

# Alzheimer's Society Response to Change NHS Consultation

The following is the Alzheimer's Society's organisational response to the Government's Change NHS Consultation. It was submitted on 2 December 2024 via the [Change NHS](#) portal.

## Q1. What does your organisation want to see included in the 10-Year Health Plan and why?

Dementia is a high-impact, complex and currently under-prioritised condition that spans the entire system and is a vital indicator of whether the NHS is performing effectively. The King's Fund recently described progress in dementia care as a "litmus test" for the success of integrated care, and we at Alzheimer's Society believe that if the health and care system works well for people living with dementia, it will work well for everyone. Dementia can and should be used as a model for success and a roadmap for getting things right across all major health conditions.

The 10-Year Health Plan is understandably being developed as a holistic and overarching strategy. Given that 73.2% of people with dementia have comorbid conditions (meaning they often have more complex health and care needs) and that the number of people with multiple long-term conditions is rising, Alzheimer's Society supports this approach to the plan. However, should there be a decision to focus on specific key conditions, we would argue that dementia would have to be one of these, given its impact across the whole of health and care. It is essential that dementia is provided with a status – in terms of governance, accountability and leadership – that reflects its huge impact and scope for improvement. Major progress has been made in other major disease areas such as stroke and cancer in recent years, in part due to strong accountability, oversight and governance within the NHS and in Government. We urge the NHS and Government to take similar steps to establish governance and accountability mechanisms which are requisite to the scale of the challenges and opportunities dementia offers.

To achieve its stated aims of bringing about the three "big shifts" from acute to community services, from sickness to prevention, and from analogue to digital, the plan does need to deliver significant improvements in dementia diagnosis, care and treatment. High levels of unwarranted variation in access, quality and outcomes from NHS services for people living with dementia saw the Darzi review specifically acknowledge that "there is an important challenge to improve both the quality and quantity of care for people living with dementia." As a condition, dementia is a whole-system challenge that requires join-up across all services to deliver the best possible outcomes for the people living with it.

## Diagnosis and treatment

Despite evidence of their effectiveness, there is insufficient investment and focus on interventions such as early diagnosis, treatment and dementia training for the care workforce. England also has the second-lowest number of Alzheimer's disease specialists per capita among the G7 countries. As a result, dementia has a huge and costly impact on NHS services: one in six hospital beds today are occupied by dementia patients. It's vital that this is addressed in the plan.

We want to see the 10-Year Health Plan include clear action on improving access to early and accurate diagnosis, and a wider focus on early intervention. Currently, the dementia diagnosis rate in England is 65.7%, leaving more than a third of people living with the condition without the vital care, support and treatment a diagnosis can bring. Overall wait times for diagnosis are on the rise, with people waiting 151 days to get a diagnosis in 2023 (up from 124 days in 2021). There's also significant variation in overall wait times across the country, ranging from 44 to 347 days.

People living with dementia account for over 36 million contacts annually across community, primary and mental health care, and a lack of diagnosis risks increasing a person's healthcare utilisation. For example, undiagnosed people with dementia attend A&E an average of 1.5 times a year, which is more than people with a diagnosis for mild, moderate and severe cohorts; and three times as much as people without dementia.

Early and accurate diagnosis coupled with provision of available treatments for dementia can help delay the progression of symptoms and the need for community or nursing home care, improving quality of life and independence and generating significant potential cost savings. Where treatments are effective, there could be savings of between £8,800 and £44,900 per person – yet just 1.4% of total healthcare spend on dementia currently goes towards diagnosis and treatment. While there are initially significant cost implications of increasing rates of dementia diagnosis, the potential to generate system-wide savings off the back of this investment through enabling better condition management is even more significant for the UK's economic growth.

By contrast, a third of dementia healthcare costs are generated by unplanned hospital admissions. It's projected that the overall cost of dementia to the UK is set to rise from £42billion today to £90billion by 2040, so a focus on cost-effective dementia interventions is key. Better utilisation of existing dementia treatments, which are affordable and clinically effective, could play a key role in helping with condition management in the community, reducing the time during which people with dementia require intensive social care support.

