Early detection of neurodegenerative conditions in primary care and the community - Executive Summary

This is a transformative time for detecting, diagnosing, and treating neurodegenerative conditions. There is an opportunity to rethink current pathways and design a future-facing service to improve health and wellbeing outcomes and optimise the use of health resources.

Neurodegenerative conditions cause damage to the nervous system, particularly the brain. These conditions include Alzheimer's disease and other causes of dementia, and Parkinson's, amongst others. Detection and confirming diagnosis of most neurodegenerative conditions is challenging and often lengthy. Improving early detection of neurodegenerative conditions has many advantages, that rely on timely access to support and treatment.

Improved early detection in primary care could help people get a timely diagnosis in secondary care. People could then access any emerging treatments and opportunities to participate in research studies earlier. There is some evidence that treating earlier may be more effective.[1,2,3] People could also address modifiable risk factors (such as high blood pressure, smoking, and lack of physical activity) earlier, which may reduce symptom severity and delay progression.[4,5,6,7] Earlier detection could give people clarity about their symptoms, allowing them to plan ahead and take part in decision making.

Emerging tools for detecting neurodegenerative conditions include blood tests, digital tests of cognition, specialist eye scans, and artificial intelligence algorithms for interpreting data. Some tools could be used by primary care clinicians[8] in general practice, pharmacies, opticians, and dentists to explore the possibility a person may have a neurodegenerative condition. They could then make faster, more accurate referrals to secondary care, leading to more focused use of secondary care resources and faster diagnosis

To explore how to enable earlier detection of neurodegenerative conditions in primary care and community services, the Academy of Medical Sciences, Alzheimer's Research UK, and Alzheimer's Society organised a FORUM meeting in February 2024. The meeting brought together people with lived experience of neurodegenerative conditions with primary and secondary care practitioners, funders, and representatives from charities, academia, and industry. Participants agreed the choice to participate (or not) in tests for neurodegenerative conditions should remain with the patient.

Five priorities emerged from discussions (outlined further in the full report):

1. The case for early detection should be rigorously assessed, considering the whole pathway from detection to diagnosis and care

Early detection enables early diagnosis and treatment. Modelling and pilot studies are needed to predict and demonstrate that introducing tools in primary care can improve speed and accuracy of referral and diagnosis, and improve health outcomes. A health-economic case for early detection

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[1] Van Dyck C, *et al.* (2022). *Lecanemab in early Alzheimer's disease.* The New England Journal of Medicine **388(1)**, 9-12.
[2] Sims J, *et al.* (2023). *Donanemab in early symptomatic Alzheimer disease: The TRAILBLAZER-ALZ 2 randomized clinical trial.* JAMA **330(6)**, 512-527.
[3] JJ Cerqueira et al. (2018). *Time matters in multiple sclerosis: can early treatment and long-term follow-up ensure everyone benefits from the latest advances in multiple sclerosis?* Journal of Neurology, Neurosurgery and Psychiatry **89**, 844-850.
[4] Livingston G, Huntley J, *et al*. (2020). *Dementia prevention, intervention, and care: 2020 report of the Lancet Commission.* Lancet **396(10248)**, 413-446.
[5] Ascherio A, Schwarzschild M, (2016). *The epidemiology of Parkinson's disease: risk factors and prevention* The Lancet Neurology **15(12)**, 1257-1272.
[6] Tsukita K, Samaki-Tsukita H, Takahashi R, (2022). *Long-term effect of regular physical activity and exercise habits in patients with early Parkinson disease* Neurology **98(8)**, 859-871.
[7] Mukadam N, *et al.* (2024). *Changes in prevalence and incidence of dementia and risk factors for dementia: an analysis from cohort studies* The Lancet Public Health **9(7)**, 443-460.
[8] Such as general practitioners, nurses, advanced clinical practitioners, pharmacists, physician associates, and optometrists.

should be developed that considers impacts on and interactions between various parts of the health and social care system. Pre- and post-diagnostic support packages should be developed with input from people living with neurodegenerative conditions, to help people navigate detection, diagnosis and care. Pathway improvement should aim to reduce regional variability. Pathways should be co-designed with people who are living with, and affected by, neurodegenerative conditions.

2. Detection requires integration of multiple sources of data

Different tools may provide different information about the presence of disease, the risk of future disease, and changes in symptoms over time. A combination of tools may be required to provide complementary data. Primary care clinicians will need training to help them interpret and communicate this data. Methods (such as artificial intelligence) to integrate data from multiple sources and generate predictions could be useful as decision-aides to primary care clinicians. Standards developed in collaboration with primary care clinicians and people living with neurodegenerative conditions will be important, so that detection and referral is consistent across services. People should be supported to understand their results, their risks, and the choices available.

3. Roles and responsibilities of health workers in early detection should be clarified across different primary care and community settings

In addition to the general practitioners, primary care clinicians from a variety of professions in general practice could be more involved in early detection. They could counsel people on test limitations, administer tests, interpret results, and manage referrals. Some tests could be used in other primary care and community settings including pharmacies, opticians, and pilot health services, such as the brain health services in Scotland.[9] Clarifying responsibilities, coordinating between services and providing relevant workforce training will be important.

