



# Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland



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Society**

Together we are help & hope  
for everyone living with dementia



### **Acknowledgments:**

Alzheimer's Society would like to thank everyone who contributed to this report – both people living with dementia and professionals – who talked openly about their experiences and provided invaluable expertise. We would also like to thank everyone who attended the diagnosis consensus roundtable events in England, Wales and Northern Ireland, who helped to identify the barriers and solutions to improving access to a timely and accurate diagnosis of dementia. Particular thanks to the chairs of these roundtable events, Fiona Carragher, Professor Dame Louise Robinson, Dr Jen Roberts and Professor Hugh Mckenna. We are also grateful to attendees for the feedback they provided during the drafting of the report and accompanying consensus statement. We would like to thank Morgan Griffith-David and Sharon Brennan, Policy Managers, for overseeing the project, Kielan Arblaster, Senior Policy Officer, for his role in writing the report, and Angela Phillips and George Parish-Wallace, Policy Officers, for supporting the roundtables and providing valuable insight.

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# Consensus Statement: Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland

We intend to advocate for practical changes and tangible solutions to improve access to good quality, timely dementia diagnosis across the three nations of England, Wales, and Northern Ireland. This statement sets the foundation for understanding what is needed now and in the future to improve access to a timely and accurate diagnosis for those living with dementia.

This consensus position was developed through research by Alzheimer's Society, in conjunction with three roundtable discussions with senior dementia stakeholders and people living with dementia across the three nations. Discussions identified the key barriers to accessing a timely and accurate diagnosis and proposed solutions. The solutions require commissioners, clinicians, patients, local systems, and Government bodies to work together to drive real change in increasing dementia diagnosis rates.

## Headline consensus statement

- As a collective, dementia stakeholders must come together to advocate for better funded and evidence-based dementia pathways. These pathways must deliver effective care, support, intervention and treatments for all those living with dementia. People living with dementia highlight the value of an early and accurate diagnosis in preparing for the future and this should be a fundamental right.
- Stakeholders should recognise the advent of new, disease-modifying treatments as a driver for immediate system change to increase diagnosis rates.
- National health systems must commit to returning diagnosis rates to pre-pandemic levels and build capacity for going beyond this in future.



## Consensus agreement on ways to improve diagnosis

### 1. Workforce and new ways of working:

#### Barriers:

- Barriers included a lack of multi-disciplinary and innovative approaches to dementia diagnosis; poor pathway planning and development; and challenges with workforce capacity, training and development.

#### Recommendations:

- A multi-disciplinary approach to diagnosis is needed along with innovative ways of working to ease workforce pressure. These include; remote appointments, upskilling staff, and scaling up pilots like NHS England's DiAdeM project. All innovations must respect the right for patients to choose what works best for them and their families.
- Local and national health system leaders must recognise recruitment and retention in relevant roles such as in memory services as part of their overall workforce reviews.

### 2. Health inequalities and public health messaging:

#### Barriers:

- Barriers included regional variation in diagnosis rates across the three nations, with those from rural and/or deprived communities and those whose first language is not English least likely to have timely access to a quality diagnosis. Further barriers were cultural differences and the stigmatisation of dementia as a condition.

#### Recommendations:

- Fair access to a dementia diagnosis for all regardless of ethnicity and other protected characteristics, as well as socio-economic status, language, or geographical location must be prioritised. Culturally relevant assessment tools and interpreters (including bilingual assessments for Welsh speakers and assessments for those who are deaf or British Sign Language users) should be introduced and made widely available, and co-production of local diagnosis pathways should reflect the local population.
- Better data collection on the impact of regional and cultural variations should be undertaken at a national and local level to allow for future-proofed commissioning of diagnosis pathways, including for bilingual Welsh-language speakers in Wales.
- An annual diagnosis public messaging campaign should be developed to overcome stigma.

### 3. Financial and system pressures:

#### Barriers:

- Barriers included funding arrangements and commissioning processes; a lack of guidance on post diagnostic care and Mild Cognitive Impairment (MCI); balancing timely with accurate diagnosis; and lack of peri-diagnosis support.

#### Recommendations:

- Local systems should have a named dementia lead accountable for outcomes.
- In advance of new dementia treatments being made available to patients, the National Institute for Health and Care Excellence (NICE) should ensure that guidance on MCI is developed so that people living with dementia are diagnosed at the earliest opportunity and can take advantage of revolutionary new treatments as soon as they are available.

- Dementia pathways across the three nations are routinely underfunded, with commissioning arrangements often disincentivising an increase in diagnosis rates. Local systems should use Leeds Beckett University's '[Taking Memory Assessment Services \(MAS\) into the Future](#)' as a commissioning framework when designing memory services, and align funding for workforce capacity with future demand for services. National health systems should invest in dementia care to help prevent costly dementia crises.
- Dementia stakeholders should push for dementia to be given parity of esteem through equitable prioritisation and funding with other conditions, such as cancer and other mental health conditions.



#### 4. Future-proofing the diagnostic system

##### Recommendations:

- We need access to subtype diagnoses, an enhanced workforce and an equitable offer to people with all types of dementia.
- National and local systems must increase the profile of dementia and recognise the ever-increasing prevalence of the condition, as a driver for change. People must be diagnosed in the early stages of their dementia, as new treatments will likely only benefit this group.
- People diagnosed with dementia must also be offered the opportunity to participate in research trials.
- Health systems must ensure equitable access to scans for memory assessment services. All diagnoses of dementia should be delivered with information on the person's specific dementia subtype.
- National health systems should plan for the introduction of blood-based biomarkers to ensure people developing dementia benefit from new treatments.
- Health systems must commit to ensuring that the advent of new treatments for Alzheimer's disease specifically does not divert resources away from diagnosing and supporting those with other subtypes of dementia. Diagnosis remains important in accessing timely care and support.

We, the undersigned, support the consensus statement and are committed to advocating for the real change needed to improve the lives of those living with dementia.

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## What we did

Alzheimer's Society held three roundtables across England, Wales and Northern Ireland (referred to here as the three nations) to gain consensus on the foremost barriers inhibiting the delivery of a timely and accurate dementia diagnosis. Each roundtable brought together key stakeholders in the field of dementia care and research with 47 people in total attending the three events (15 each for Northern Ireland and England, and 17 for Wales). Attendees at each roundtable included people affected by dementia, representatives from NHS trusts, commissioners, clinicians and academics. Representatives from NHS England, the Department of Health in Northern Ireland, and politicians from Wales and Northern Ireland also attended.

The roundtables were held on the following dates:

- Northern Ireland – October 18, 2022
- Wales – October 20, 2022
- England – October 26, 2022

This report summarises the key issues that were discussed across all three nations. Debate focused on four pre-identified themes around dementia diagnosis – set out below – with barriers and potential solutions identified following each discussion.



## Key Themes

### 1. Workforce and new ways of working

- Multidisciplinary and innovative approaches to dementia diagnosis.
- Pathway planning and development.
- Workforce capacity, training and development.

### 2. Health inequalities and public health messaging

- Regional variation in rurality and deprivation as a barrier to diagnosis.
- Language and cultural barriers to diagnosis (including in the Welsh language in Wales).
- Public health messaging and the stigmatisation of dementia as a condition.

### 3. Financial and system pressures

- Funding arrangements.
- Commissioning processes.
- National guidance on Dementia and Mild Cognitive Impairment.
- Balancing timely diagnoses with accurate diagnoses.
- Peri-diagnostic support.

### 4. Future-proofing the diagnostic system

- Building the right populations for disease-modifying treatments.
- Improved access to subtype diagnoses.
- Workforce for the future.
- Ensuring new treatments do not widen inequalities.



## Why we did it

A diagnosis of dementia is vitally important. We know from an Alzheimer's Society survey that 91% of people affected by dementia see clear benefits to getting a diagnosis.<sup>i</sup> It is instrumental in facilitating access to care and support that enables people to live well with the condition. Everyone living with dementia has the right to an early and accurate diagnosis – it is vital in order to draw on evidence-based, appropriate, compassionate and properly funded care and treatment.<sup>ii</sup> Yet not every person living with dementia has a diagnosis – over 300,000 people in the three nations do not have a diagnosis. This leaves them and their families at risk of crises, such as unplanned hospitalisation, which can have an adverse effect on people living with dementia and their carers' health and wellbeing, as well as the wider health and social care system.

There are many factors that can affect a person's access to a dementia diagnosis, and Alzheimer's Society has done significant research on the barriers contributing to this lack of access.<sup>iii</sup> There is a stigma and lack of awareness surrounding dementia as a condition that prevents people from coming forward to get a diagnosis. People may feel that many of the symptoms caused by dementia are 'simply a part of getting old' but this is not the case. 53% of people listed 'not being certain if it is dementia or just part of getting old' as a reason why they did not seek a diagnosis, and 34% listed 'not wanting people to think they were losing their mind' as a reason for not seeking a diagnosis.<sup>iv</sup>

Since the Covid-19 pandemic, we have seen dementia diagnosis rates drop across all three nations, and recovery to pre-pandemic levels has been slow. In England, diagnosis rates have dropped by approximately five percentage points and stagnated between 61 and 63%.<sup>v</sup> In Northern Ireland, the number of people on the dementia register has dropped by around 10%, meaning that diagnosis rates are approximately 60%.<sup>vi</sup> In Wales, the dementia diagnosis rate has dropped to approximately 50% following the pandemic.<sup>lv</sup> Post-pandemic, there is a lack of clarity around the causes of the ongoing stagnation in dementia diagnosis rates and the foremost barriers health and care systems face in delivering a timely, accurate diagnosis of dementia.

The purpose of these roundtables was to bring together stakeholders in the dementia diagnosis space across England, Wales, and Northern Ireland to discuss, agree and build consensus on the main barriers to diagnosis.

Through Alzheimer's Society's own research and influencing since March 2020, we have identified important issues relating to the barriers to dementia diagnosis in advance of the roundtables and grouped these into four themes (laid out above) to facilitate discussion across all three roundtables.

## Key evidence

### Workforce and new ways of working

- An Alzheimer's Society and Royal College of Psychiatrists survey conducted in 2022 found that 71% of respondents from memory assessment services across England, Wales and Northern Ireland reported workforce challenges as a barrier to ensuring people receive a timely diagnosis.<sup>x</sup>
- The same survey found that 90% of respondents across England, Wales and Northern Ireland agreed or strongly agreed that staff vacancies in their memory services decreased the likelihood of patients accessing a diagnosis in a timely way.<sup>xi</sup>
- It also found that 9% of trusts and health boards across England, Wales and Northern Ireland reported over 30 Full Time Equivalent (FTE) vacancies in their memory services.<sup>xii</sup>

### Health inequalities and public health messaging

- Previous Alzheimer's Society research found that 61% of dementia advisers, 64% of then-Clinical Commissioning Groups and 73% of memory services said deprivation and health inequalities were significant factors affecting local diagnosis rates.<sup>xiii</sup>
- 54% of memory services report language barriers as significant obstacles to a dementia diagnosis for ethnic minority communities, as well as stigma and taboo (72%) and cultural perceptions of dementia, health and caregiving (64%).<sup>xiv</sup>
- Research suggests that people from an ethnic minority community are less likely to receive a diagnosis compared to the general population.<sup>xv</sup> If they do receive a diagnosis, it is likely to be at a later stage of the disease.
- Cultural variations also occur, with first language Welsh speakers noted to be delayed in accessing formal support compared to those that spoke English as a first language.<sup>xvi</sup>
- People with higher socioeconomic status may have a greater understanding and awareness of dementia symptoms and are therefore more likely to contact their GP with concerns around symptoms.<sup>xvii</sup>
- Research finds that higher levels of deprivation were associated with higher rates of patients diagnosed with dementia.<sup>xviii</sup>
- Alzheimer's Society research shows 91% of people affected by dementia reported that they saw benefits in receiving a diagnosis.<sup>xix</sup>

## Financial and system pressures

- Alzheimer’s Society has found that the lack of consistent support means people living with dementia are at greater risk of crisis which has a damaging impact on them, their carers, and NHS services.<sup>xxii</sup>
- Since the beginning of the pandemic, there are an additional 30,000 people in England who do not have a diagnosis.<sup>xxiii</sup> In Wales, where central diagnosis data is not collected, currently unpublished data indicates that the diagnosis rate has dropped. In Northern Ireland, the number of people on the dementia register has dropped by approximately 10%.<sup>xxiii</sup>
- A survey by Alzheimer’s Society and the Royal College of Psychiatrists found that 85% of respondents from memory assessment services across England, Wales and Northern Ireland reported people presenting and being diagnosed later in their condition compared to pre-pandemic.<sup>xxiv</sup>
- A patient survey conducted by Alzheimer’s Society in October 2022 found that 17% of people with dementia did not have a subtype diagnosis detailing the specific type of dementia they have. Dementia is an umbrella term for several diseases and describes a set of symptoms that over time can affect memory, problem-solving, language and behaviour, while Alzheimer’s disease, for example, is a specific type of dementia.<sup>xxv</sup>
- There is significant variation in the delivery of subtype diagnoses at service level which is also a concern because it can affect treatment options. The 2019 National Memory Service Audit found that while 46% of patients were diagnosed with dementia due to Alzheimer’s disease nationally, this varied between 7% and 82% at service level. Similarly, for vascular dementia, while nationally 25% of patients were diagnosed with this subtype of dementia, it varied between 0% and 80% across services.<sup>xxvi</sup>
- The survey from Alzheimer’s Society and the Royal College of Psychiatrists in 2022 found that 24% of respondents from memory assessment services across England, Wales and Northern Ireland identified waits for brain scans as one of the biggest barriers to timely diagnosis.<sup>xxvii</sup>

## Future-proofing the diagnostic system

- It is important that the system is prepared for future disease modifying treatments, which require individuals to have an early and specific sub-type diagnosis in order to inform treatment options.
- The survey from Alzheimer’s Society and the Royal College of Psychiatrists conducted in 2022 found that less than half (47%) of respondents from memory assessment services across England, Wales and Northern Ireland were ‘often’ or ‘always’ diagnosing patients in the early stages.<sup>xxviii</sup>
- The 2022 national memory service audit showed that 62% of people were asked about being contacted about participation in dementia research.<sup>xxix</sup>
- The survey from Alzheimer’s Society and the Royal College of Psychiatrists conducted in 2022 found that for standard neuroimaging such as computerised tomography (CT) scans, patients with suspected dementia had to wait on average eight to ten weeks, and for advanced neuroimaging such as positron emission tomography (PET), magnetic resonance imaging (MRI) or dopamine transporter (DAT) scans, patients with suspected dementia had to wait an average of 11 to 13 weeks. Respondents also reported they had seen patients waiting over six months for both standard (10% of patients) and advanced (10% of patients) neuroimaging, which is over four times longer than the diagnostic waiting time target of a maximum of six weeks.<sup>xxx</sup>
- The latest National Audit of Dementia states that 23% of memory assessment services are not able to refer for PET scans, 12% for DAT scans, 56% for cerebrospinal fluid (CSF) examination and 22% for single-photon emission computerized tomography (SPECT) scans (which are all different methods of diagnosing dementia subtypes).<sup>xxxi</sup>
- The most recent memory assessment service audit found that just 38.8% of services were able to view scan images through medical imaging technology such as Picture Archiving and Communication Systems (PACS).<sup>xxxii</sup>
- The survey from Alzheimer’s Society and the Royal College of Psychiatrists found that 33% of trusts and health boards in England, Wales and Northern Ireland reported up to five Full Time Equivalent (FTE) staff vacancies across their memory services, and 21% report up to ten FTE vacancies in memory services.<sup>xxxiii</sup>
- The 2021 Memory Assessment Service Spotlight Audit showed that over one in ten (11%) memory services do not have the opportunities for joint working with neurology and one in five (19%) memory services do not have an opportunity for joint working with neuroradiology.<sup>xxxiv</sup>





## Key themes from events

### 1. Workforce and new ways of working

#### a. Multidisciplinary and innovative approaches to dementia diagnosis

A shared challenge across the three nations identified during discussion was the lack of a coordinated multidisciplinary approach to diagnosis. A dementia diagnosis is often complex and necessitates the involvement of a wide range of services and professionals. It was agreed that, to provide a comprehensive assessment and diagnosis of dementia, specialisms such as psychiatry, geriatrics, neurology, psychology as well as occupational therapy and speech and language therapy may all need to be drawn upon.

