



Are UK health systems dementia ready?

Comparing dementia policy across the four nations of the UK



FUTURE
HEALTH

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ABOUT FUTURE HEALTH AND THIS REPORT

Future Health is a public policy research centre focused on creating healthier, wealthier people, communities and nations. Future Health publishes regular research papers across its three policy research programmes of health prevention, health technology and the links between improvements in health and economic growth.

This is Future Health's fourth report exploring dementia policy. This report is UK wide and focuses on the readiness of healthcare systems in the four nations to adopt new dementia treatments.

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The statements, findings, conclusions and recommendations in the report are the views of Future Health alone and not of the interviewees. The interviews and research to inform the report were conducted between August 2023 and February 2024. All references in this document were last accessed in February 2024 unless otherwise stated. This research builds from Future Health's previous work on dementia diagnosis.

In May 2022 Future Health published *Levelling up dementia diagnosis: tackling variations in diagnosis rates* in England which examined the impact of the pandemic

on dementia diagnosis rates.¹ This was followed by *Levelling up dementia diagnosis: exploring the impact of population health factors on dementia diagnosis rates* in England in January 2023 which re-modelled dementia prevalence and diagnosis based on a Lancet study of population health risk factors.²

Future Health has also published work on how social care reform could improve dementia care. The report *Stabilise, Energise and Realise*³ – in partnership with the Alzheimer’s Society - is available [here](#).

¹ <https://www.futurehealth-research.com/new-report-reveals-pandemic-impact-on-dementia-diagnosis/>
[accessed February 2024]

² <https://www.futurehealth-research.com/site/wp-content/uploads/2023/01/FH-Dementia-Report-Hi-Res.pdf>

³ <https://www.alzheimers.org.uk/sites/default/files/2021-09/stabilise-energise-realise.pdf>

EXECUTIVE SUMMARY

The potential arrival of new treatments for dementia presents a substantial challenge for health systems in ensuring they are system-ready to improve diagnosis rates, deliver treatment access and provide patients with follow-up and post diagnostic support.

These treatments are already available in other countries and the changes that are needed across the health systems of the UK to deliver them to patients are complex and multi-faceted.⁴

The UK is entering this new era for dementia treatment on the back-foot. Diagnosis rates for dementia have fallen below national targets, national strategies and plans have lapsed, many commissioning and clinical guidelines require a refresh, data is poor and incomplete, and action on the modifiable risk factors for dementia in areas such as smoking and obesity has been too slow or non-existent. Only one in four dementia policies across the four UK nations is up to date and being delivered.

Long standing capital investment and workforce shortages in important roles such as neurology, psychiatry and radiology cannot be quickly addressed, particularly when Government finances are so tight. Whilst diagnostic innovation, including blood biomarker tests, present exciting potential, many patients are struggling to access existing diagnostic tests leaving over 300,000 people with dementia currently undiagnosed. Public understanding of dementia remains mixed, with the condition still seen by a sizeable portion of the population as a social care issue that is an inevitable consequence of old age.

If nothing substantial is done to improve dementia diagnosis rates in the UK then the number of people undiagnosed could rise to over a half a million by 2040.

Across the UK work is now needed to accelerate the changes that can make services dementia ready. Scotland has published a new national dementia strategy and is working on some immediate improvement milestones. The NHS in England has set out its work plans for getting services treatment ready. Northern Ireland has a new Executive in place and Wales is developing a successor to the Dementia Action Plan. At a service level, pockets of innovation have grown-up including Brain Health Clinics and Services aimed at diagnosing dementia earlier. Pilots such as those in Wales have supported improved access to scanners and diagnostics.

These are promising developments but clear accountability and delivery commitments are now needed. Each of the individual UK Governments and health systems should by the end of the year commit to and publish a readiness plan for potential new dementia treatments. This should cover the full pathway from action on prevention and public health to reduce or delay the numbers of dementia cases

⁴ <https://www.alzheimers.org.uk/blog/three-promising-drugs-for-treating-alzheimers-disease-bring-fresh-hope>

overall, to new enhanced co-ordinated NHS dementia services that bring together the right professional mix and blend of local services with tertiary specialisms to support improved diagnostic and treatment access, as well as easily accessible post diagnostic support and follow-up. Levers such as improvements in diagnosis targets and incentives with a track record of delivering improvements should be used to underpin action.

A dementia diagnosis remains one of the most feared by the public. The potential arrival of new treatments creates an opportunity to improve patient outcomes. But to do so will require health systems to be dementia ready quickly. Urgent action is now needed to make them so.

DEMENTIA – STATE OF THE NATIONS: MAIN FINDINGS

The research sought to understand the state of dementia services and policies across each of the four UK nations. This included assessing dementia prevalence, diagnosis rates and the status of national policies designed to improve outcomes for patients. The following were the main findings from the research.

- There are an estimated 850,000 people with dementia in the UK, with an estimated 315,000 undiagnosed
- In England Dorset Integrated Care Board (ICB), Norfolk and Waveney ICB and Lincolnshire ICB all have dementia prevalence rates of 0.97%, the highest recorded, 2.9 times higher than the rate in North East London ICB. Only 15 of 42 (36%) ICBs are currently meeting the national two thirds dementia diagnosis target
- In Wales, Powys Teaching Health Board, the Health Board with the highest prevalence rate has the lowest diagnosis rate. In contrast Cardiff and Vale University Health Board has the lowest prevalence rate and the highest diagnosis rate - 20% higher than in Powys
- In Northern Ireland prevalence rates vary between 0.57% in the Southern Commissioning Group region to 0.79% in the South Eastern Commissioning Group region
- In Scotland regional data on prevalence and diagnosis is incomplete
- Diagnosis rates between nations vary. Neither England nor Wales are meeting their targets for dementia diagnosis. In England the rate is 64.6%, and is recovering from the impact of the pandemic – but is still below the two thirds national target. In Wales the diagnosis rate is 53.9%. This represents an improvement since 2018 – when the Dementia Action Plan was published – but not at the rate of improvement set (3% a year).⁵ Diagnosis rates in Northern Ireland and Scotland are difficult to accurately assess. The rate in Northern Ireland has been estimated to be 62%.⁶ In Scotland estimates vary from 30-65% depending on methodologies and timeframes used⁷
- The number of people with dementia in the UK is set to increase significantly to over 1.5 million by 2040 as a result of an ageing population
- If all four nations were to meet the current England target of two thirds diagnosed by 2040, there would be 490,000 people undiagnosed with dementia – an increase of 175,000 on the numbers today

5 <https://www.gov.wales/sites/default/files/publications/2019-04/dementia-action-plan-for-wales.pdf>

6 <https://www.health-ni.gov.uk/publications/202223-raw-disease-prevalence-trend-data-northern-ireland>; <https://www.alzheimers.org.uk/sites/default/files/2021-12/Dementia%20UK%20prevalence%20estimate%20for%202021%20methodology.pdf>

7 Scotland data is explored more fully in Chapter 2

- It is only if all four nations were to significantly increase dementia diagnosis rates to 80% that there will be a reduction in the numbers of undiagnosed people with dementia overall by 2040 in comparison with today. And even under this scenario, there would still be close to 300,000 people undiagnosed
- The scale of the dementia challenge will require cohesive and robust policy frameworks to deliver what patients need. Whilst dementia is regularly cited as a political priority by ministers across the nations of the UK, national strategies in many cases have lapsed, nominated clinical leadership for dementia is unclear, guidelines, commissioning policies and standards require revision, and diagnosis targets are not being met
- Analysis of eight indicators of policy development and prioritisation across the four countries found that just eight of the 32 (25%) policies assessed are up to date, in operation and being delivered. Nearly 40% of policies require some revision or greater effort to deliver, with a similar number rated as 'red' – either out of date, well off track from being delivered or both
- Whilst innovative service pilots are being delivered locally – such as Brain Health Clinics and Services – to identify and diagnose dementia earlier, national funding has been piecemeal to support them
- No UK country has yet published a full health system readiness plan for new treatments. England appears to be the furthest health system along in preparation; with Northern Ireland perhaps in the most challenged position with no current dementia strategy, assigned ministerial priority, clinical leadership or system readiness plan published

SUMMARY OF RECOMMENDATIONS

- **System readiness plans** – All UK nations should publish national plans for system readiness in relation to dementia treatments by the end of 2024. A UK wide formal cross border collaboration to share good practice on service set-up and design should be established to accelerate processes between nations
- **Investment in diagnostics and services** – The publication of system readiness plans should be supported by Governments through (a) new investments in dementia diagnostics at future national Budgets; (b) funding to support the development of new enhanced dementia services – building and learning from service pilots that have proven effective such as Brain Health Clinics and Brain Health Services working alongside Memory Assessment Services
- **Public health and prevention** – Governments in each nation should establish cross Government public health taskforces aimed at improving healthy life expectancy and the health of the nation. Public health agencies in all nations should run new brain health public campaigns to support stronger preventative action
- **Workforce** – As part of system readiness plans for new treatments Governments and health systems should set out the transparent workforce requirements for delivering new services, including neurologists, psychiatrists and radiologists, and updated care pathways that will need to be commissioned
- **Post diagnostic support** – Health service commissioners should work with primary and community care to develop a local service map for post diagnostic support options for people diagnosed with dementia. This should be co-ordinated with local agencies and voluntary sector partners so a full range of services are available for those living with dementia
- **Targets** – Governments and health systems across the UK should commit to annual improvements in diagnosis rates of at least 1% per year to 2040 to help reduce the numbers of undiagnosed people with dementia
- **Incentives** – Governments should introduce an incentive for dementia screening in primary care – which was successful in the past in improving diagnosis rates – through the Quality and Outcomes Framework to help support improvements in diagnosis rates⁸
- **Digital** – Use new digital tools such as a revised NHS Health Check in England to engage people in preventative activities that can help support improved brain health, as well as tests and tools that can be used to identify the early signs and symptoms of dementia and generate referrals for further investigation and diagnoses

⁸ <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/03/facilitate-tmly-diag-dementia.pdf>

- **Data** – Within two years, all UK nations should commit to publish regular and accurate rates of dementia diagnosis at a regional level. Alongside this, data should be captured and published on (a) the stage and type of diagnosis, (b) measures on the quality of dementia services such as waiting times and patient experience. Dementia prevalence data should also be updated using models that reflect higher risk factors amongst certain populations



**CHAPTER 1 - THE DEMENTIA
CHALLENGE**

The rising impact and costs of dementia in the UK

Dementia is a syndrome associated with an ongoing decline of brain functioning. There are many different causes of dementia, and many different types.

Alzheimer's disease is the most common cause of dementia.⁹ 95% of dementia cases are one of four types: Alzheimer's disease, Vascular dementia, Dementia with Lewy Bodies, and Frontotemporal dementia.¹⁰

The Alzheimer's Society estimates that one in 14 people over the age of 65 have dementia, and the condition affects one in 6 people over 80.¹¹

Across the UK there are nearly 850,000 people with dementia. The latest data from the NHS, shows that 717,596 people have dementia in England and 41,603 in Wales.^{12,13} In Scotland and Northern Ireland estimates from the Alzheimer's Society have put the number of people with dementia in each country at 66,000 and 22,000 respectively.¹⁴

The impact of an ageing population will result in dementia cases around the UK rising by 80% by 2040, with the number of 'severe' cases doubling.¹⁵ Under this modelling dementia prevalence in the UK amongst older people in 2040 will be 8.8% – an increase from 7.1% in 2019.¹⁶

This rise in cases will result in a significant increase in the costs of dementia. A model from the London School of Economics (LSE) predicts cost rising from £34.7 billion to £94.1 billion by 2040.¹⁷ Direct health system costs will increase nearly threefold from £4.7 billion to £12.5 billion.¹⁸

The importance of timely and accurate dementia diagnosis

Early identification of Alzheimer's disease is based on measuring relevant "biomarkers", a distinctive biological indicator that may indicate the presence of the disease.