To access these treatments, people with dementia first need a diagnosis. Alzheimer's Society therefore wants to see the 10-Year Health Plan setting bold, ambitious and achievable new diagnosis rate targets to ensure more people get the early and accurate diagnosis they need. This should be coupled with dedicated funding in the plan to improve the quality of diagnosis and to run targeted awareness campaigns that will improve recognition of dementia symptoms to improve access to diagnosis and treatment. It's vital that the NHS adopts a more proactive and less reactive approach to dementia to

reduce its impact on health and care systems. Greater focus on, and investment in, diagnosis and early intervention would go a long way to achieving this.

### **Dementia care**

We also want to see the plan ensuring that all of the health and care workforce have training on dementia. Only 45% of ward-based patient facing hospital staff have received Tier 2 dementia training. Nearly a fifth of primary care staff believe there is little benefit to diagnosis, suggesting a lack of awareness and relevant training. Meanwhile, just 29% of care staff in England undertake any kind of dementia training. The plan should therefore introduce mandatory dementia training, particularly in care settings. This is another cost-effective action that would enhance quality of patient care as well as reduce pressure on GPs and hospitals by enabling better condition management.

### **Data**

Lastly, Alzheimer's Society wants to see the 10-Year Health Plan utilised to implement improvements to the recording, collation and analysis of health data, particularly dementia data, including through greater use of secure data environments. The recently published Sudlow Review highlights how much national NHS England data is only accessible for COVID-related analysis and research, but not to tackle other health conditions like cancer, heart disease, stroke, diabetes and dementia. It calls for national data capability to be maintained and improved beyond the COVID-19 pandemic to address the challenges of a health and care system in crisis that is facing dementia as an ongoing 'pandemic'.

There is a serious disconnect between the scale and urgency of dementia, the biggest killer in the UK, and the relative paucity of data that exists around the condition. There is a significant inequality in data and evidence between dementia and other major disease areas. Improved data is a critical foundation for essential improvements in care, increasing understanding of the dementia pathway, improving service planning and aiding the prioritisation of resources. Improvements in diagnosis and treatment are dependent on real-time snapshots and future modelling, which are also underpinned by better data.

While Alzheimer's Society has commissioned research to bridge the gap in data (which will be key to identifying and implementing levers required to delay system pressure resulting from dementia), there are still significant limitations around evidence and data availability. Accessing more data is essential to improving NHS performance and preparing the health and social care system for the rising prevalence of dementia, with 1.4m people expected to be living with the condition by 2040. Better data will also allow for greater accountability amongst local systems where good practice and guidance are not being followed.

### **Section links to relevant supporting documents**

Alzheimer's Society reports:

- <https://www.alzheimers.org.uk/sites/default/files/2024-09/Dementia-contribution-health-metrics.pdf>
- <https://www.alzheimers.org.uk/sites/default/files/2024-09/Modelling-impacts-early-diagnosis.pdf>
- <https://www.alzheimers.org.uk/sites/default/files/2024-05/the-annual-costs-of-dementia.pdf>

External reports:

- <https://assets.publishing.service.gov.uk/media/66f42ae630536cb92748271f/Lord-Darzi-Independent-Investigation-of-the-National-Health-Service-in-England-Updated-25-September.pdf>
- [https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-\(2023-2024\)/mas-r6/nad-mas-2023-national-report-05082024-final.pdf](https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-(2023-2024)/mas-r6/nad-mas-2023-national-report-05082024-final.pdf)
- <https://www.kingsfund.org.uk/insight-and-analysis/long-reads/role-integrated-care-systems-improving-dementia-diagnosis>
- <https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/round-5/nad-r5-report/national-audit-of-dementia-round-5-national-report-0823-final.pdf>
- <https://www.hdruk.ac.uk/helping-with-health-data/the-sudlow-review/>

Data set reports:

- [https://fingertips.phe.org.uk/documents/Dementia\\_New\\_Indicator\\_Factsheet\\_Part1.html](https://fingertips.phe.org.uk/documents/Dementia_New_Indicator_Factsheet_Part1.html)
- <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/october-2024>

## **Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?**

Dementia as a condition should largely be diagnosed and managed in the community. However, there are three specific challenges that are preventing this from happening: a lack of diagnosis, a lack of proper treatment, a lack of join-up between health and care, and not enough access to good care in the community.

Inadequate diagnosis and management of dementia results in crisis, unplanned admissions and prolonged stays in hospitals. Too few people with dementia currently get the early and accurate diagnosis they need, which causes major pressure on the health system.

As mentioned in response to Q1, a third of all dementia healthcare spending is due to unplanned admissions in acute settings, compared to just 1.4% spent on diagnosis and treatment in the community. This is a stark illustration of Lord Darzi's finding that "hospitals have attracted a greater share of NHS spending, meaning that other settings have received a smaller share."

Without adequate support in the community, people with dementia may have little choice but to attend hospital. As well as people with undiagnosed dementia attending A&E more frequently than those with diagnosed dementia and those without dementia, they also experience more hospital inpatient bed days. In 2024, it's estimated that people with dementia will have an estimated 8.2m bed days, rising to 11.7m bed days by 2040.

On average, people with severe dementia will be in hospital for around a month following an unplanned admission. Additionally, people with severe dementia have an average length of stay in hospital for unplanned admissions that is more than three times longer than for people with mild dementia. There is therefore a strong incentive to invest in interventions like diagnosis and treatment as enablers, as they can help people to manage their condition, stay in the milder stages of dementia for longer, and avoid unplanned trips to hospital.

After receiving a diagnosis, many people with dementia do not have access to NICE approved treatments – only 31% of patients at memory clinics are referred for cognitive stimulation therapy, despite it being recommended in the NICE guideline for dementia.

Acetylcholinesterase (AChE) inhibitors, a symptomatic treatment for dementia, are “cheap with relatively few side-effects [and] attenuate cognitive deterioration to a modest extent, with good evidence of a long-term effect.” However, while estimates vary on the exact level of prescriptions of these treatments, it is clear they are currently under-prescribed. This under-prescription puts pressure on the health system, because without treatment and support, people living with dementia are more likely to experience unplanned hospital admissions.

As AChE inhibitors can help delay the onset of severe dementia symptoms, they can also enable patients to stay in their own homes for longer, avoid earlier admission to residential care settings, improve quality of life, and generate cost savings. These savings are generated because of the rising costs of dementia as the condition progresses – the average annual per person cost of mild dementia is £29,000, compared to £81,000 for severe dementia.

The Darzi review clearly noted that “successive governments have promised to shift care away from hospitals and into the community,” but that “in practice, the reverse has happened,” with hospital expenditure and staffing levels on the rise compared to other parts of the NHS. Investing in early diagnosis and treatment would help properly enact a shift towards community care by helping people living with dementia and their carers to manage their condition independently for longer.

Underinvestment in adult social care continues to contribute to delays in discharging people from hospital, placing further pressures on the NHS. People with dementia are some of the largest users of social care, and social care is the second largest cost associated with dementia. The average per-person cost of social care is nearly three times higher for people with severe dementia than people with mild dementia.

Though social care is largely out of scope of the 10-Year Health Plan, there is a clear case for investment in social care as an enabler to help the NHS. This investment should include funding for dementia training for care staff, which can reduce unplanned hospital admissions and GP appointments, offering significant return on investment. Rolling out the good-practice model of dementia training to all CQC-registered care homes would release £29.4million cost savings to the Government.

Ultimately, a lack of appropriate care in the community for people living with dementia results in people attending hospital when they shouldn't and getting stuck in hospital without discharge. Research

conducted by Alzheimer's Society previously found that nearly two-thirds of all emergency admissions for people living with dementia were for avoidable illnesses and injuries caused by failures in care.

