis pathway had a positive influence on diagnosis rates. While this is important health services typically involved in diagnosis such as GPs and memory services, other health, care and voluntary sector organisations can significantly contribute to improvements.

There is a need for a system to ensure that all services regularly come together to discuss diagnosis in their local area. It is particularly beneficial to discuss emerging issues, relating either to the diagnostic pathway as a whole or to individual services.

For example, one memory service in an area with a high diagnosis rate reported that opportunities to engage, build relationships, and promote their service to other healthcare professionals had many benefits. This included improving understanding of referral processes as well as increasing referrals for memory assessment. Others reported that regular time for multiagency working led to more strategic thinking and innovative ways of working.

Another reported benefit was that established groups and networks helped create a culture of driving improvements in diagnosis rates for local areas. **Even within some commissioning areas, diagnosis rates of individual GP practices can vary significantly. Bringing together GPs, commissioners, memory services and the voluntary sector can help identify low-performing practices and measures to increase their diagnosis rate.** This can include provision of workforces or sharing of best practice.[119]

The largest gains in local diagnosis rates would be made by improving the lowest-performing practices.

It is essential that these networks represent all those involved in the diagnostic process. This includes representation of commissioners, public health, acute trusts, local authorities and the voluntary sector.[120] Integrated Care Systems and Primary Care Network (PCN) Multidisciplinary Teams may provide a solid foundation to enable this.

What is best practice?

Staffordshire and Stoke-on-Trent

Staffordshire and Stoke-on-Trent CCG had a diagnosis rate of 71.7% in January 2020. One reported contributing factor was the provision of effective operational links and opportunities for healthcare professionals across the diagnostic pathway to come together.

North Staffordshire and Stoke-on-Trent have a Dementia Steering Group and an Operational Pathway Group. These include representatives from all local providers, including the local authority, the CCG, the local memory assessment service, secondary service professionals and the voluntary sector, as well as patients and carers. The Steering Group's role is to monitor progress of the implementation of the local Dementia Strategy. The meeting usually includes a presentation to share learnings, particularly from those with lived experience, and broader research opportunities. It is also a chance for members to give updates on the services they offer and any new developments.

The Operational Pathway Group is made up of all stakeholders from the dementia pathway. It meets and reviews the diagnostic pathway and resolves any issues that have arisen. It also works on projects to progress the implementation of the Dementia Strategy, reporting back to the Steering Group.

It also engaged with primary care services. Practices under the national target of 66.7% were contacted and offered support to reach the target. An appointment was made with the practice, attended by the commissioner, the Memory Clinic Manager and the Dementia Connect Local Services Manager, to provide information on the support available to the practice and its patients and carers. Advice was given to check the current Dementia Register and to add any patients with a diagnosis who were missing from it. Advice was also given about what to look for in possible dementia patients and how to refer them to the local memory service, and about care home residents.

Local GP practices also benefit from a dedicated Dementia Adviser, allocated by Alzheimer's Society, who provide consistency for ongoing working relationships and a direct point of contact for patients, as well as regular communication on updates and service delivery.

Doncaster CCG

Doncaster CCG, as part of an analysis of dementia diagnosis, ran a series of workshops with a wide range of stakeholders. These included representatives from primary care, the local memory service and the local authority, as well as voluntary and community groups. Clinicians included GPs, practice nurses and memory service clinicians. The workshops explored issues and challenges in the diagnostic pathway and proposed a series of opportunities for service developments.

Eliminating the variance of diagnosis rates between the five local PCNs was proposed as a key area for improvement. As in most of England, there is significant variance between practices in Doncaster CCG, where the lowest variance is 0.37% and the highest is 1.64%. The CCG is currently working with individual PCNs, sharing available data, and exploring the development of a best practice protocol to increase the consistency of diagnosis rates.

Conclusion

The value of a dementia diagnosis cannot be overstated. It facilitates access to emotional, practical and legal support that enables people to live well with the condition. For commissioners and services, enabling diagnoses leads to better understanding of the prevalence of dementia, and therefore to the provision of better and more appropriate services. However, some regions of England diagnose more people living with dementia than other regions.

This report finds that processes at each step of the diagnostic pathway can disrupt improvements in diagnosis rates. This includes how proactive areas are in identifying possible dementia, how smooth referral processes are, which professionals are enabled to diagnose and how dementia is captured in reporting. Regional challenges such as deprivation and rurality also have an impact.

For areas to improve diagnosis rates, they must understand that a diagnosis is not done solely by any one organisation. It can be a long process and involves a range of healthcare professionals. Integrated Care Systems are best-placed to consider and implement these recommendations, to ensure that all people living with dementia receive an equally timely diagnosis.

Appendix:
Methodology

Literature review

We carried out a literature review of local diagnostic pathways, datasets and documents relating to dementia diagnosis and ethnic minority communities.

Engagement with health, care and voluntary sector organisations and professionals

To supplement our understanding of issues within the dementia diagnostic pathway, we conducted semi-structured interviews with a range of health and care professionals.

These included commissioners, General Practitioners, psychiatrists, psychologists, geriatricians, nurse consultants, memory service managers, Voluntary Sector and Community Organisation staff, researchers working in dementia care, as well as our own support services such as Dementia Advisers/Dementia Support Workers and Dementia Connect Local Service Managers.

We spoke mainly with commissioners and memory services in areas with either a high or a low diagnosis rate.

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