These biomarkers can be detected using analysis of cerebrospinal fluid (CSF) and positron emission tomography (PET) imaging. The presence of biomarkers – which in the future may be found through a blood test – can help support action in making a timely diagnosis, which is important for patients and their loved ones to access the care and support they need.¹⁹

⁹ <https://www.nhs.uk/conditions/dementia/about-dementia/what-is-dementia/>

¹⁰ <https://www.alzheimers.org.uk/about-dementia/types-dementia/what-is-dementia>

¹¹ <https://www.alzheimers.org.uk/about-dementia/types-dementia/what-is-dementia>

¹² <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/december-2023>

¹³ <https://www.gov.wales/general-medical-services-contract-quality-assurance-and-improvement-framework-interactive-dashboard>

¹⁴ <https://www.alzheimers.org.uk/sites/default/files/2021-12/Dementia%20UK%20prevalence%20estimate%20for%202021%20methodology.pdf>

¹⁵ https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

¹⁶ https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

¹⁷ https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

¹⁸ https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

¹⁹ <https://www.sciencedirect.com/science/article/abs/pii/S1474442221000661?via%3Dihub>

An accurate diagnosis – which identifies the specific disease or diseases causing a person’s dementia – will be increasingly important as new disease modifying treatments become available following marketing authorisation. Disease-modifying treatments will be most effective for people with early stages of disease progression.²⁰ Side effects from the treatments reported in the trials, such as brain swelling and infusion related reactions, mean that it is expected that patients will require ongoing monitoring with MRI scans whilst taking the medication.²¹

These new disease modifying treatments are already available in the United States.²² The availability of the treatments in the UK is currently unclear, and will be based on discussions between the regulators, National Institute for Health and Care Excellence (NICE) / the Scottish Medicines Consortium (SMC), health systems and manufacturers. A recent analysis by NHS England has estimated that between 50,000 to 280,000 people could be eligible for treatment at a cost of £500 million to £1 billion.²³

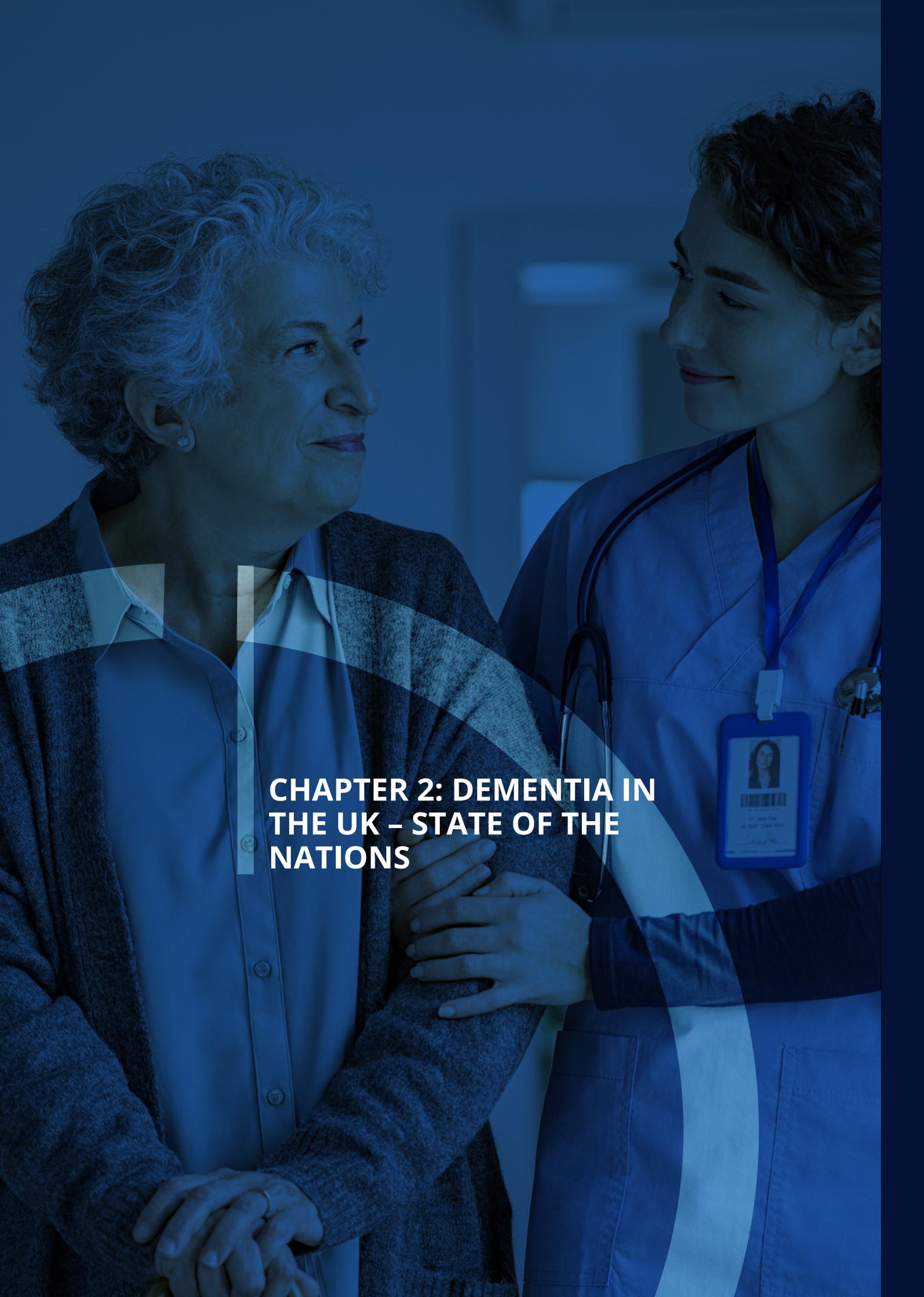
This policy report focuses on the challenges and considerations facing Governments and health systems across the UK in making their health systems ready for potential new dementia treatments and improving patient outcomes.

²⁰ <https://www.alzheimersresearchuk.org/wp-content/uploads/2023/08/Tipping-Point-Report.pdf>

²¹ <https://www.alzheimersresearchuk.org/another-milestone-successful-phase-3-trial-of-alzheimers-drug-donanemab-confirmed/>

²² <https://www.alzheimersresearchuk.org/wp-content/uploads/2023/08/Tipping-Point-Report.pdf>

²³ <https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/>



**CHAPTER 2: DEMENTIA IN
THE UK – STATE OF THE
NATIONS**

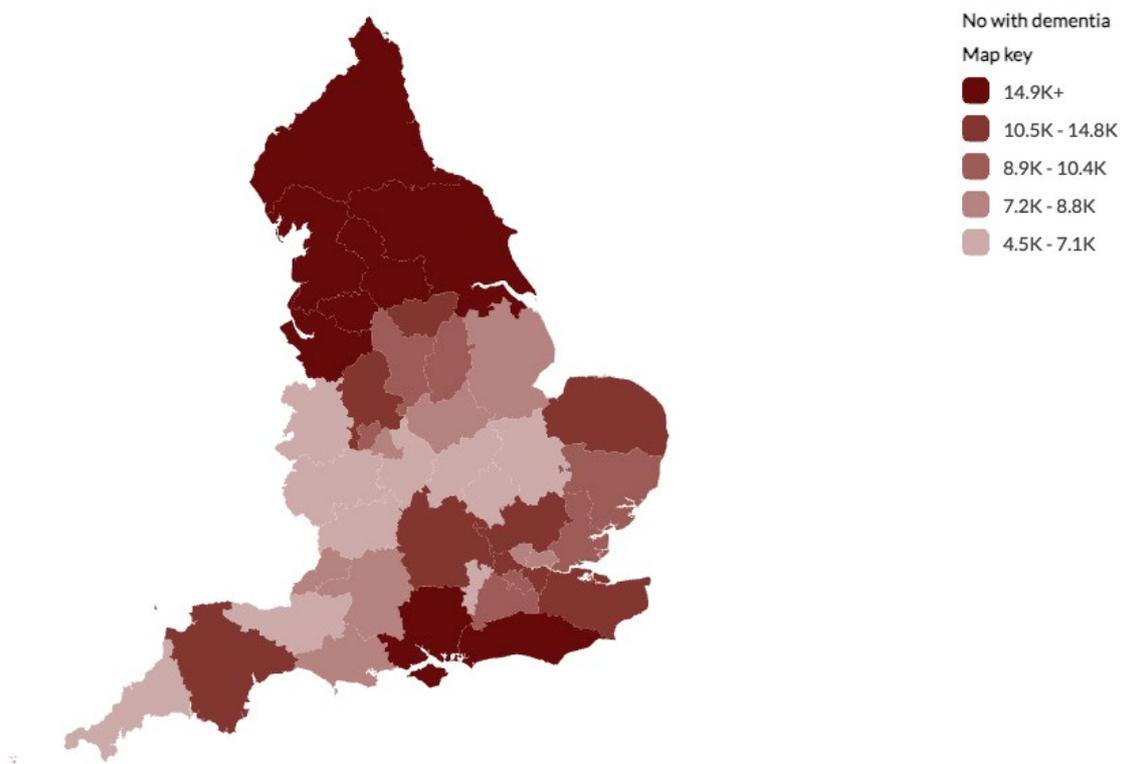
Across the four nations of the UK the numbers of dementia cases continues to rise and there are challenges for patients in receiving a timely and accurate diagnosis.

England

Data from the NHS in England estimates that there are 717,596 people with dementia in England.²⁴ The region with the highest estimated number is the Midlands with over 140,000 people. London has the lowest estimated number, with an estimated 74,361 people with dementia.

As part of the Health and Social Care Act 2022, the NHS in England was divided into 42 Integrated Care Boards (ICBs). The size of these Boards varies depending on their geography, the largest are the North East and North Cumbria ICB, and Greater Manchester ICB covering populations of over 3.1 million. The smallest is Shropshire, Telford and Wrekin ICB covering a population of just over 500,000.²⁵ When looking at the overall estimated numbers with dementia, the North East and North Cumbria ICB has a population of over 40,000 people with dementia, whilst Shropshire, Telford and Wrekin ICB has a population of less than 25% of this (7,743).