Better public and professional awareness of dementia is also a key enabler in the shift towards community care. By raising awareness of the signs and symptoms of dementia via resources like the Alzheimer's Society dementia symptoms checklist, and by promoting the benefits of diagnosis, we could encourage more people to get a diagnosis and utilise the benefits this brings to individuals and systems. As such, Alzheimer's Society wants to see the 10-Year Health Plan specifically commit to funding a public awareness campaign on dementia, and to better disseminate the dementia symptoms checklist, which has been endorsed by the Royal College of GPs.

### Section links to relevant supporting documents

Alzheimer's Society reports:

- <https://www.alzheimers.org.uk/sites/default/files/2024-09/Dementia-contribution-health-metrics.pdf>
- <https://www.alzheimers.org.uk/sites/default/files/2024-09/Modelling-impacts-early-diagnosis.pdf>
- <https://www.alzheimers.org.uk/sites/default/files/2024-11/Why-dementia-training-matters.pdf>
- <https://www.alzheimers.org.uk/sites/default/files/2024-09/Alzheimer%27s-Society-Final-Draft-Autumn-Budget-2024-Submission.pdf>
- <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/dementia-diagnosis/how-to-get-dementia-diagnosis/dementia-symptoms-checklist>
- <https://www.alzheimers.org.uk/news/2024-11-22/emergency-admissions-dementia-care-failures-soaring-and-worse-come-warns-charity>

External reports:

- <https://assets.publishing.service.gov.uk/media/66f42ae630536cb92748271f/Lord-Darzi-Independent-Investigation-of-the-National-Health-Service-in-England-Updated-25-September.pdf>
- [https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-\(2023-2024\)/mas-r6/nad-mas-2023-national-report-05082024-final.pdf](https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-(2023-2024)/mas-r6/nad-mas-2023-national-report-05082024-final.pdf)
- <https://www.thelancet.com/commissions/dementia-prevention-intervention-care>
- <https://pubmed.ncbi.nlm.nih.gov/29253388/>

### **Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?**

As stated in response to Q1, we currently have very poor data on dementia which is a significant challenge. While dementia diagnosis rates and associated data are reported monthly in England, in Wales, there is only annual data on national and local diagnosis rates (published in July 2024 and backdated to 2020) and in Northern Ireland, no diagnosis rate data is published.

Additionally, dementia diagnosis rates in England and Wales are currently calculated using CFAS II study data which is now outdated (having not been updated since 2011) and does not consider characteristics such as rurality, deprivation, and other risk factors. This could lead to inaccuracy in currently published diagnosis rates.

The Sudlow review has specifically highlighted that as well as strategic investment in some areas, progress on data will only be made by recognising and addressing key barriers with a combination of financial, political, and technical solutions. A major identified challenge is the present data ecosystem complexity and fragmentation, which applies to both the NHS and many non-NHS organisations. It notes that alignment of national organisations around common goals and priorities was behind the delivery of several health data-driven initiatives during the COVID-19 pandemic, some of which occurred at unprecedented pace and scale. The report suggests that similar approaches should be taken to the UK's other epidemics, including the global pandemic of dementia, which is a call that Alzheimer's Society supports.

The shift from analogue to digital must therefore achieve better collection, publication and analysis of data so that we can improve utilisation of technology in health and care. In the words of the Chief Medical Officer for England in his 2023 annual report, "what gets measured gets done."

Examples of the kind of data we need to see include:

- Recording of disease severity in primary care records using a uniform severity measurement indicator;
- Prescribing data on the use of NICE-recommended medicines;
- Diagnosis data providing insight into the huge variance seen between services;
- Regularly published data on waiting times for diagnosis.

Better data can be embedded across other parts of the system. It can be used by regulators to assess performance, and to provide a better picture of performance variation within the NHS. This would empower systems to intervene more appropriately and confidently, because good data is an enabler. It allows for better targeting of resources, including technological resources, and provides a clear source of accountability.