4. A greater focus on early detection may require changes in mindset among clinicians, policymakers and the public

Neurodegenerative conditions are often considered to be untreatable or an unavoidable part of ageing, which may discourage people coming forward for early detection. There is growing awareness that symptoms may be a late-stage manifestation of declining brain health, that could potentially be delayed or prevented. Lessons on prevention could be learned from disease areas like cardiovascular disease, including by building scalable, inexpensive brain health assessments into routine health checks. [10] Awareness should be raised amongst healthcare staff, policymakers, and the public of the evidenced benefits of maintaining brain health and early detection. A public brain health campaign based on recent progress could create hope and expectation that these conditions can be treated, delayed, or prevented.

5. Equity, evidence, and iterative improvement should underpin future developments

Access to detection and diagnostic services should be made equitable and inclusive – for example, removing financial barriers (e.g. for specialist eye scans). The rapid progress in this area should be reviewed regularly to highlight opportunities. Research should be embedded to iteratively improve detection, diagnosis, and treatment of neurodegenerative conditions.

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[9] https://www.brainhealth.scot/brainhealthservices
[10] https://www.nhs.uk/conditions/nhs-health-check/

Proposed next steps

Workshop participants proposed next steps for earlier detection of neurodegenerative conditions in primary care and the community and highlighted remaining evidence gaps. These are listed here in brief. For details of the full discussion, please see the full report.

1. The case for early detection should be rigorously assessed, considering the whole pathway from detection to diagnosis and care

1.1. More evidence should be gathered about whether earlier treatment with pharmacological and non-pharmacological interventions is more effective for various neurodegenerative conditions, investigating whether effectiveness varies according to each stage of the disease. The potential causal relationship between lifestyle risk factors and different neurodegenerative conditions should be explored and the impact of lifestyle modifications assessed.

1.2. How and when to embed opportunities to participate in clinical research alongside early detection should be investigated.

1.3. Current clinical pathways for people coming forward with symptoms of neurodegenerative conditions should be reviewed, including regional variations and health outcomes. The logistical and economic impact of introducing different detection tools on diagnostic and treatment pathways should be modelled.

1.4. Based on modelling data, the use of different tools should be piloted within various primary and community health settings and in different populations. Lessons can be learned from ongoing pilot schemes, such as the Blood Biomarker Challenge.[11] These pilot schemes could gather and consolidate real-world data on test usage, performance, impact on the detection and diagnostic pathway, and outcomes.

1.5. Pre- and post-diagnosis packages of information and support for people living with and affected by a neurodegenerative condition should be developed, to help people navigate the diagnostic journey. Medical charities and patient support groups may be well placed to do this.

1.6. The National Institute for Health and Care Excellence (NICE) should be encouraged to develop guidelines for the management, and eventually treatment, of mild cognitive impairment.

2. Detection requires integration of multiple sources of data

2.1. The feasibility and acceptability of integrating data from multiple sources/tests to assess a person's risk of a neurodegenerative condition (potentially using technologies such as machine learning/AI) should be investigated. Such technologies could be used to build a decision-support tool. The desired characteristics and communication preferences for a decision-support tool for use in primary care should be established, in collaboration with primary care clinicians and people living with neurodegenerative conditions.

2.2. It will be important to investigate what information people want from tests that detect neurodegenerative conditions and when, and how best to communicate about test results, health risks, and the choices available to people who may have a neurodegenerative condition. Existing guidance and approaches to communication in other disease areas, such as cardiovascular disease, should be learned from.[12,13]

2.3. Standardised criteria and data standards for the use of tools in the detection, referral, and diagnosis should be developed for different relevant neurodegenerative conditions at different stages, to improve consistency across services.

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[11] https://www.alzheimers.org.uk/news/2024-04-04/uk-comes-step-closer-blood-tests-diagnosing-dementia

[12] Patient Information Forum (2023). *Communicating benefits, risks and uncertainties.* https://pifonline.org.uk/resources/how-to-guides/communicating-benefits-risks-and-uncertainties/.

[13] Schulberg SD, *et al.* (2022). *Cardiovascular risk communication strategies in primary prevention. A systematic review with narrative synthesis.* Journal of Advanced Nursing **78(10),** 3116–3140.

3. Roles and responsibilities health workers in early detection should be clarified across different primary care and community settings

3.1. The circumstances in which it may be appropriate for practitioners in primary and community services beyond general practice to refer directly to relevant specialists should be considered, and the acceptability to various practitioners and the public explored.

3.2. The potential for different staff (such as nurses) in general practice to be involved in detecting neurodegenerative conditions, along with relevant training needs, should be explored.

4. A greater focus on early detection may require changes in mindset among clinicians, policymakers and the public

4.1. The training and continuing professional development of general practitioners and other relevant primary care clinicians should reflect the latest advances in the detection, diagnosis, and treatment of neurodegenerative conditions.

4.2. Integration of brain health assessments into both pre-existing routine health checks and care plans for people with a condition that puts them at risk of developing a neurodegenerative condition should be explored.

4.3. The potential for an evidence-based public health campaign to promote brain health and prevention should be explored. Some workshop participants suggested that the government in collaboration with medical charities would be well-placed to deliver this campaign.

Taking forward many of these next steps would require a multi-stakeholder approach, particularly including input from people with lived experience of neurodegenerative conditions, those affected (including their families), and clinicians.

In partnership with:

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