Figure 1: Estimated number of people with dementia by ICB



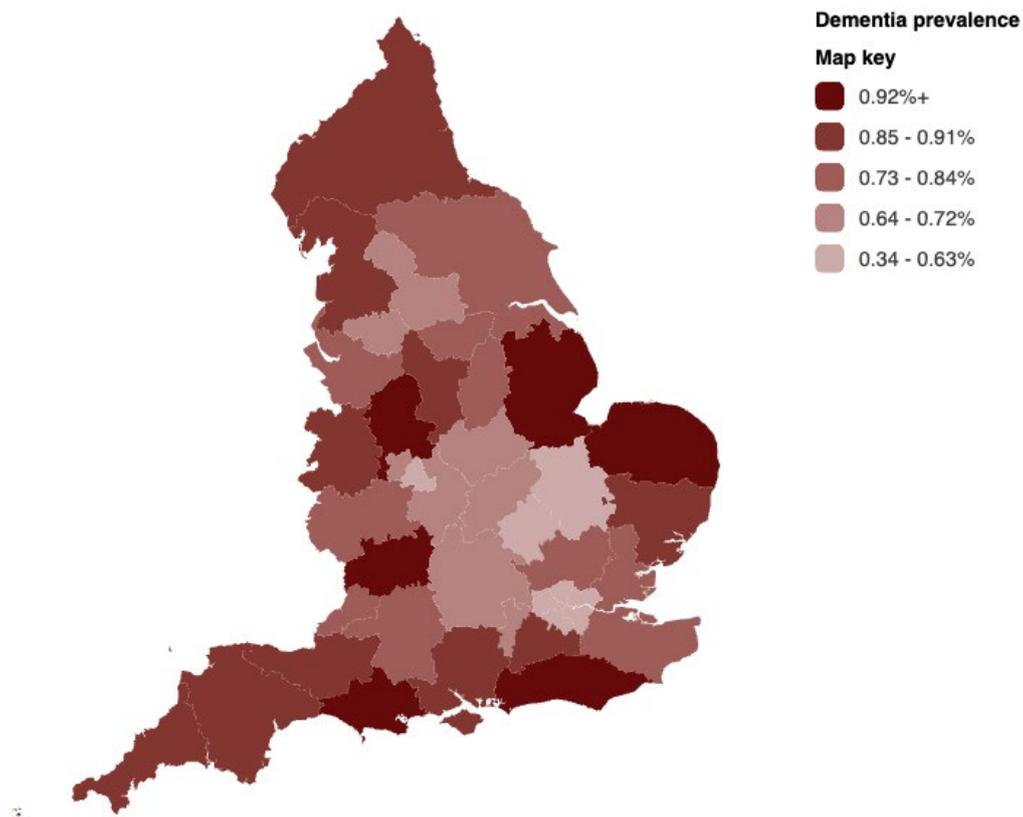
²⁴ <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/december-2023> [accessed on 1st February 2024]

²⁵ <https://www.england.nhs.uk/publication/allocation-of-resources-2022-23/>

The NHS Quality and Outcomes Framework (QOF) supports GPs in maintaining a register of people with dementia in their area.²⁶ Figure 2 maps the variation in rates of dementia across ICBs using the QOF. All five London ICBs are in the bottom six overall for dementia prevalence along with Birmingham and Solihull ICB. All have rates of dementia below 0.6% of the population. North East London ICB has the lowest dementia prevalence rate of 0.34%.

The ICBs with higher rates of dementia are by contrast more rural and coastal. Dorset ICB, Norfolk and Waveney ICB and Lincolnshire ICB all have prevalence rates of 0.97%, the highest recorded, 2.9 times higher than the rate in North East London ICB. The ICBs with the highest rates of dementia are in the South West, East of England and Midlands. There are no ICBs from the North East, London or North West in the upper quintile.

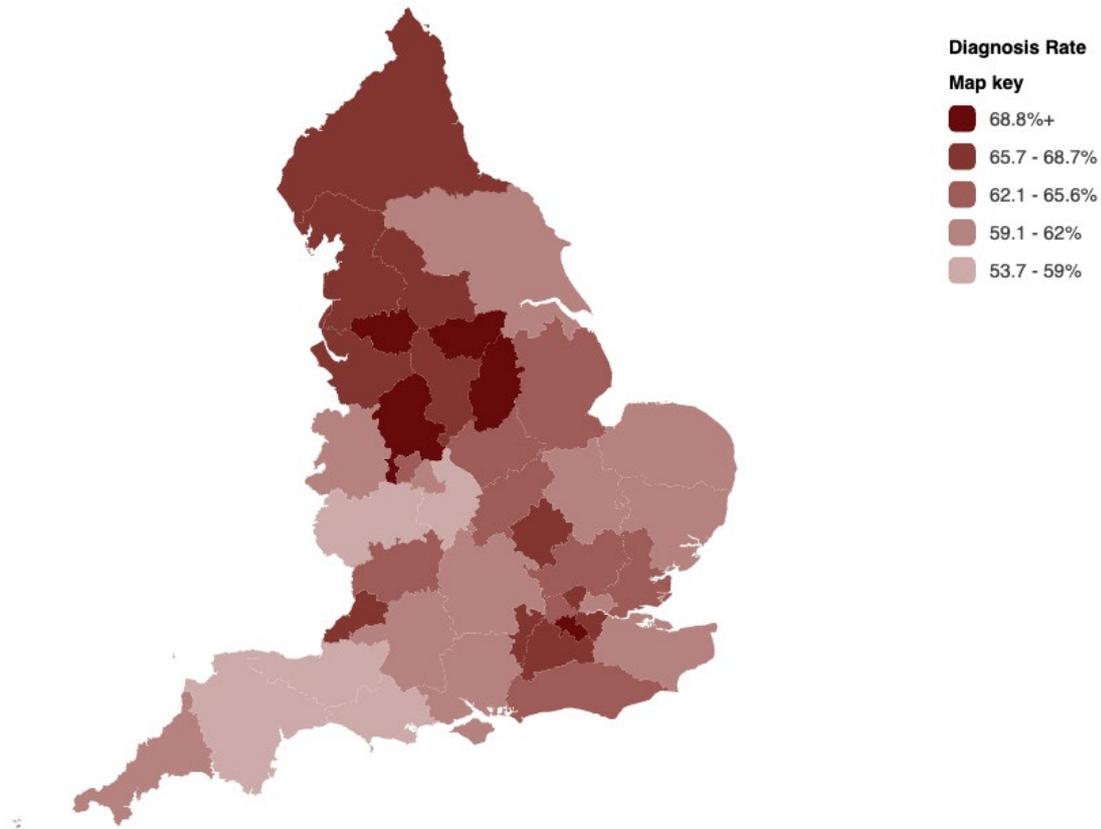
Figure 2: Dementia prevalence rate by ICB



²⁶ <https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2022-23> [accessed on 1st February 2024]

Not everyone with dementia receives a diagnosis. Data from NHS England calculates the diagnosis rate by each ICB.²⁷ Nationally there is a target to diagnosis two thirds of people with dementia. Nationally at the end of 2023, the overall performance of the NHS in England stood just below this at 64.6%. The rate has recovered from a low of 61.8% in January 2023.²⁸

Figure 3: Dementia diagnosis rate by ICB



Across ICBs there is widespread variation in the dementia diagnosis rate.²⁹ Only 15 of 42 (36%) ICBs are meeting the two thirds dementia diagnosis target. 10 ICBs record a rate of below 60%. Herefordshire ICB has the lowest rate nationally of 53.7%, followed by Somerset ICB with 55.3% and Dorest ICB with 56.5%. Five of the bottom ten ICBs for diagnosis are in the South West (Somerset ICB, Dorset ICB, Bath, North East Somerset, Swindon and Wiltshire ICB, Devon ICB and Cornwall ICB).

By contrast five ICBs (Nottingham and Nottinghamshire ICB, Staffordshire and Stoke on Trent ICB, South West London ICB, Greater Manchester ICB and South Yorkshire ICB) have diagnosis rates above 70%.

²⁷ <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/december-2023>

²⁸ <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data>

²⁹ <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/december-2023> [accessed on 1st February 2024]

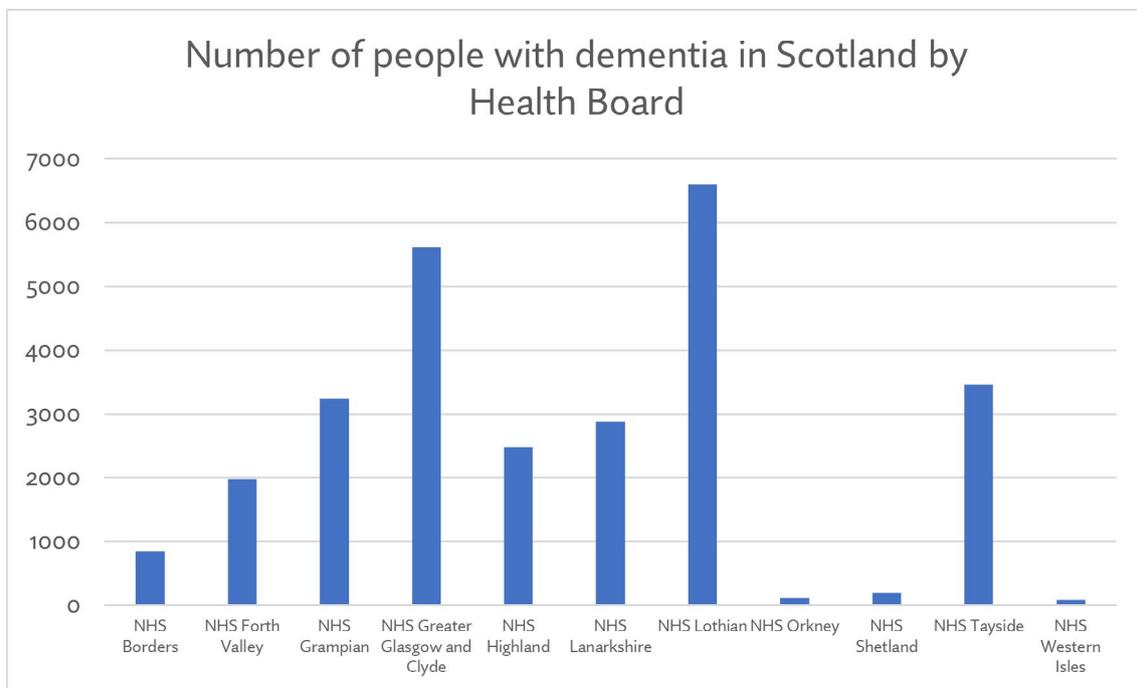
Scotland

The Scottish Government has estimated that 90,000 people in Scotland have dementia.³⁰ However this is based on prevalence data from Europe (Eurocode) being applied to the Scottish population and not on Scotland based studies. A separate, more recent analysis by the Alzheimer’s Society – using excess mortality – has estimated that the figure is 66,000.³¹

The data on the numbers diagnosed is incomplete. Data from the Scottish Primary Care Information Resource recorded 27,466 people with dementia in Scotland.³²

However the primary care data does not include information from all GP practices and three health boards (Ayrshire & Arran, Fife and Dumfries and Galloway) are not included.

Figure 4: Number of people with dementia by Health Board in Scotland



When the 27,466 dementia cases are applied to the Government’s 90,000 overall estimated figure, this results in a diagnosis rate of just 30.5%. If the Alzheimer’s Society estimate of 66,000 people with dementia is used then the rate improves to 41.6%, but the picture is incomplete. A previous study by the Alzheimer’s Society in 2013 had put the diagnosis rate in Scotland at 64.4%.³³

³⁰ <https://www.gov.scot/policies/mental-health/dementia/>

³¹ <https://www.alzheimers.org.uk/sites/default/files/2021-12/Dementia%20UK%20prevalence%20estimate%20for%202021%20methodology.pdf>

³² <https://publichealthscotland.scot/publications/general-practice-disease-prevalence-data-visualisation/general-practice-disease-prevalence-visualisation-27-june-2023/>

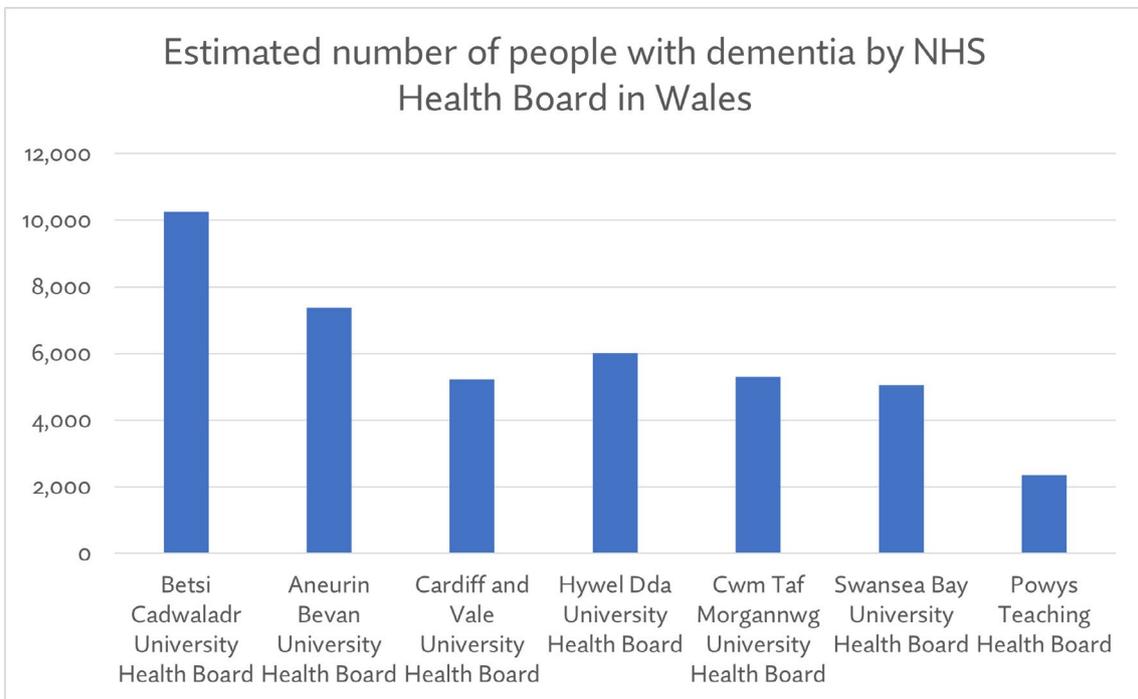
³³ <https://www.thedetail.tv/articles/disparity-in-dementia-diagnosis-across-northern-ireland>

The Scottish Government’s new dementia strategy has identified addressing these data issues as a priority to ensure prevalence and diagnosis rates are accurately captured.³⁴³⁵

Wales

There are an estimated 41,603 people living with dementia in Wales.³⁶ Over 25% of the estimated people with dementia are in Betsi Cadwaladr University Health Board (10,255). In contrast Powys Teaching Health Board has the lowest estimated number (2,358).

Figure 5: Estimated number of people with dementia by NHS Health Board in Wales



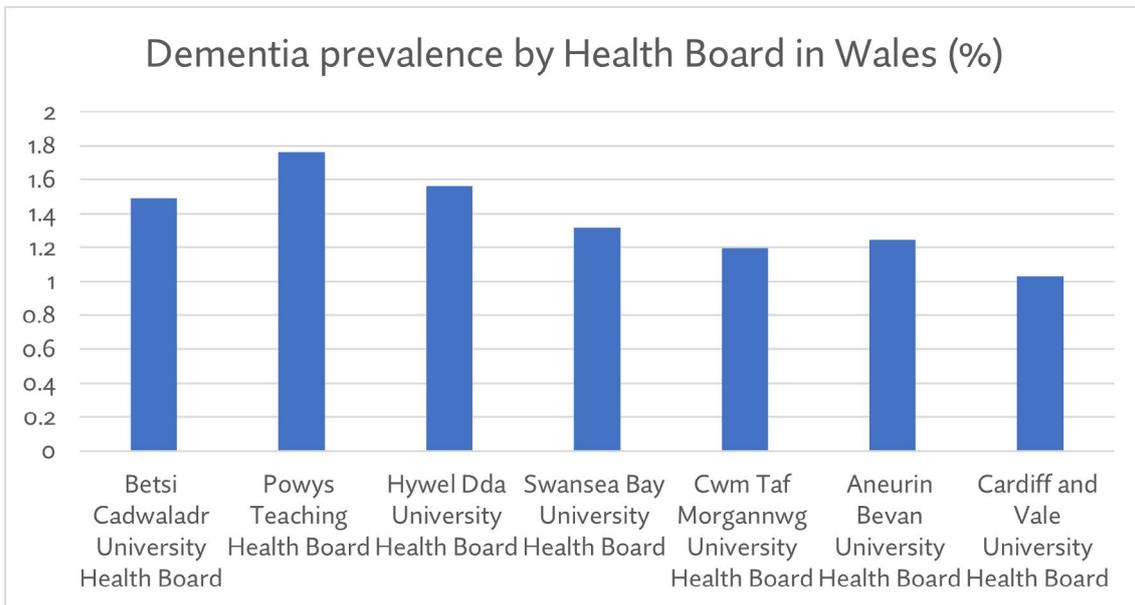
The highest estimated dementia prevalence rate is recorded in Powys Teaching Health Board (1.8%). This is nearly double the rate of the Cardiff and Vale University Health Board (1.0%) which has the lowest prevalence rate by Health Board.

³⁴ <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2023/05/new-dementia-strategy-scotland-everyones-story/documents/dementia-scotland-everyones-story/dementia-scotland-everyones-story/govscot%3Adocument/dementia-scotland-everyones-story.pdf>

³⁵ <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2024/02/new-dementia-strategy-scotland-initial-2-year-delivery-plan-2024-2026/documents/dementia-scotland-everyones-story-delivery-plan-2024-2026/dementia-scotland-everyones-story-delivery-plan-2024-2026/govscot%3Adocument/dementia-scotland-everyones-story-delivery-plan-2024-2026.pdf>

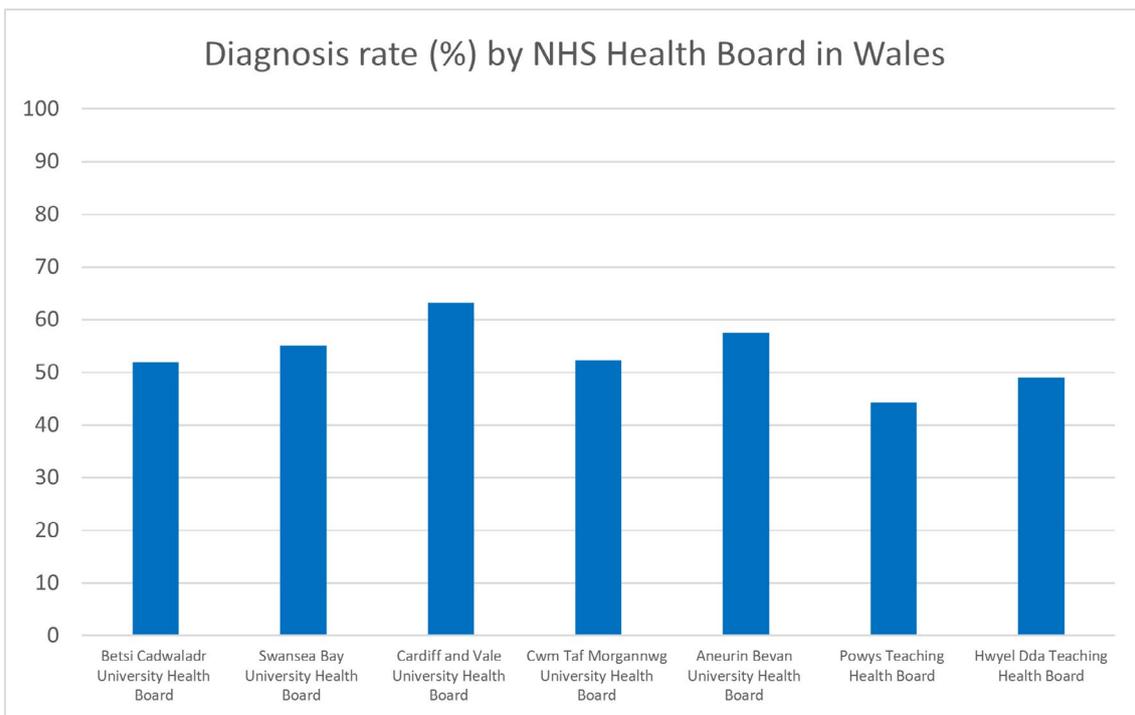
³⁶ <https://www.gov.wales/general-medical-services-contract-quality-assurance-and-improvement-framework-interactive-dashboard>

Figure 6: Dementia prevalence by Health Board in Wales (%)



Across Wales the dementia diagnosis rate is 53.9%.³⁷ Cardiff and Vale University Health Board records the highest rate at 65.3%. This is over 20% higher than Powys Teaching Board, which has the lowest rate (44.3%). Over half of the seven health boards in Wales (Powys, Hywel Dda, Betsi Cadwaladr and Cwm Taf Morgannwg) record diagnosis rates below the lowest ICB in England (Herefordshire) of 53.7%.

Figure 7: Diagnosis rate (%) by NHS Health Board in Wales

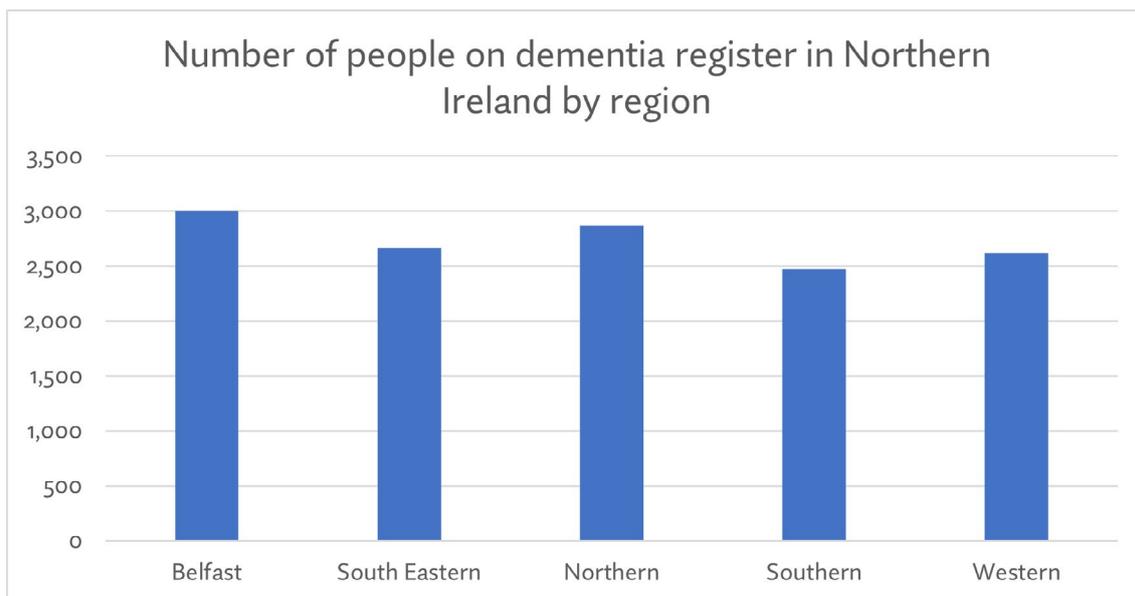


³⁷ <https://www.gov.wales/general-medical-services-contract-quality-assurance-and-improvement-framework-interactive-dashboard>

Northern Ireland

There are 13,625 people on the dementia register in Northern Ireland.³⁸ The largest number is found within the Belfast Commissioning Group region (3,002). The smallest number of people is recorded in the Southern Commissioning Group region (2,472).

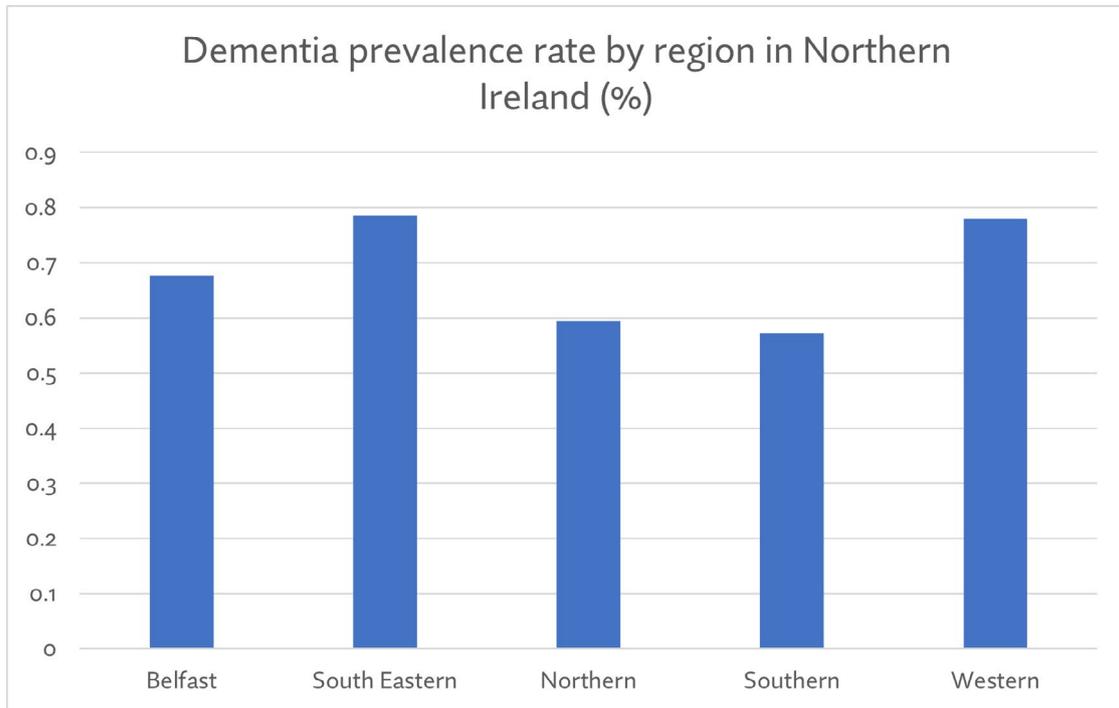
Figure 8: Number of people on dementia register in Northern Ireland by region



Dementia prevalence rates vary between 0.57% in the Southern Commissioning Group region to 0.79% in the South Eastern Commissioning Group region.

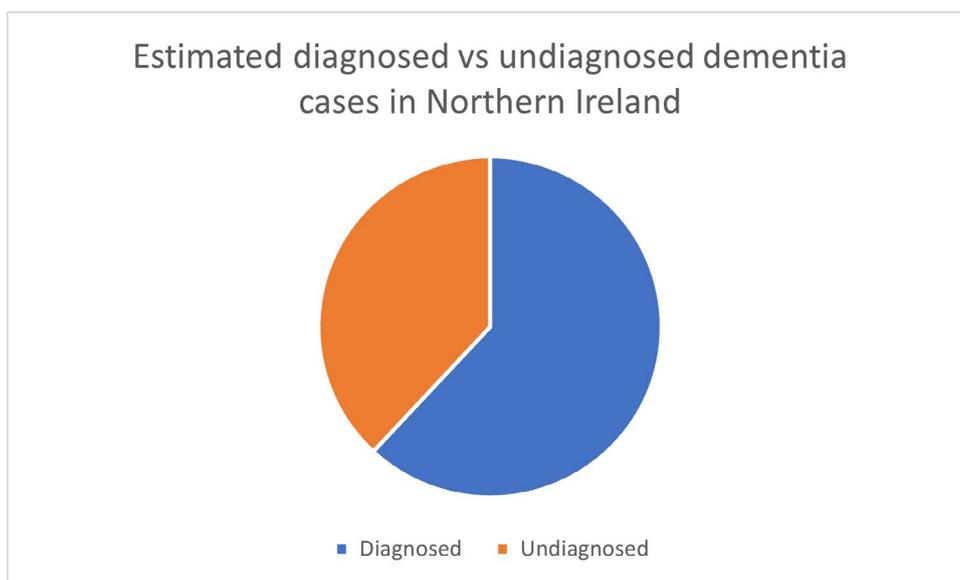
³⁸ <https://www.health-ni.gov.uk/publications/202223-raw-disease-prevalence-trend-data-northern-ireland>

Figure 9: Dementia prevalence rate by region in Northern Ireland (%)



Northern Ireland does not publish regular data on dementia diagnosis rates. The Alzheimer’s Society has estimated that there are 22,000 people in Northern Ireland with dementia.³⁹ If this overall number is used, the estimated diagnosis rate for Northern Ireland is 62%.

Figure 10: Estimated diagnosed vs undiagnosed dementia cases in Northern Ireland



³⁹ <https://www.alzheimers.org.uk/sites/default/files/2021-12/Dementia%20UK%20prevalence%20estimate%20for%202021%20methodology.pdf>

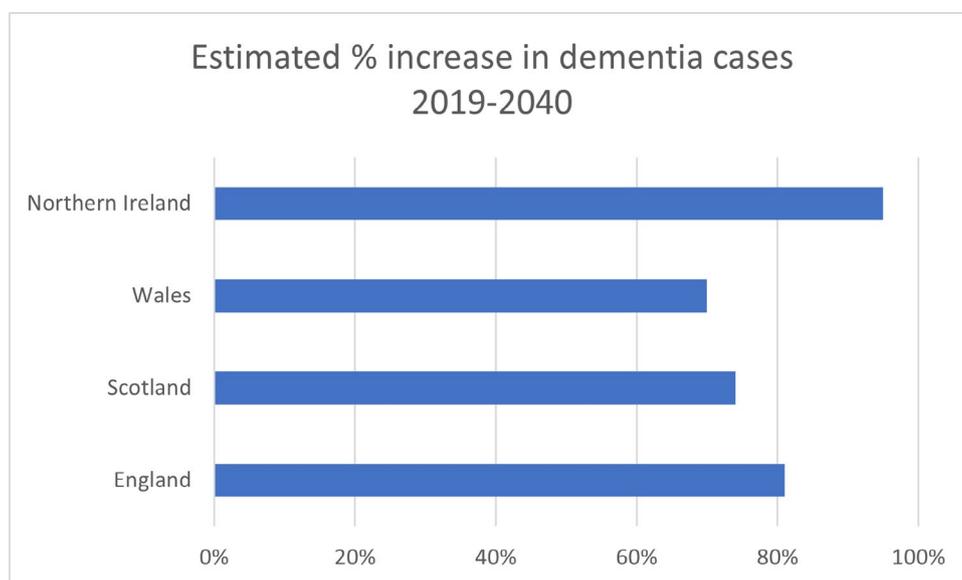
Looking ahead: the growing dementia challenge

An ageing population is set to see the rates of dementia increase significantly over the next two decades.

By 2040, 81% more people in England will be diagnosed than in 2019. Across the four nations, Northern Ireland will see the greatest increase of 95%. Scotland will see a 74% rise, whilst Wales is expected to see a 70% increase.⁴⁰

According to the LSE model this will see the number of people with dementia rise by over 700,000 by 2040.⁴¹

Figure 11: Estimated % increase in dementia cases 2019-2040



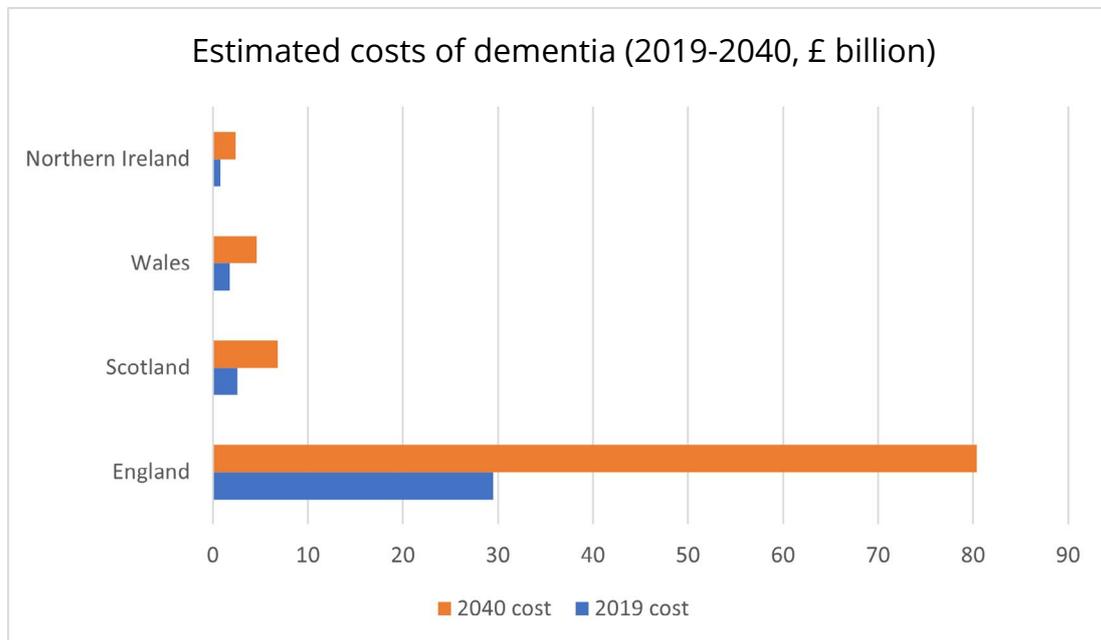
Each nation will see a sharp increase in the associated costs related to dementia. Northern Ireland will see costs treble from £0.8 billion to £2.4 billion. In England costs are set to rise by over £50 billion. Scotland will see an increase of £4.2 billion from £2.6 billion to £6.8 billion, and in Wales costs will rise from £1.8 billion to £4.6 billion.⁴²

⁴⁰ https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

⁴¹ https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

⁴² https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

Figure 12: Estimated increases in costs of dementia by 2040





**CHAPTER 3: DEMENTIA
READY POLICY?**

Against a backdrop of rising dementia cases, costs and the potential arrival of new treatments, Future Health undertook a comparison of the different policy responses from each of the four nations of the UK.

Governments and health systems were assessed in their approaches to prioritising dementia within national policy against the following criteria:

- The presence of a national strategy and plan for dementia
- Clear national ministerial and clinical accountability
- Performance on diagnosis rates
- Data collection and publication
- Up to date clinical guidelines
- Up to date commissioning policies
- A readiness plan for delivering potential new treatments to patients

Countries were given a Red, Amber, Green (RAG) rating against each of the criteria, using the following methodology:

- Red – Either there is no relevant policy in place or where a policy does exist it was published over five years ago and requires revision given environmental developments.⁴³ If the criteria being assessed was a performance measure (e.g. diagnosis rates), then red was attributed when performance was assessed to be well below expectations
- Amber – Either (a) There is a policy in place but it will likely need revision shortly as it was published between two and five years ago or (b) There was a relevant policy in place until recently but it has expired and requires updating or (c) The policy is drafted but not finalised. If the criteria being assessed was a performance measure (e.g. diagnosis rates), then amber was attributed when performance was assessed to be slightly below expectations
- Green – There is a policy in place and the policy has been revised and updated in the last 2 years. If the criteria being assessed was a performance measure (e.g. diagnosis rates), then green was attributed when performance was assessed to be meeting or exceeding expectations

⁴³ It is important to note that a 'red' rating does not mean no work is underway or planned. Rather it indicates that current approaches are out of date and require updating

Question	England	Scotland	Wales	Northern Ireland
Does the country have a current national strategy or plan for dementia?	<p>The Prime Minister’s Challenge on dementia ran until 2020.⁴⁴</p> <p>Dementia has been named as one of the six priority areas in the forthcoming Major Conditions Strategy.⁴⁵</p>	<p>The Scottish Government published a dementia strategy in 2023.⁴⁶ A two year delivery plan for the strategy was published in February 2024.⁴⁷</p> <p>National dementia strategies were published 2010, 2013, 2017.⁴⁸</p>	<p>The most recent strategy, the Dementia Action Plan for Wales, ran until 2022.⁴⁹</p> <p>A companion document to the action plan (2021) was produced to highlight the support available to people with dementia and their families during the pandemic.⁵⁰</p> <p>The Welsh Government has commissioned an independent evaluation of the Dementia Action Plan.⁵¹</p>	<p>There is no current national dementia strategy. The most recent Government dementia strategy was in 2011.⁵²</p>

⁴⁴ <https://assets.publishing.service.gov.uk/media/5a80d3ce40f0b62302695b8c/pm-dementia2020.pdf>

⁴⁵ <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2>

⁴⁶ <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2023/05/new-dementia-strategy-scotland-everyones-story/documents/dementia-scotland-everyones-story/dementia-scotland-everyones-story/govscot%3Adocument/dementia-scotland-everyones-story.pdf>

⁴⁷ <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2024/02/new-dementia-strategy-scotland-initial-2-year-delivery-plan-2024-2026/documents/dementia-scotland-everyones-story-delivery-plan-2024-2026/dementia-scotland-everyones-story-delivery-plan-2024-2026/govscot%3Adocument/dementia-scotland-everyones-story-delivery-plan-2024-2026.pdf>

⁴⁸ <https://www.alzscot.org/our-work/campaigning-for-change/scotlands-national-dementia-strategy>

⁴⁹ <https://www.gov.wales/sites/default/files/publications/2019-04/dementia-action-plan-for-wales.pdf>

⁵⁰ <https://www.gov.wales/dementia-action-plan-strengthening-provision-response-covid-19-html>

⁵¹ <https://research.senedd.wales/research-articles/planning-ahead-dementia-services-in-wales/#:~:text=The%20Welsh%20Government%20has%20commissioned,care%20and%20support%20in%20Wales>

⁵² <https://www.health-ni.gov.uk/publications/improving-dementia-services-northern-ireland-regional-strategy>

Question	England	Scotland	Wales	Northern Ireland
Does the country have dementia as a Ministerial priority?	Dementia is a named priority of the current Care Minister, Helen Whately MP. ⁵³	Dementia is a named ministerial priority for Maree Todd, MSP Minister for Social Care, Mental Wellbeing and Sport. ⁵⁴	Dementia is a named Ministerial priority for Eluned Morgan, Minister for Health and Social Services. ⁵⁵	The Northern Ireland Executive has recently been re-established. Robin Swann has been named as Health Minister but there is no reference to dementia as a Ministerial priority. ⁵⁶
Does the country have a dedicated national medical lead for dementia?	The NHS in England does have a National Clinical Director for Dementia. It is currently recruiting for a new clinical leader. ⁵⁷	No	No	No
Is the Government/health system meeting targets for dementia diagnosis?	The current target is for two thirds of people to be diagnosed. The most recent data recorded a diagnosis rate of 64.6%. This has improved since early 2023.	Data issues make it difficult to accurately determine Scotland's dementia diagnosis rate. The diagnosis figure in the public domain is widely believed to be well below the actual figure. ⁵⁸	The Dementia Action Plan noted in 2018 that the dementia diagnosis rate was 53% and called on health boards in Wales to raise it by 3% a year. The current diagnosis rate is 53.9% , meaning the target has been missed. ⁵⁹	Unclear as data issues make an assessment of the diagnosis rate difficult. The estimated rate is 62%, placing Northern Ireland below England but ahead of Wales.

⁵³ <https://www.gov.uk/government/people/helen-whately>

⁵⁴ <https://www.gov.scot/about/who-runs-government/cabinet-and-ministers/minister-for-social-care-mental-wellbeing-and-sport/>

⁵⁵ <https://www.gov.wales/eluned-morgan-ms>

⁵⁶ <https://www.health-ni.gov.uk/profiles/minister-health>

⁵⁷ <https://www.hsj.co.uk/acute-care/nhse-announces-eight-new-directors/7036373.article>

⁵⁸ <https://dementiastatistics.org/about-dementia/diagnosis/>

⁵⁹ <https://www.gov.wales/sites/default/files/publications/2019-04/dementia-action-plan-for-wales.pdf>

Question	England	Scotland	Wales	Northern Ireland
Does the Government/ NHS publish regular data on dementia prevalence and diagnosis?	The NHS in England publishes monthly regional data on dementia at ICB level. ⁶⁰ NHS England has also developed a dashboard to support commissioners and providers in assessing their dementia services performance - although this is not in the public domain. ⁶¹	The Scottish Government publishes incomplete data annually on the number of people on the dementia register. Diagnosis rates are difficult to accurately calculate. The recent Dementia Strategy and two year implementation plan commits to improve data collection and publication. ⁶²	The Welsh Government publishes annual data on dementia prevalence and diagnosis but the most recent data available is from 2021-22. ⁶³	The Northern Ireland health system publishes annual data on the number of people on the dementia register. Diagnosis data is not published. ⁶⁴
Are up to date clinical guidelines in place for dementia care?	The current NICE dementia guideline is from 2018 ⁶⁵ and the Quality Standard from 2019. ⁶⁶	Clinical guidelines were published in November 2023. ⁶⁷	The current NICE dementia guideline is from 2018 and the Quality Standard from 2019. ⁶⁸	The current NICE dementia guideline is from 2018 and the Quality Standard from 2019. ⁶⁹

⁶⁰ <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data>

⁶¹ <https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/>

⁶² <https://www.gov.scot/publications/new-dementia-strategy-scotland-summary/#:~:text=This%20includes%3A,live%20their%20best%20possible%20life>

⁶³ <https://www.gov.wales/general-medical-services-contract-quality-assurance-and-improvement-framework-interactive-dashboard>

⁶⁴ <https://www.health-ni.gov.uk/publications/202223-raw-disease-prevalence-trend-data-northern-ireland>

⁶⁵ <https://www.nice.org.uk/guidance/ng97>

⁶⁶ <https://www.nice.org.uk/guidance/qs184>

⁶⁷ <https://www.sign.ac.uk/our-guidelines/assessment-diagnosis-care-and-support-for-people-with-dementia-and-their-carers/>

⁶⁸ <https://www.nice.org.uk/guidance/ng97>; <https://www.nice.org.uk/guidance/qs184>

⁶⁹ <https://www.nice.org.uk/guidance/ng97>; <https://www.nice.org.uk/guidance/qs184>

Question	England	Scotland	Wales	Northern Ireland
Are up to date commissioning guidelines in place for dementia services?	The existing commissioning guideline for dementia is from 2016. ⁷⁰ An implementation guide was published in 2018. ⁷¹ A model pathway for dementia based on each component of the dementia well pathway is being developed. ⁷²	A new framework for post diagnostic support was published in 2021. ⁷³ Care standards for dementia were published in 2011. ⁷⁴	The Welsh Government updated the standards for dementia care pathway in 2021. ⁷⁵ A separate Dementia Friendly Hospital Charter was published in 2022. ⁷⁶	A regional dementia care pathway was published in 2018. ⁷⁷
Has a system readiness plan been published setting out how health systems will deliver new treatments to patients?	NHS England has established a team to plan for the arrival of new treatments. ⁷⁸ In January 2024 an NHS England Board paper was published setting out the work underway. ⁷⁹	No	No	No

⁷⁰ <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>

⁷¹ https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf?sfvrsn=cdef189d_8

⁷² <https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/>

⁷³ <https://ihub.scot/media/8976/a-quality-improvement-framework-for-pds-in-scotland-2nd-edition.pdf>

⁷⁴ https://www.sehd.scot.nhs.uk/mels/CEL2011_20.pdf

⁷⁵ <https://abuhb.nhs.wales/files/dementia/dementia-standards-pathway-document-english-finalpdf/>

⁷⁶ <https://phw.nhs.wales/services-and-teams/improvement-cymru/our-work/mental-health/dementia-care/dementia-friendly-hospital-charter-for-wales/>

⁷⁷ <https://www.alzint.org/u/Northern-Ireland-Dementia-Care-Pathway-Book.pdf>

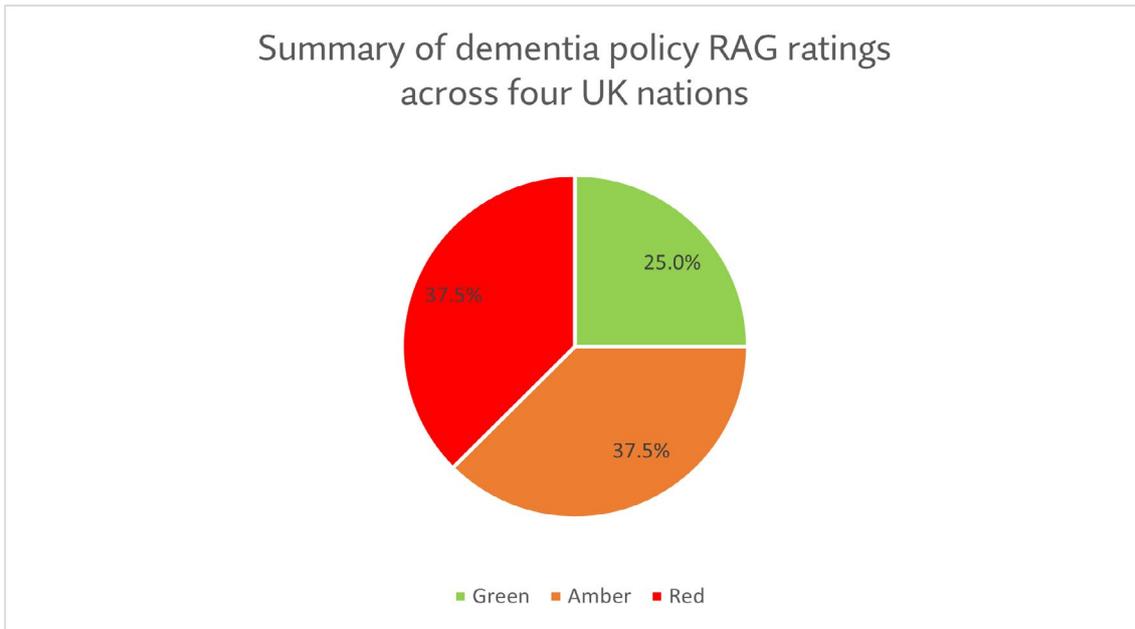
⁷⁸ <https://www.england.nhs.uk/blog/preparing-for-a-new-chapter-disease-modifying-treatments-for-early-alzheimers-disease/>

⁷⁹ <https://www.england.nhs.uk/wp-content/uploads/2024/01/item-9-annex-b-small.png>

Analysis

Across the 32 recorded indicators in the eight criteria assessed, just eight (25%) are recorded green. There were 12 amber and 12 red indicators recorded (37.5% respectively).

Figure 13: Summary of dementia policy RAG ratings across four UK nations



Three of the eight green indicators recorded overall are in England. England had no red indicators and NHS England has recently published an update on its progress in developing commissioning policies and system readiness for new treatments.⁸⁰

Scotland also has three green indicators recorded. Scotland published a new national dementia strategy and clinical guidelines in 2023 and dementia is a named ministerial priority.

Wales has two green indicators recorded. Dementia is a named ministerial priority and up to date commissioning guidelines and hospital standards in place.

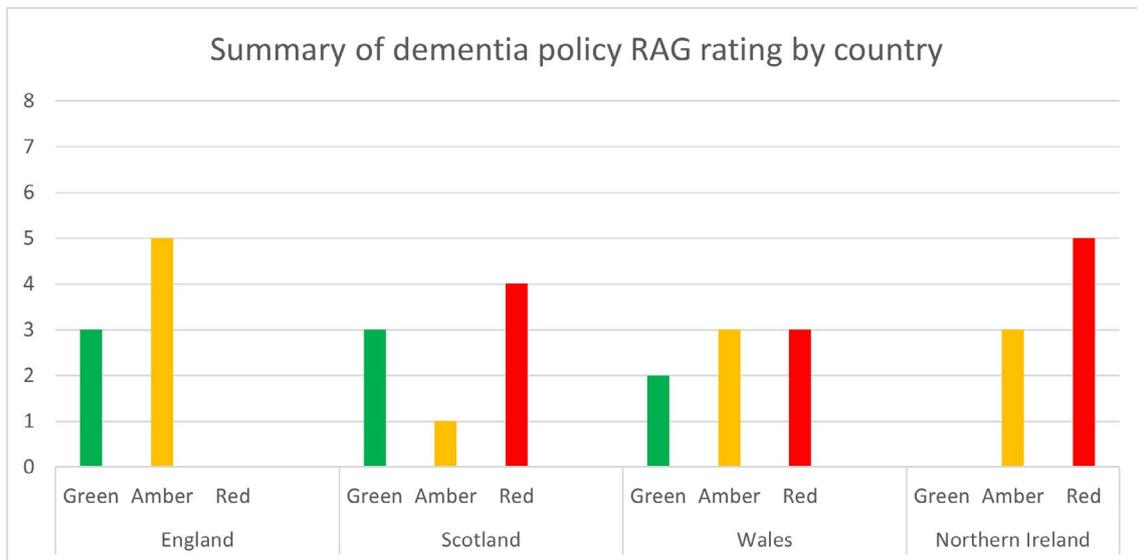
Northern Ireland has no green indicators recorded and red indicators covering national leadership with no current dementia strategy, ministerial prioritisation, clinical leadership or system readiness plan published.

Scotland has four indicators marked red covering its diagnosis rate, data collection and publication and system readiness plan for new treatments. The recent dementia strategy has committed action in these areas which should see new progress made.⁸¹ Scotland along with all three devolved nations does not have a dedicated national clinical lead for dementia. Wales has three red indicators covering its diagnosis rate, lack of dedicated national clinical leadership and absence of a system readiness plan for new treatments.

⁸⁰ <https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/>

⁸¹ <https://www.gov.scot/publications/new-dementia-strategy-scotland-initial-2-year-delivery-plan-2024-2026/>

Figure 14: Summary of dementia policy RAG rating by country



Summary

- *Dementia is a political priority but national strategies have in many cases lapsed* – Three of the four nations have dementia as a named ministerial priority. But while all have at some point published a national strategy – most are now out of date (with the exception of Scotland who have recently published a 10-year vision). England’s strategy has lapsed and the Government is instead progressing with dementia as a priority within the forthcoming Major Conditions Strategy. Wales is evaluating its previous strategy to determine the best next steps. Northern Ireland’s most recent dementia strategy was published in 2011
- *Health system dementia policy requires revision* – In a number of areas health system policies relating to dementia such as commissioning and clinical guidelines require updating. Whilst the NHS in England has a National Clinical Director, there are not equivalent roles in the devolved nations.⁸² NICE quality standards and guidelines are several years old and will require updating to support the delivery of high quality clinical care and practice. England’s commissioning pathway is now several years old, but work is underway to revise this based on advances in dementia treatment. Wales has recently updated its dementia care pathway and produced guidance on hospital standards for people with dementia
- *Diagnosis rates are below Government targets* – No country is meeting its dementia diagnosis targets with considerable variation in regional diagnosis rates. In England rates are improving towards the two thirds targets. In Wales the diagnosis rate remains below 55% and commitments in the Dementia Action

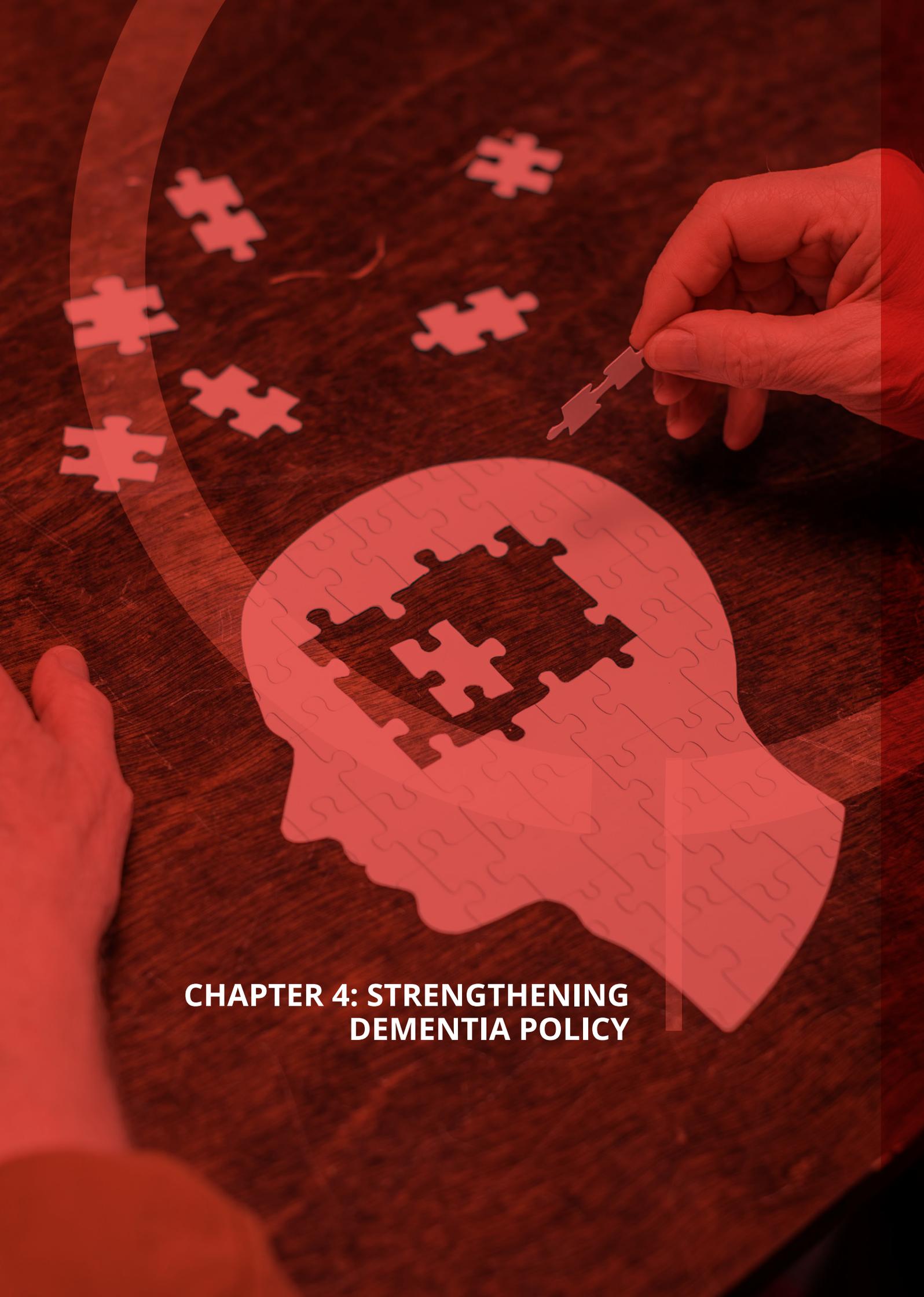
⁸² Though it is important to note that recruitment to the post in England at the time of publication is being advertised.

Plan have not been realised

- *Important dementia data is not regularly published* – Whilst England publishes regular prevalence and diagnosis rate data, data in Wales is not published as regularly. Northern Ireland publishes prevalence data, but accurate diagnosis data is not available. Scotland's data is patchy making it difficult to assess the full national picture. National audits of services provide some insights on service quality in England and Wales but are not comprehensive
- *Health system readiness plans have yet to be published* – None of the four nations has yet put in place a system readiness plan for potential new treatments. There is a team in place in NHS England tasked with developing a plan for new treatments and an update to the NHS England Board was delivered in January 2024⁸³⁸⁴

⁸³ <https://www.england.nhs.uk/blog/preparing-for-a-new-chapter-disease-modifying-treatments-for-early-alzheimers-disease>

⁸⁴ <https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/>



**CHAPTER 4: STRENGTHENING
DEMENTIA POLICY**

With the number of dementia cases set to increase significantly, each of the four nations of the UK will need to ensure dementia is suitably prioritised in policy making and that a strong policy framework is in place that can support health systems in meeting patient needs.

As set out in the previous chapter all countries across the UK have gaps or areas where policy requires updating to meet these challenges. The potential arrival of new disease modifying treatments is an opportunity to improve outcomes for patients, whilst also creating a need for re-designing pathways of care and ensuring diagnostic capacity and post diagnostic support services are scaled to meet demand.

The following sets out a framework for how Governments and health systems should strengthen their approach to meeting the dementia challenge.

New public engagement on dementia and brain health

Analysis by ARUK has predicted that if current trends continue one in two people will be directly affected by dementia, either by developing the condition, caring for someone with the condition or both.⁸⁵ Dementia remains a significant public concern with 49% of people saying that it is the health condition that they fear most.⁸⁶

Recent public research has found that attitudes and understanding of dementia across the population however remain mixed. 35% of people agree that dementia is an inevitable part of ageing and one in five disagree that the condition is a cause of death. This is despite dementia being the leading cause of death in the UK. Younger people (18-24) are more likely to not see dementia as a cause of death.⁸⁷

Stigma remains a challenge in people coming forward for support. This is particularly the case amongst ethnic minorities who were 7% more likely than white respondents to ARUK's survey to agree with the statement 'I would find it hard to talk to someone who has dementia'.⁸⁸ Diagnosis rates amongst Asian and black ethnic groups have been found to be lower than white ethnic groups.⁸⁹

Just 36% of people think it is possible to reduce the risk of dementia despite strong evidence that taking steps to protect your brain throughout life can preserve your cognitive abilities for longer and help protect against dementia.⁹⁰⁹¹ A 2020 study in the Lancet identified twelve modifiable risk factors for dementia set out in Box 1 below.

⁸⁵ <https://www.dementiastatistics.org/attitudes/Dementia%20Attitudes%20Monitor%20-%20Wave%203%20report.pdf>

⁸⁶ <https://www.dementiastatistics.org/attitudes/Dementia%20Attitudes%20Monitor%20-%20Wave%203%20report.pdf>

⁸⁷ <https://www.dementiastatistics.org/attitudes/Dementia%20Attitudes%20Monitor%20-%20Wave%203%20report.pdf>

⁸⁸ <https://www.dementiastatistics.org/attitudes/Dementia%20Attitudes%20Monitor%20-%20Wave%203%20report.pdf>

⁸⁹ https://www.alzheimers.org.uk/sites/default/files/2021-09/ethnic_minorities_increasing_access_to_diagnosis.pdf

⁹⁰ <https://www.dementiastatistics.org/attitudes/Dementia%20Attitudes%20Monitor%20-%20Wave%203%20report.pdf>

⁹¹ <https://www.alzheimersresearchuk.org/brain-health/think-brain-health/>

Box 1: Lancet 2020: 12 modifiable risk factors for the prevention of dementia

- Less education
- Hypertension
- Hearing impairment
- Smoking
- Obesity
- Depression
- Physical inactivity
- Diabetes
- Low social contact
- Excessive alcohol consumption
- Traumatic brain injury
- Air pollution⁹²

A new cross government drive on improved public health and healthy life expectancy that addresses the modifiable risk factors of dementia (see Box 1 above) will help delay and prevent the projected level of increase anticipated, reducing the direct and indirect costs associated with the condition. Any new cross government working group should set clear targets for reducing the modifiable risk factors of dementia and regularly report back on progress in delivering against them.

Alongside this, the mixed and at times misunderstood public perceptions of dementia create a compelling case for introducing a new public health campaign aimed at improving brain health. The campaign can be used to help tackle stigma and misinformation associated with dementia and support a greater shift to prevention. Work undertaken to improve vaccine confidence amongst ethnic minority groups during the pandemic will provide some helpful learnings and actions to ensure such a campaign resonates as widely as possible.⁹³

At the individual level, the re-design and digitisation of the NHS Health Check programme, that helps identify if you are at greater risk of conditions such as cardiovascular disease, diabetes and stroke in England, should be used to help identify people at risk of dementia earlier.^{94,95} Currently the Health Check

⁹² [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

⁹³ <https://assets.publishing.service.gov.uk/media/6001808ed3bf7f33af7bdc20/s0979-factors-influencing-vaccine-uptake-minority-ethnic-groups.pdf>

⁹⁴ <https://www.gov.uk/government/news/patients-to-carry-out-health-checks-in-comfort-of-own-home-to-ease-pressure-on-frontline-services#:~:text=Press%20release-,Patients%20to%20carry%20out%20health%20checks%20in%20comfort%20of%20own,%2Dto%2Dface%20health%20check>

⁹⁵ <https://www.nhs.uk/conditions/nhs-health-check/>

provides advice for those over 65 about the symptoms of dementia.⁹⁶ Using online questionnaires and tests for younger participants in the programme could help identify people at greater risk of or with dementia earlier.

Alongside this, health systems working with organisations such as NICE, the SMC, clinical groups and charities will need to build patient facing materials that can help support clinicians in their discussions with patients about new dementia treatments if authorised. There will be significant patient and public interest in disease-modifying treatments if they become available and not all patients will be eligible. It will be important in these circumstances that health professionals have access to high quality, patient centred information to support informed discussions with patients.

Improving the rate and timeliness of diagnosis rates

As set out in Chapter 2 diagnosis rates vary significantly both between the four nations of the UK and within each nation. None of the nations that have set targets for dementia diagnosis rates have met them in recent years.

Patients are also struggling to access a timely diagnosis that can help unlock the care and support they need earlier. Memory Assessment Services (MAS) are specialist services run by teams including medical staff, specialist dementia nurses, psychologists, and occupational therapists. People are referred to a MAS if there are concerns about their memory. They provide advice and assessment, leading to a diagnosis if a person has dementia, as well as treatment and follow-up support.⁹⁷

The most recent audit of MAS across England and Wales in 2021-22 demonstrated the increased pressure that services were under as a result of the pandemic. The audit found that the time from a referral to a formal diagnosis of dementia had risen to 17.7 weeks, up from 13 weeks in 2019.⁹⁸ In March 2021, the UK Government did commit an additional £17m to support the recovery of the dementia diagnosis rate in England.⁹⁹ There are signs that such investment has had a positive impact with the diagnosis rate increasing from 61.6% in March 2021 to 64.6% in December 2023. However this improved performance is still below the two thirds target.¹⁰⁰

In Wales the pandemic saw diagnosis waits of over 12 weeks in places and the Welsh Government responded by investing an extra £3 million in dementia services.¹⁰¹ Given the lag in the reporting on dementia diagnosis rates in Wales it is not yet clear if this has translated into a meaningful improvement.

⁹⁶ <https://www.nhs.uk/conditions/nhs-health-check/>

⁹⁷ https://www.hqip.org.uk/wp-content/uploads/2022/08/Ref-317-NAD-Memory-Assessment-Services-Spotlight-Audit-2021_FINAL.pdf

⁹⁸ https://www.hqip.org.uk/wp-content/uploads/2022/08/Ref-317-NAD-Memory-Assessment-Services-Spotlight-Audit-2021_FINAL.pdf

⁹⁹ <https://www.gov.uk/government/news/mental-health-recovery-plan-backed-by-500-million>

¹⁰⁰ <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/march-2021>; <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data>

¹⁰¹ <https://www.gov.wales/written-statement-update-dementia-care-wales>

The scale of the dementia diagnosis challenge is seen when looking ahead at the projected increases in the condition over the next two decades. Using the latest Office for National Statistics population projections and the anticipated increase in the dementia prevalence rate as set out in the LSE paper, we can estimate that nearly 1.5 million people will have dementia by 2040 in the UK, an increase of over 650,000 on the latest figures.¹⁰²

Future Health ran three models for what these increases in dementia cases by 2040 could mean for the numbers of people undiagnosed with dementia.

The first model projected no improvement in the diagnosis rate from today.¹⁰³ This found that if current performance was replicated the number of people with dementia who are undiagnosed would nearly double from just over 315,000 to over 565,000.

The second model assumed that each country would deliver a diagnosis rate of two thirds, the target for the NHS in England today. Under this model the numbers of undiagnosed people with dementia would increase by just under 200,000 to 490,000.

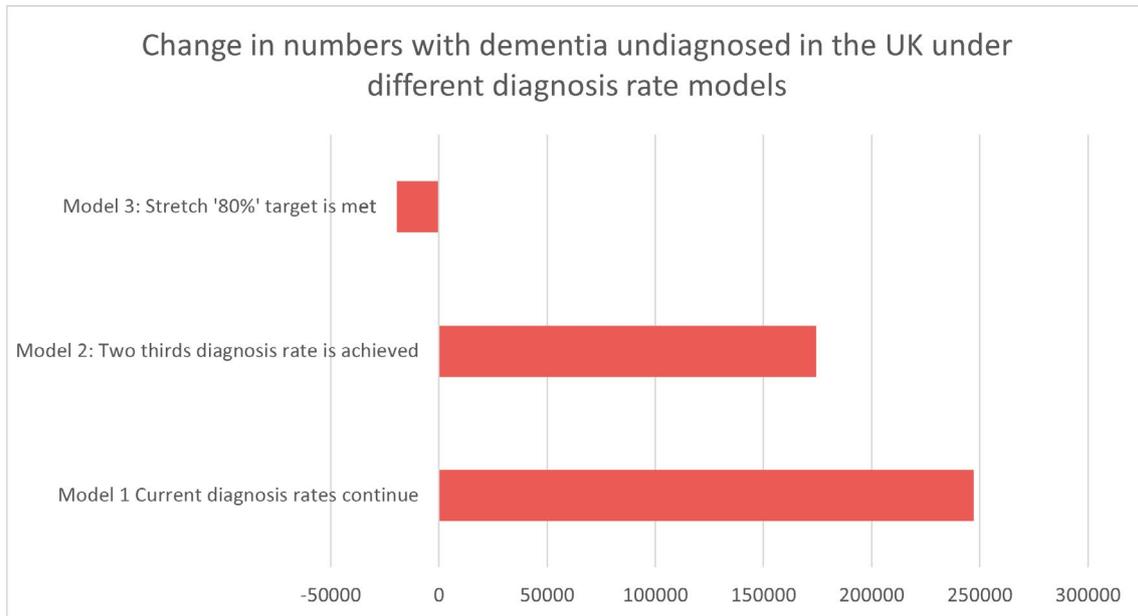
The third model assumed a significant level of improvement in the diagnosis rate to 80%. Whilst a 'stretch' target this is less than 10% higher than the 74.7% recorded by NHS South Yorkshire ICB which is the highest published rate of any NHS organisation in the UK. Under this model there would be a decrease in the numbers undiagnosed by 20,000 to just under 300,000 overall.

These models demonstrate the scale of the dementia diagnosis challenge. Continuing with existing levels of performance or even hitting a two-thirds rate of diagnosis will lead to a sharp rise in the number of those undiagnosed as overall numbers with the condition rise. Even reaching a 'stretch' target of 80% will only result in a slight decrease in the numbers undiagnosed and still see close to 300,000 people with dementia undiagnosed by 2040.

¹⁰² https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

¹⁰³ For this the current rates England (64.6%), Scotland (41.6%), Wales (53.9%), