Improving dementia diagnosis: what could change in primary care?

Policy paper

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Introduction

Dementia is the leading cause of death in the UK, with almost one million people currently living with it. With an ageing population and no treatments available in the UK to delay the onset or slow the progression of the underlying diseases like Alzheimer’s, this number will increase to 1.6 million by 2050. The cost of dementia is expected to nearly double by 2050, from £25bn to more than £47bn.\(^1\)

But there is hope: investment in research and development has resulted in significant advances in our understanding of the diseases that cause dementia. With over 140 drugs for Alzheimer’s disease currently in clinical trials and the recent positive results from a phase III clinical trial of lecanemab,\(^2\) it’s a question of when, not if, new treatments will be approved for use in the UK. The arrival of disease-modifying treatments and novel diagnostic tools means current clinical approaches will need to move towards diagnosing people at earlier stages of disease. As the new Dementia 10-Year Plan for England is being written, now is the time to reimagine the dementia diagnostic pathway so people at the earliest stages of disease, who are most likely to benefit from new treatments, can be identified effectively.\(^3\)

Recommendations

- National-level policy must enable primary care to go beyond the challenges dementia poses now and prepare for the challenges of the future. The Dementia 10-Year Plan for England currently in development should:
  - Establish infrastructure across the NHS that allows more effective data-sharing between primary care and other settings.
  - Address immediate backlogs and workforce issues in primary care that are holding back recovery of the dementia diagnosis rate to pre-Covid levels.
  - Provide strategic, long-term support and investment in primary care to prepare for the increased prevalence of dementia associated with an ageing population.
  - Pave the way for innovation to be piloted and adopted in primary care.

- NHS England and Health Education England should work to support Integrated Care Systems to ensure appropriate training is given to primary care practitioners:
  - To improve recognition of the value of earlier, more accurate dementia diagnoses, and confidence in communicating this to patients.
  - In the use of currently available cognitive tests used for initial assessments.

- Supported by their local Integrated Care System, Primary Care Networks should explore and invest in the best diagnostic pathway for their patients, including evaluating innovative diagnostic tests such as cognitive assessment tools, and alternative service models such as Brain Health Clinics.

- Investment is needed to enable data to be effectively curated and shared between primary care and memory assessment services.

- The National Institute for Health and Care Excellence (NICE) should work with clinicians, people living with or affected by dementia and the third sector to develop national clinical guidelines on the diagnosis of people living with Mild Cognitive Impairment (MCI).
1. Why does earlier, more accurate diagnosis matter?

Earlier, more accurate diagnosis of dementia and its underlying disease(s) is the key to improving the lives of people living with dementia, as well as enabling breakthroughs in research that could deliver new treatments. It helps people get access to the care and support they need to plan for their future and gives them the opportunity to participate in clinical research.4

Alzheimer’s disease, the most common cause of dementia in older adults, is more likely to be treatable in its earlier stages. But without accurate and early diagnoses, finding suitable candidates for clinical trials is challenging, and this is slowing down research into disease-modifying treatments. Unless we transform dementia diagnosis, it will be too late for many people to benefit from new treatments.

2. The role of primary care in dementia diagnosis

Primary healthcare practitioners play a crucial role at several points along the dementia diagnosis pathway. The early signs of cognitive impairment and dementia are subtle and often only noticeable to the person experiencing them or those close to them. Whilst not all patient journeys look the same, a typical journey to diagnosis often begins when they or their loved one speak to their General Practitioner (GP). Their GP will then take a history, exclude other causes with a physical assessment and blood test, and perform a basic cognitive test. If they still suspect dementia, the GP usually refers the person to a specialist memory assessment service (MAS) where further investigations can confirm the diagnosis and determine the type and underlying cause of the dementia. They may be prescribed medication to manage their symptoms and are often referred for post-diagnostic support and provided with an annual review by their GP.

3. Current challenges and potential solutions

There is strong support for formal diagnosis and early testing for dementia, even before symptoms show: 89% of respondents to a recent public survey were likely to seek a diagnosis if they were concerned they might be in the early stages of dementia.5 But there are challenges in the current diagnostic pathway for both patients and carers, meaning many people find that securing a diagnosis is difficult and time-consuming, often taking too long and happening too late.7,8

Case study

Frank, 76, a retired probation officer from Wolverhampton, was diagnosed with Alzheimer’s disease in February 2020. Frank and his wife Alison found his experience of being diagnosed with Alzheimer’s very different to his diagnosis with prostate cancer in 2015. Alison says: “The prostate cancer diagnosis was quick because it’s so important to get on with the treatment as quickly as possible. But the Alzheimer’s diagnosis took a long time, with several visits to his GP to get referred to the consultant psychiatrist at the memory clinic and then numerous visits to her.” Although it is difficult to receive a diagnosis of Alzheimer’s disease when it cannot yet be stopped or slowed, Alison still believes it’s important to get one. “For me and Frank, and all people in our situation, we need to see all avenues being explored to find successful treatments and better ways to accurately diagnose dementia.”
3.1. Strategic support to address a long-term lack of capacity in the diagnosis pathway

A high-quality diagnostic experience is dependent on whether staff have the time, skills and knowledge to manage the diagnosis, but this can be difficult to achieve in primary care settings where there are increasing expectations of a broader clinical workload and declining workforce capacity. Strategic support is needed to improve and increase capacity in the diagnosis pathway.