GPs were recognised as key stakeholders in dementia diagnosis, and they hold an important role in the diagnostic pathway. There were examples of innovation in redeveloping the workforce to cope with demand. In one area, retired GPs were rehired as part-time GPs with Extended Roles to cope with rising diagnosis demand following the Covid-19 pandemic, and this had increased the number of people on the local dementia register.

However, there were also concerns about capacity, specialist skills and confidence of primary care colleagues to complete diagnostic assessments and deliver diagnoses as well as ongoing support. One person with dementia who attended the England event told us: “I don’t have a consultant and people are surprised because it’s a neurological condition. If I have symptoms I don’t recognise, I go to my GP but he’s not an expert.”

Attendees also recognised that the Covid-19 pandemic had facilitated the development of flexible models of diagnosis, particularly around widespread adoption and development of online dementia assessments. This allowed memory services to undertake a greater proportion of caseloads remotely, and widened access to diagnosis for people who may not have been physically able to attend services. These new ways of working have the potential for memory services to increase diagnosis rates by increasing capacity to get through patient waiting lists.

However, it was strongly noted that the provision of remote appointments must be balanced against access requirements, quality of diagnoses and patient choice.

#### b. Pathway planning and development

People living with dementia described how they had experienced a lack of guidance and signposting to information about how to receive a diagnosis and the different stages of the diagnostic process. They told us that it wasn’t clear how to access referral pathways and expressed concerns about the risk this presents to people who continue to live with undiagnosed dementia.

All attendees noted the importance of developing clear referral pathways that offer equality of access between and

within all three nations. Participants recognised significant variation in how memory services are commissioned and the different models of diagnosis that exist, which creates inequality in access and in the quality of dementia diagnoses. Additionally, depending on the care setting in which a diagnosis is delivered (e.g. GP, care home, memory assessment service etc.), it was reported that some diagnoses may be omitted from official data reporting, artificially lowering the local diagnosis rate, meaning a person with dementia may not be receiving the primary care support they are entitled to. Work is being done to standardise data reporting and it’s important that the same coding is used across both primary and secondary care.

Also noted was the need to recognise dementia as a terminal (life-limiting) illness to allow for appropriate conversations and care planning to happen at the right time and to open up opportunities for people living with dementia and their carers to receive more specific and tailored support.

#### c. Workforce development, capacity, and training

Workforce recruitment and retention was noted as a key barrier to a timely dementia diagnosis. All nations reported vacancies in memory services, particularly in psychiatry, as a barrier that prevented services coping with demand.

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Workforce challenges are exacerbated by the local design of diagnostic pathways. It was reported in England that many services operate a consultant-led service in which nurses complete the diagnostic work-up and consultants sign-off and deliver the diagnosis. However, this can create bottlenecks given all diagnoses need to be confirmed by a consultant. It also affects the quality of a diagnosis, with many people wanting continuity of professional involvement from assessment to diagnosis, which supports a person-centred approach to care and support. Embedding Advance Care Planning in care pathways and ensuring that staff are comfortable and confident to approach these conversations should also be an important part of this care and support in order that people in the early stages of dementia are given the opportunity and supported to engage in discussion and decisions about their future care and treatment preferences.

These bottlenecks can be mitigated through developing staff skills to cope with diagnostic demand. Some services had pivoted quickly to the challenges of the pandemic and adopted innovative changes, predominantly through a multidisciplinary way of working.

Attendees noted that to cope with demand, there was a need to think innovatively to deliver services more efficiently, such as identifying other professionals that could be involved in the core diagnostic work-up of patients and then develop their skills to deliver diagnoses.

One example of this discussed in England was the 14 NHS England pilot sites for DiADeM (Diagnosing Advanced Dementia Mandate) which have been rolled out to increase diagnostic rate performance. The tool does not necessarily require a specialist memory assessment service workforce to assess and diagnose dementia. This is because DiADeM is likely to be used in care home settings, with residents who are displaying clear symptoms of dementia, who don't necessarily need specialist investigation.

## 2. Health inequalities and public health messaging

### a. Regional variation in rurality and deprivation as a barrier to diagnosis

The roundtable in England discussed forthcoming research from the Office for Health Improvement and Disparities (OHID) showing that rurality and deprivation account for around half of diagnostic variation, with the other half of variation caused by systemic challenges within the diagnostic pathway. In more deprived areas, it was also noted by participants in England that those who attend memory assessment services are self-selecting – they tend to be better educated, middle class and wealthier. Those who are not in this group are less likely to present to services with concerns around symptoms.