A recent OHE report noted that better data collection, reporting and publishing on dementia could improve how health inequalities are measured and tracked. Inequalities can be far more effectively addressed if they are clearly articulated and identified. We support the report's recommendations to update and enhance methods of calculating dementia prevalence estimates; to remove disparities in data collected and published across England, Wales and Northern Ireland; and to start collecting data on the stages along the 'time to diagnosis' pathway.

The report notes that NHS England waiting time standards for cancer diagnosis and care mean data are consistently collected and published. While there is an NHS time target that people should go from referral to dementia diagnosis in 6 weeks, this is not enshrined in standards and waiting time data on dementia diagnosis is only published intermittently for England and Wales via the National Audit of Dementia's Spotlight Audits on Memory Assessment Services. Audit data is extremely valuable, but we must have waiting time data published more regularly and consistently.

We also support the Sudlow review's recommendations for the creation of a coordinated joint strategy that recognises health data as a critical national infrastructure; for the reduction of unnecessary complexity and duplication of effort when it comes to data; for a shift towards a health data ecosystem that promotes the uses of health data for patient and public benefit, with senior leadership of NHS England, National Institute for Health and Care Research (NIHR) and UK Research and Innovation (UKRI) held to account; and for the appointment of a senior executive leader with responsibility and ring-fenced budget to deliver a national health data service. The report is clear that in a difficult economic climate, many opportunities exist for savings, including through standardising and streamlining data to reduce existing costs. In the dementia data space, there are plenty of examples of data that is gathered but not published. As previously mentioned, having more publicly available data on dementia, particularly dementia diagnosis, would allow for better use of resources.

Underfunding of diagnostic technology and innovation in dementia is another barrier to good use of technology overall. England has the lowest number of PET and MRI scanners among the G7 countries. This poses challenges in getting people an early and accurate diagnosis – and, if a disease-modifying treatment for dementia is approved for use on the NHS in the future, investment in increased scanning capacity will be all the more important for both the diagnosis and monitoring of patients.

In its 2024 manifesto, the Labour Party pledged to introduce a Fit for the Future Fund which would double the number of CT and MRI scanners in the NHS. We're aware of significant competition across disease areas for scanning capacity but, given the rising prevalence of dementia and the significant benefits early diagnosis brings to individuals and the wider health system, we believe some scanning capacity delivered via the Fit for the Future Fund should be ringfenced for dementia.

Alzheimer's Society, Alzheimer's Research UK and the National Institute for Health and Care Research are currently running the Blood Biomarker Challenge, supported by £5million raised by players of the People's Postcode Lottery. The aim of the Challenge is to revolutionise dementia diagnosis by rolling out a blood test for dementia on the NHS. Technological innovations such as this will be vital to getting more people diagnosed with dementia, so as well as seeing charities and lottery funding enabling projects like the Challenge, the 10-Year Health Plan should ensure there is continued investment into health research and innovation.

Alzheimer's Society is also partnered with Innovate UK and Challenge Works on the Longitude Prize on Dementia. This is a £4million prize to drive the creation of personalised, technology-based tools that are co-created with people who are living with the early stages of dementia.

Its aim is to help them live independent, more fulfilled lives and to be able to do the things they enjoy. £3.42million will be awarded in seed funding and development grants to the most promising solutions, with a £1million first prize to be awarded in 2026.

Examples of innovation happening through this project include an augmented reality map to prevent people from getting lost or confused, high-tech specs for facial recognition, and a virtual speech assistant to help fill in missing words. These are all brilliant examples of how tech can be an enabler for better



quality of life for people living with dementia but, to keep innovation such as this going, we need to see continued investment and support from Government for projects like the Longitude Prize.

### Section links to relevant supporting documents

Alzheimer's Society reports:

- [https://www.alzheimers.org.uk/sites/default/files/2024-10/Alzheimer%27s%20Society%20-%20Final%20Draft%20Autumn%20Budget%202024%20Submission%20%5Bupdated%20Oct%202024%5D\\_0.pdf](https://www.alzheimers.org.uk/sites/default/files/2024-10/Alzheimer%27s%20Society%20-%20Final%20Draft%20Autumn%20Budget%202024%20Submission%20%5Bupdated%20Oct%202024%5D_0.pdf)
- <https://www.alzheimers.org.uk/news/2023-11-07/blood-biomarker-challenge-dementia-diagnosis>
- <https://www.alzheimers.org.uk/research/our-research/dementia-innovation/longitude-prize>

External reports:

- <https://www.ohe.org/wp-content/uploads/2024/06/Inequalities-in-Dementia-OHE-AS-Report-.pdf>
- <https://www.hdruk.ac.uk/helping-with-health-data/the-sudlow-review/>
- <https://link.springer.com/article/10.14283/jpad.2024.24>
- <https://assets.publishing.service.gov.uk/media/6674096b64e554df3bd0dbc6/chief-medical-officers-annual-report-2023-web-accessible.pdf>

## **Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?**

As dementia significantly crosscuts health and social care, it poses a unique whole-system challenge that cannot be solved by one organisation, sector, or profession alone. Dementia prevalence is on the rise and as a result, healthcare utilisation associated with the condition is rising too.

High-quality, early and accurate diagnosis and care relies on many different parts of the health and social care system working together effectively. While this is challenging to do, strengthening relationships between primary care, memory clinics and other services (as in case study examples cited in the King's Fund report on the role of ICSs in dementia diagnosis) enables improvements to system approaches to dementia that emphasise the condition's status as a litmus test for the overall success of integration.

We therefore need to see the NHS being far more proactive in its approach to dementia, particularly through greater focus and investment in diagnosis and early intervention. In his independent investigation of the NHS, Lord Darzi noted that "dementia diagnosis rates have not improved in recent years." Over a third of people living with dementia in England are without a diagnosis, despite the condition being the UK's biggest killer and prevalence being on the rise.

Regional variation in dementia diagnosis is multifactorial and linked to deprivation, rurality and deprivation, as well as a lack of a consistent approach or nationally led action on variation. It is clear that dementia,

especially dementia diagnosis, is not the political priority it needs to be, and this is hampering progress in getting people the early and accurate diagnosis they deserve.

Dementia diagnosis takes, on average, 3.5 years from the onset of symptoms, which is far too long and indicates a need for action to improve the quality of dementia diagnosis in England. Huge variability in the proportion of patients diagnosed with different types of dementia (Alzheimer's disease diagnosis as a percentage of dementia diagnosis ranges from 6%–90%) suggests major issues around diagnostic accuracy and thus effective and targeted patient care.

Many memory assessment services experience difficulty in accessing brain scans, with large variation between services in scans performed (ranging from 0%–90%). The Spotlight Audit of Memory Assessment Services conducted in 2023 notes that “varying operational procedures may affect whether a scan is carried out, rather than consistently basing this decision on clinical judgement.” It also found that waiting times from requests for a brain scan to the scan being performed had increased from 36 days in 2021 to 42 days in 2023.

Market research conducted on behalf of Alzheimer's Society in 2023 found that almost a fifth of primary care staff believed that there is little benefit in formal diagnosis for an incurable, progressive disease. Yet this conception that there is little support post-diagnosis does not recognise the treatment and interventions a person can access once diagnosed, and the benefits early diagnosis can bring. A lack of understanding of the benefits of diagnosis is likely to have an impact on how a clinician approaches referral for diagnosis and subsequent management and is a key driver for the impacts on services outlined in previous questions.

Without major improvements to the scale, pace and quality of dementia diagnosis, the system response to dementia will inevitably be reactive, leading to worse outcomes and higher costs. We need to see specific investment in diagnostics that can catch dementia early. This becomes especially important in the context of emerging disease-modifying treatments. Currently just 2.1% of patients at memory services have a specialist investigation such as a PET scan or CSF test performed and, while progress is being made on blood tests for dementia, they cannot yet be relied upon to provide sole confirmation of a dementia diagnosis.

Dementia research generally has been historically underfunded compared to other conditions, with 31p spent on dementia research for every £1 spent on cancer research. More research funding is needed to help develop innovative testing methods that can detect dementia at even earlier stages.

### **Section links to relevant supporting documents:**

Alzheimer's Society reports:

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

External reports:

- <https://www.kingsfund.org.uk/insight-and-analysis/long-reads/role-integrated-care-systems-improving-dementia-diagnosis>

- <https://assets.publishing.service.gov.uk/media/66f42ae630536cb92748271f/Lord-Darzi-Independent-Investigation-of-the-National-Health-Service-in-England-Updated-25-September.pdf>
- <https://pubmed.ncbi.nlm.nih.gov/32310343/>
- [https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-\(2023-2024\)/mas-r6/nad-mas-2023-national-report-05082024-final.pdf](https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-(2023-2024)/mas-r6/nad-mas-2023-national-report-05082024-final.pdf)
- [https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-\(2023-2024\)/mas-r6/mas-2023-appendices-ii-v.pdf](https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-(2023-2024)/mas-r6/mas-2023-appendices-ii-v.pdf)

**Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and in what timeframe you would expect to see this delivered.**

**i) Quick to do, that is in the next year or so**

Establish governance, leadership and accountability mechanisms which are requisite to the scale of the challenges and opportunities dementia offers. With this in place, rapid improvement is possible in the next year, bringing some of the benefits outlined in this submission forward and delivering the progress made in other major disease areas through such an approach.

As mentioned in response to question 2, rolling out mandatory dementia training for the health and care workforce would be an inexpensive, easily implementable, and cost-effective action that would also ease pressure on the NHS by enabling better condition management. This is a high priority ask.

Better utilising existing health data and gathering new data to improve the overall data picture for dementia is also a quick fix that would create better accountability and allow for improved targeting of resources to address inequalities in dementia. This is a medium priority ask.

Currently, there is a high level of unwarranted variation in the dementia care pathway. We believe that statutory guidance for dementia care should be developed and enforced to help address this – and that this recommendation could be easily implemented via the 10-Year Health Plan. We have already been collaborating with the NHS and DHSC on a toolkit that could form a major (and quick) part of this puzzle and provide the guidance needed. We also have the structures and expertise to support a rapid roll out to systems. This is a medium priority ask.

**ii) In the middle, that is in the next 2 to 5 years**

We want to see the Government and NHS set bold, ambitious but achievable new targets for dementia diagnosis rates in England, and welcome positive soundings from the Parliamentary Under-Secretary of State for Public Health and Prevention on this.

As well as setting an overarching percentage target for what the national diagnosis rate should be, there should also be additional targets associated with the dementia pathway, including on:

- All diagnoses including dementia type
- Access to imaging
- Access to MDTs (that include dementia expertise)
- Diagnosis happening early in disease progression
- Waiting times
- Diagnosis being accompanied by a management plan
- Patients given access to relevant treatment upon diagnosis.

These targets would help ensure people are getting an early, accurate and high-quality diagnosis and should be underpinned by improvements to data.

Setting new diagnosis rate targets is one of our top policy priorities given the individual and system benefits early and accurate dementia diagnosis can bring.

### **iii) Long term change, that will take more than 5 years**

In the longer term, we need to see long-term investment in dementia diagnosis and treatment, including both existing dementia treatments and the disease-modifying treatments of the future. Alzheimer's Society is currently gathering evidence on the investment required to meet new diagnosis rate targets in the future and would welcome the opportunity to discuss this with both NHS and Ministerial colleagues in more detail, to enable it to be a credible, costed and accurate part of the longer-term plan.

Ends