Recognising the value of early and accurate diagnoses
There is considerable variation in dementia diagnosis rates and diagnostic accuracy across the UK, both between GP practices and memory clinics. There is also some doubt amongst GPs in the later stage of their career about the benefits of an early diagnosis. Trainee GPs tend to be more positive about their role in dementia care and recognise the importance of training and ongoing professional development but tend to be less confident in diagnosing and giving advice about dementia.

Recommendation
NHS England and Health Education England should work with Integrated Care Systems (ICSSs) to improve recognition amongst primary care practitioners of the value of earlier, more accurate dementia diagnoses in unlocking access to the right care and support, and to opportunities to participate in research and clinical trials.

Recovering the dementia diagnosis rate to pre-Covid levels and beyond
The impact of the global pandemic on the NHS means delays in dementia diagnosis have worsened at key stages along the diagnosis pathway. For primary care, the tremendous pressures faced by GP practices was compounded by patients being more isolated and reluctant to attend appointments for fear of contracting Covid-19. Before the pandemic, England consistently met its target to increase diagnosis rates to 66.7% in those aged 65 and over. The impact of Covid-19 led to the diagnosis rate dropping from 67% at the start of 2020 to 62% in September 2022, with an estimated backlog of approximately 35,000 people aged 65 and over waiting for a dementia diagnosis.

The role of national-level policy
We need to go beyond addressing the challenges dementia poses now and prepare for the challenges of the future. National-level policy must enable primary care to do so by providing support for an integrated approach to diagnosing dementia. Primary Care Networks must be able to work alongside Integrated Care Systems, care homes, and voluntary, community and social enterprise groups to support assessments and referrals across the diagnostic pathway. Investment will be needed across all parts of this pathway, including investment in primary care to increase capacity and skills of practitioners and to support the exploration of new ways of working.

Recommendation
National-level policy must enable primary care to go beyond the challenges dementia poses now and prepare for the challenges of the future. The Dementia 10-Year Plan for England currently in development should:
- Address immediate backlogs and workforce issues in primary care that are holding up recovery of the dementia diagnosis rate to pre-Covid levels.
- Provide strategic, long-term support and investment in primary care to prepare for the increased prevalence of dementia associated with an ageing population.
There is currently little routinely collected and published data on dementia in England, making it very difficult to assess the status of dementia diagnosis, or to measure the impact of innovative tools, treatments, practices or policy interventions. The Dementia 10-Year Plan for England should establish a National Dementia Observatory to provide data and intelligence on dementia in an easily accessible and useful form, creating an accurate benchmark of the state of diagnosis across primary and secondary care against which progress can be measured. This should include data on:

- People’s age at the time of their diagnosis.
- The underlying cause of their dementia.
- Information on characteristics where health inequalities are known to exist, such as gender, socioeconomic background, ethnicity and educational attainment.

**Recommendation**

National-level policy, such as the Dementia 10-Year Plan for England currently in development, should facilitate **more effective data-sharing** between primary care and other settings, including establishing a National Data Observatory.
3.2. Creating a culture of innovation in diagnosis, driven by local agendas

There has been limited innovation in the dementia diagnostic pathway, and what progress has been made in research and innovation often has not been implemented in clinical practice. Challenges range from the potential cost of diagnostic infrastructure and the need to train staff in new techniques, to there being few incentives to implement new innovations in e.g., cognitive tests or digital tools, and few opportunities to pilot new techniques.

Driving improvements at a local level

The development of Integrated Care Systems (ICSs) presents an opportunity to drive improvements to dementia diagnosis at a local level and create a culture of innovation in primary care. This will be more effective if appropriate levels of specialist dementia knowledge are embedded in ICSs. Primary care needs support and investment from health systems to pilot and implement new diagnostic approaches like new cognitive tests and blood-based biomarkers, and to explore alternative service models like Brain Health Clinics.

Recommendation

Supported by their local Integrated Care System, Primary Care Networks should **explore and invest in the best diagnostic pathway for their patients**, including evaluating innovative diagnostic tests such as cognitive assessment tools, and alternative service models such as Brain Health Clinics.

National-level policy, such as the Dementia 10-Year Plan for England currently in development, should pave the way for **innovation to be piloted and adopted** in primary care.

Case study

The Bristol Dementia Wellbeing Service is an integrated dementia service set up in 2015 to provide a personalised package of care to provide long term support from assessment and diagnosis until the end of life. The service operates from three hubs across Bristol, supporting people in their own homes, care homes, residential homes, GP practices and other community services. It differs to many other services as there are no physical memory clinics, and assessments can take place in someone’s home. For cases where diagnosis is uncomplex, GPs can diagnose dementia and start appropriate symptomatic treatment following a locally agreed protocol. For more complex cases GPs can refer to the community dementia team. There are regular meetings with the community team to discuss these more complex cases and the service is perceived to be more accessible for GPs than traditional models.
Cognitive testing
Cognitive tests such as the Mini-Cog, GPCOG or Free-Cog\textsuperscript{15} are used in primary care as one part of a holistic initial assessment of patients to assess for diagnosis, and decide whether a referral to a specialist setting is needed. The tests used tend to be quick and simple compared to the more nuanced tools used in secondary care and are less effective for detecting mild or early dementia. There are also inherent biases in the tests that can disadvantage people with lower levels of educational attainment, visual impairments, people who don’t have English as a first language or who come from different cultural backgrounds.

A recent study outlining the positive role of primary care-led services in reducing dementia referral times and improving diagnosis rates found the adoption of quicker screening tests suitable for use by non-specialists improved both the diagnosis rate and the confidence of GPs in making diagnoses.\textsuperscript{16}

Recommendation
NHS England and Health Education England should support Integrated Care Systems to ensure that adequate training is given to primary care practitioners in the use of currently available cognitive tests used for initial assessments.

Recommendation
Investment is needed at local levels to enable data to be more effectively curated and shared between primary care and memory assessment services.

Discussion with GP dementia leads\textsuperscript{17} determined that whilst new cognitive tests have the potential to provide better screening for underserved communities and mild or early dementias, to be considered for adoption into primary care, any new test would need to be:
- validated for use in primary care
- quick enough to complete as part of a wider assessment in a standard GP appointment
- easy enough to use with minimal training by both clinical and non-clinical staff
- inexpensive or free
- require limited or no additional equipment.

Case study
The ADePT study examined the dementia diagnosis pathway and investigated the potential impact of the Integrated Cognitive Assessment tool developed by Cognetivity (CognICA).\textsuperscript{18} The study gathered real-world evidence of CognICA’s use in existing clinical pathways in the NHS to improve triage and diagnosis in memory services. The tool aids dementia diagnosis by assessing the patient on rapid visual categorization, measuring accuracy and speed, to provide a percentage probability of cognitive impairment. It is a 5-minute, self-administered computerised cognitive test that uses a culturally generalisable Artificial Intelligence model to improve its accuracy in detecting cognitive impairment. CognICA has the potential to be a more accurate and sensitive tool to aid diagnosis, which could help to improve the diagnosis of dementia by reducing false positive results from GP referrals. This would minimise the need for further, expensive and time-consuming assessments.
Blood-based biomarkers

Blood-based biomarkers are just starting to reach clinical practice in specialist settings but what role could they play within primary care? They potentially offer a scalable, low-cost test to identify people at the early stages of Alzheimer’s disease but would need to be piloted in non-specialist settings to understand their benefits and challenges.

As well as unlocking access to personalised support and symptomatic treatment, such tests would make it easier to match people with the most appropriate clinical trials, in turn increasing the likelihood of finding new disease-modifying treatments. It is likely that investment would be needed to provide necessary infrastructure in primary care settings, workforce capacity, and skills and resources for sample analysis. Specialist services such as memory clinics would also need investment to ensure they can accommodate referrals from primary care. We need to support services to explore the potential of new diagnostic tests and understand impact across the care pathway.

3.3. Providing better diagnostic support for people with Mild Cognitive Impairment

People with Mild Cognitive Impairment (MCI) face difficulties getting a diagnosis and receiving on-going care. MCI is a clinical syndrome for people experiencing change in cognitive function and is an at-risk state for further cognitive decline. Up to 15% of people each year with MCI will go on to be diagnosed with dementia.

Due to a lack of consistency about the definition and clinical use of MCI there is a huge service gap, with memory clinics discharging patients, and GPs not routinely reviewing patients with MCI. This means that many patients only present again to a clinician when their symptoms have significantly progressed. These patients aren’t captured within routinely collected data, so are a relatively hidden and underserved group.

Recommendation

The National Institute for Health and Care Excellence (NICE) should work with clinicians, people living with or affected by dementia and the third sector to develop national clinical guidelines on the diagnosis of people living with Mild Cognitive Impairment (MCI).
About Alzheimer’s Research UK
Alzheimer’s Research UK is the UK’s leading dementia research charity. Our mission is to bring about the first life-changing dementia treatment by 2025.

Alzheimer’s and other dementias are one of the UK’s leading causes of death and with no treatments to slow, stop or cure them, they are diseases that no-one has yet survived. However, we are committed to changing that. Backed by our passionate scientists and supporters, we are challenging the way people think about dementia, bringing together the people and organisations who can speed up progress, and investing in research to make these breakthroughs possible.

Contact us
We would be happy to discuss any of the issues raised in this paper in more detail. Please contact us at policy@alzheimersresearchuk.org

12 Prime Minister’s challenge on dementia 2020 - GOV.UK (www.gov.uk)
17 Discussion held at GP Dementia Leads meeting convened by NHS England on 15 February 2022.