Better data collection and reporting may provide a greater understanding into the impact of deprivation. It is likely, for instance, that there will be a higher prevalence of vascular dementia in more deprived areas. This is because higher prevalence may be linked to higher risk factors for cardiovascular disease and stroke (the main cause of vascular dementia) in more deprived areas.<sup>xxxv</sup> However, current diagnosis rate data in England and Northern Ireland does not report on subtype diagnoses. Work is ongoing to develop centralised data for diagnosis rates by subtype in Wales.

Participants from all three nations reported that people living in rural communities are more likely to struggle to access a dementia diagnosis. It was noted by roundtable attendees that those who live in rural communities tend to be less likely to come across public health information or to talk about health issues, both of which reduce their proactive outreach to services. People in rural communities may also experience additional transport barriers accessing specialist services as these often tend to be in inner city areas.

### b. Language and cultural barriers to diagnosis

Participants across all three nations noted that people from ethnic minority communities face additional barriers to diagnosis. A strong theme shared was the importance of working with community-based organisations such as third-sector partners, community leaders, and faith groups to provide accessible information, reduce stigma and develop inclusive diagnosis pathways.

Language challenges often prevent people who are concerned they may have dementia from reaching out to services such as primary care. It was reported at the events that often people do not have equal access to services in their language (including people who are bilingual), throughout the patient pathway. In Wales, the importance of providing assessments bilingually was noted, and that assessing people in a second language is not accurate and should be avoided,<sup>xxxvi</sup> as recognised in the Welsh Dementia Action Plan. In addition, standardised assessments should also be provided bilingually as a clinical need and be incorporated into workforce development and planning.

People with intellectual disabilities and those with limited literacy skills were also reported to be a group who do not have equal access to services and diagnosis. Similarly, those with sensory impairments, such as people who are deaf and use British Sign Language (BSL), may require additional consideration and support throughout the diagnosis pathway, including through the provision of interpreters in primary care and hospital settings when requested in-line with NHS guidance.

In secondary care, attendees recognised improvements in culturally appropriate dementia assessments, such as cultural and language-appropriate cognitive tests, yet conceded that services still need the staff to speak specific languages to administer the tests. Too often, younger family members of ethnic minority groups – particularly first-generation immigrants – are being relied on to act as interpreters, and this unethically burdens them with being asked to deliver diagnoses to their loved ones. The Rowland Universal Dementia Assessment Test (RUDAS) was noted as a particularly effective and culturally sensitive test that can be administered without the support of an interpreter.

### c. Public health messaging and the stigmatisation of dementia as a condition

It was agreed among attendees that dementia continues to be a stigmatised condition, which deters people from accessing services and receiving a diagnosis. There remains a feeling that 'nothing can be done' for those living with dementia, which prevents people from seeking their own diagnosis.

Roundtable attendees added that public messaging campaigns must target high-risk dementia cohorts and include effective signposting to support in primary and community care settings, so people know how to take action.



It was felt that for messaging to have the greatest impact, it must be focused on how a diagnosis can improve access to treatment, services and support, and promote a positive 'living well with dementia' message. Messaging must also be made available in national and community languages.

Similarly, it was reported that messaging around reducing the risk of developing dementia should include information around the causes of dementia and help people understand their individual risk. To make preventative messaging more palatable, attendees felt it should be focused around 'brain health', targeted towards younger cohorts.

It was also agreed that people from ethnic minority communities, including those that use languages other than English, people with learning disabilities, people with sensory difficulties and people with poorer levels of health literacy may need specific consideration.

One positive example given in England was community-based assets such as social prescribing link workers that could help facilitate local public health messaging. Often linked into community groups, social prescribers can play a significant role in raising awareness and supporting access to the dementia diagnosis pathway. This may be particularly important for protected characteristic groups such as ethnic minority communities.

### 3. Financial and system pressures

#### a. Funding arrangements

One reported challenge was the variation and complexity in how commissioning processes affect the delivery of memory assessment services. A driver of this variability is how dementia is perceived by the health and care system, and a resulting lack of ownership of the condition. Dementia is currently classed as a mental illness but doesn't receive the same level of funding as other mental illnesses, as reported by one GP and researcher in England. Specifically, there is a significant lack of funding for psychiatry, which is compounded by the lack of broader ring-fenced funding within secondary care for dementia itself.

It was stated that without appropriate recognition, dementia may fail to take precedence within funding arrangements. This is being shown with the lack of appropriate funding for diagnosing dementia in the recovery of the health system following the Covid-19 pandemic; in England, government spent £17m on recovering the dementia diagnosis rate in 2021/22, but spent £8bn in total for elective recovery in the NHS.<sup>xxxvii</sup>

A shared concern across all three nations was the lack of funding attached to national strategies for dementia. For example, in Northern Ireland, both the 2011 Dementia Strategy and the 2018 Regional Dementia Care Pathway were not fully funded for implementation. In England, the lack of national direction and support for local systems has been exemplified by the absence of a new national strategy for dementia since 2015.

Locally, it was also reported that there needs to be a change in how local system budget holders think about the cost of dementia. Systems are forced to spend funding on people with dementia once they hit crises and present at emergency departments, for example, due to carer support breakdowns. Crises are costly on an economic, social and individual basis, as well as putting increasing pressure on system bottlenecks such as accident and emergency departments. However, it was reported that a diagnosis, with proper, effective post-diagnostic support, may help reduce crisis admissions and therefore costs for the NHS.

#### b. Commissioning processes

A shared challenge across all three nations concerned commissioning arrangements for memory assessment services. There was strong appetite from attendees to develop memory services beyond the delivery of diagnoses alone, which is what they are most commonly commissioned to provide. This sole focus on diagnosis has acted as a driver in the delivery of poor post-diagnostic support.

People living with dementia spoke at the Welsh roundtable about experiencing a lack of coordinated follow-up support and guidance following diagnosis. They described how this led them to feel isolated, undervalued, and not in control of post-diagnosis planning for their future.

Steps have been taken locally in one area of England to transition their memory service to a more comprehensive 'Memory Service and Intervention Service' that is better suited to local patient need. Similarly, the term 'memory service' may also act as a barrier to those patient cohorts presenting with non-memory related symptoms.

There was strong resistance from attendees around block contract and commissioning, which is not currently conducive to delivering services for a condition in which prevalence is always rising. A block contract asks a memory service to see all patients that need support within the contract timespan regardless of demand, rather than a contract that pays for each diagnosis delivered. Such local commissioning arrangements can adversely impact the national drive to increase dementia diagnosis rates as it does not provide the necessary funding uplift to increase workforce capacity to match rising demand.

Participants in the England roundtable reported that commissioners regularly struggle to access information on what works well in relation to dementia care. It was noted that the NHS England-commissioned Leeds Beckett University project on developing innovative memory services was a key document commissioners could use to develop their local services.

### c. National guidance

The National Institute for Health and Care Excellence (NICE) guidance on dementia was reported to be insufficiently prescriptive. Whilst the diagnostic pathway guidance is strong there is little guidance on how best to set up services and deliver quality care post-diagnosis.<sup>xxviii</sup>

A challenge reported in the England roundtable was NICE guidance for dementia not covering Mild Cognitive Impairment (MCI). In comparison, national diabetes guidance prescribes that GPs should hold a register of patients with impaired glucose tolerance (people with pre-diabetes) so a patient's health can be tracked, and a diagnosis quickly delivered if they go on to develop diabetes. A lack of guidance around MCI means that those diagnosed with the condition are not tracked at secondary care level.<sup>xxix</sup> Instead, people with an MCI diagnosis are referred back to primary care which also does not have an official requirement to monitor those with the condition. This reduces the opportunity for those who transition to dementia to receive a timely diagnosis.

One memory service reported it held a paper list of those with an MCI diagnosis so it could instigate yearly follow-ups and provided this care despite it not being part of its commissioned services.

### d. Balancing increased, timely and quality diagnoses

One key challenge experienced across all three nations was the reduction in the number of people receiving a diagnosis. Moreover, when people do access a diagnosis, all three nations reported they are accessing it later in their disease progression. Timeliness of diagnosis is important since many interventions are more effective when delivered in the earlier stages of dementia, such as those prescribed by NICE. Furthermore, early diagnosis will be vital for accessing new disease-modifying treatments such as Lecanemab.

The dementia diagnosis rate, while necessary, does not reveal the quality of diagnostic performance at local system level. It was noted there is a need to include other quality markers for diagnosis, such as subtype, which can then help local systems standardise their approach to diagnosis.

Across the three nations, it was reported that there is a need to balance both timeliness and accuracy of diagnosis. Ensuring access to scanning availability improves the accuracy of a diagnosis, but it can equally delay a person receiving a diagnosis. Future diagnostic planning should consider both the timeliness and quality of diagnosis.

### e. Peri-diagnostic support

Peri-diagnostic support refers to support around and during the diagnostic process. A shared challenge across all three nations was the lack of peri-diagnostic support, with funding and commissioning arrangements a barrier to providing comprehensive support from symptom presentation to post-diagnosis. While it was considered beneficial for patients to receive support while waiting for a memory service assessment, a lack of capacity means many memory services are unable to offer this.

One attendee of the Northern Ireland event spoke about the difficult experience of being diagnosed with early onset dementia. Following a brief appointment in primary care a referral was made to the memory assessment service. However, due to a lack of information and 'no real idea' of why the referral was made, he attended the service alone. Poor communication was described throughout the assessment process with multiple appointments for tests and scans, with little information given at each point on what to expect. At the final appointment there was poor communication and lack of empathy from the clinician when the diagnosis was given, with no explanation as to what the diagnosis meant on an individual level and no additional written information, support or contact numbers provided following the diagnosis. An attendee at the Wales event described a similar experience, with a lack of follow-up support and guidance provided following a diagnosis.

While capacity is an issue, a key driver in this lack of peri-diagnostic support was also the lack of integration across services involved in dementia care which spans primary, secondary, acute, community and social care. It was noted that there is a need to coordinate services from within primary care, as this is where most people are supported pre- and post-diagnosis, to ensure that people can be signposted to the right types of community support. Strategically, it was noted in England that having a system-wide dementia lead appointed in each integrated care system can bring conversations around dementia to the fore in local health and care systems. Often, such a lead was in place under prior clinical commissioning group arrangements but were dissolved in the move to integrated care systems.

It is also important that people have access to bilingual or translated guidance, for example for Welsh language speakers.



## 4. Future proofing the diagnostic system

### a. Building the right populations for disease-modifying treatments

Attendees across the three nations recognised a need to understand and identify the right population groups who can benefit from potential disease-modifying treatments in the future. This means ensuring that people are diagnosed in the early stages of their dementia, given the treatments will likely only benefit this group. Relatedly, it was noted that people who are diagnosed with dementia need to have the opportunity to participate in research trials.

Alongside this, to future-proof the diagnostic system, national and local systems will need to increase the profile of dementia and recognise the ever-increasing prevalence of the condition, which will act as a driver for change.

### b. Improved access to subtype diagnoses

Across the three nations, waiting times for brain scans was a key barrier to ensuring a timely diagnosis.

An impact of this lack of access is the ability of services to identify dementia subtypes, which would help to further identify which patient cohorts would benefit from disease modifying treatments. This includes ensuring services have equitable access to CSF testing (more commonly known as a lumbar puncture) and PET scans. However, there is an inequity of access to subtype diagnosis services, including emerging and innovative diagnostic tools and technology.

Moreover, CSF testing is an invasive test, relies on significant numbers of clinicians with an appropriate skill mix and may become superfluous in the context of future 'amyloid positive' testing such as through blood-based biomarkers. It was noted that national health systems would need to consider a trade-off between focusing their immediate attentions on improving access to CSF testing or investing in blood-based biomarkers, the latter of which are yet to be clinically validated. There is currently no timeline for when we may be able to see the use of blood-based biomarkers for dementia in a clinical setting.

Participants also noted that not all memory services have access to Picture Archiving and Communication Systems (PACS). PACs allows memory services to physically view brain scans, which can support a more accurate diagnosis.

It was noted there is a real opportunity to utilise the advent of disease-modifying treatments as a driver to call for immediate system change to drive up diagnosis rates and ensure equitable access to scans for memory assessment services and people being delivered a diagnosis alongside a subtype.

### c. Workforce for the future

Developing a workforce for the future to deliver disease modifying treatments was a key consideration shared across all three nations. While access to specialist tests is required, clinicians with the right skill mix across primary and secondary care are needed to administer those tests and interpret those results.

Neurology in particular was noted as important, especially for identifying a subtype. In England, it is thought there may not be enough neurologists for neurology-led clinics, but there may be enough for each memory service to have a named neurologist they can seek advice from on complex cases.

### d. Ensuring new treatments do not widen inequalities

Whilst systems should plan for emerging treatments, attendees in England reiterated that post-diagnostic support is vital to ensuring people live well with dementia. Currently, pathways are driven by the availability of treatments, so there is a need to ensure that those with non-Alzheimer's disease dementia are still fully supported with their condition. For example, people with Alzheimer's disease eligible for medication to ease symptoms tend to have more contact time with specialists since they will need a medication review.<sup>14</sup> This inequality of support is at risk of widening when new treatments become available as currently the most promising only treat Alzheimer's disease. Attendees suggested lessons can be learnt from the treatment of depression, for which people are offered both drug and non-pharmaceutical approaches.



## Recommended solutions

### Workforce and new ways of working

- Data cleansing and review of the GP dementia register should be carried out routinely and monitored for accuracy, with local systems also ensuring consistent use of dementia coding across primary and secondary care.
- Workforce recruitment and retention is a key barrier to a timely dementia diagnosis. All local systems should ensure a multidisciplinary approach to dementia diagnosis. This includes memory services having clear referral pathways to enable access to psychiatrists, psychologists, geriatricians, occupational therapists, speech and language therapists, as well as interpreters during the diagnostic process. The Welsh Government has published the Allied Health Professionals Dementia Framework which should guide the support available in Wales. Local and national health system leaders must recognise and respond to this challenge as part of their overall workforce reviews.
- Following completion of the pilot in England, if successful, national health systems in England, Wales and Northern Ireland should roll-out the use of DiADeM. All innovations must respect the right for patients to choose what works best for them and their families.

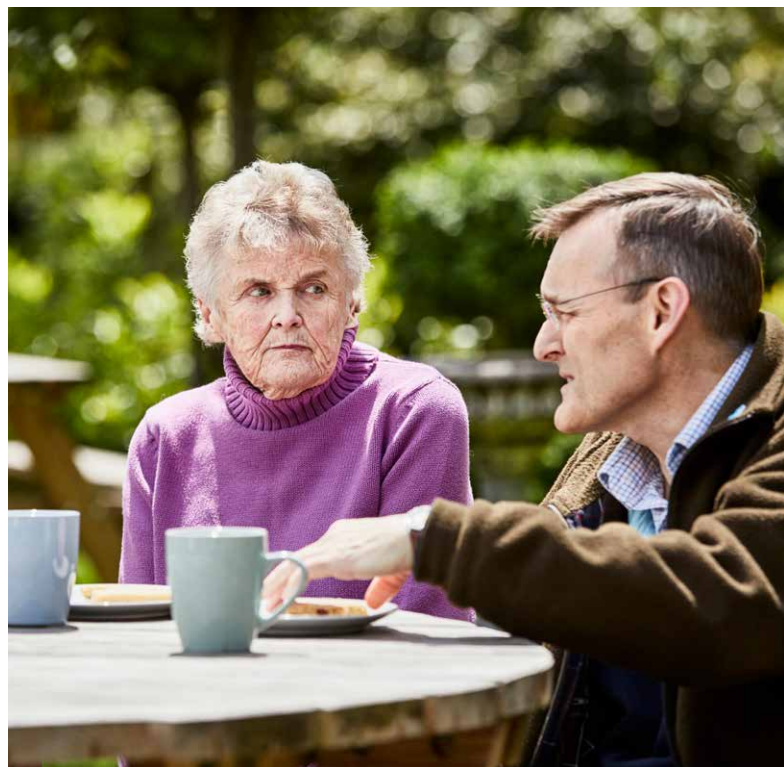
### Health inequalities and public health messaging

- Local health systems should review the use of cognitive assessment instruments and ensure that memory services can access, are trained in the use of, and have staff with the necessary language skills, to deliver validated tools for the assessment of those from ethnic minority communities, such as RUDAS, as well as those with intellectual disabilities and low literacy levels. Standardised assessments should be available in Welsh for Welsh speakers and other bilingual service-users.
- Local health systems should identify cultural community interest groups and include them in the planning and delivery of dementia diagnostic pathways. They should also consider the provision of dedicated Community Link Workers to improve awareness and understanding of dementia and access to services in ethnic minority communities. This should be accompanied by baseline and referral data to test efficacy for further implementation.
- Local health systems should consider cultural and linguistic skill provision when commissioning memory services. They should also review access to interpretation services to ensure provision aligns to the language needs of the local population, and that these services have sufficient dementia training.
- Local health systems should identify future projections of ethnic minority dementia populations in each area and commission services that are culturally appropriate. This should be accompanied by separate minority ethnic community diagnosis rate targets.

- National health systems in England, Wales and Northern Ireland should publish both subtype diagnosis and ethnicity breakdown in diagnosis data dashboards.
- An annual diagnosis public messaging campaign should be developed by Government and public health agencies - the Office for Health Improvement and Disparities, Public Health Wales and the Public Health Agency - which highlights dementia symptoms and how to seek help with receiving a diagnosis. Prevention messages should focus on risk reduction, promote 'brain health' messaging, and consider tailoring messages for marginalised groups such as younger people and ethnic minority communities. Any public messaging introduced should also be available in national and community languages.

### Financial and system pressures

- When designing or redeveloping memory services local systems should use the Leeds Beckett University's '[Taking Memory Assessment Services \(MAS\) into the Future](#)' as a commissioning framework and for the identification and sharing of best practice. They should also use the [Memory Services National Accreditation Programme](#). Workforce capacity should be aligned with future demand for services.
- Local systems should have a named senior responsible officer who is accountable for the implementation of dementia priorities and outcomes.
- Local systems should ensure that services recognise MCI and diagnose it where appropriate, with a clear pathway provided to better track and support cases that go on to develop dementia.



- National health systems should commit to returning diagnosis rates to pre-pandemic levels:
  - NHS England and the Department of Health and Social Care will be publishing the Major Conditions Strategy, which should make dementia a priority. As part of this, the government should invest £70 million to increase diagnosis rates in England.
  - In Wales, the National Dementia Action Plan should be accompanied by additional funding to support the prioritisation of timely and accurate diagnoses.
  - In Northern Ireland, the Regional Dementia Care Pathway should be fully funded and urgently implemented to improve diagnosis rates and reduce waiting times.
- NHS England should develop guidance for commissioners of memory services to ensure contracting arrangements focus on patient outcomes and account for the increasing prevalence of dementia.
- NICE should ensure that national guidance is developed on Mild Cognitive Impairment.
- Dementia stakeholders should push for dementia to be given parity of esteem through equitable prioritisation and funding with other conditions, such as cancer and other mental health conditions.
- Local systems should ensure all memory assessment services are able to access specialist investigations for diseases which cause dementia, including PET brain scans and CSF examinations.
- All memory assessment services should be designed to provide an equal offer of support for all subtypes of dementia, including appropriately timed discharge and provision of interventions, and that the needs of ethnic minority groups and Welsh language speakers, along with other protected characteristics are catered for.
- National health systems in England, Wales and Northern Ireland must undertake an audit of PET brain scanning and CSF testing availability as a matter of urgency to ensure capacity keeps up with demand for timely diagnoses, that memory services are staffed appropriately and that there is equity of access to these tests geographically.
- National health systems in England, Wales and Northern Ireland should plan for the introduction of blood-based biomarkers to ensure that people at risk of developing dementia can benefit from new treatments as soon as possible. National health systems in England, Wales and Northern Ireland should plan for the introduction of new treatments, including reviewing the diagnosis pathway, to ensure all those that might benefit from the treatment can do so.

#### **Future-proofing the diagnostic system**

- Local health systems should ensure that all memory services have access to PACS, so that memory services can view brain scans and their reports directly.
- Local health systems should ensure there are formalised arrangements in place that enable multidisciplinary team meetings between memory service clinicians, neurology and neuroradiology.
- Dementia stakeholders should utilise the advent of disease-modifying treatments as a driver to call for immediate system change to drive up diagnosis rates, and ensure equitable access to scans for memory assessment services, with people being delivered a diagnosis alongside a subtype.





## Conclusion

The diagnosis consensus roundtables have shown that barriers to diagnosis are wide-ranging and most often shared by local systems across all three nations. People concerned about symptoms enter a diagnosis system that is underfunded, under-resourced and unable to meet their needs.

As a collective, dementia stakeholders must come together to tackle the challenges we see present in health systems now, so we can develop dementia pathways that can deliver effective care, support, interventions and treatments for those living with dementia.

The consensus statement sets the foundation for understanding what is needed now and for the future to make real change for those living with dementia. The advent of new disease-modifying treatments in the near future necessitates getting diagnosis right today.



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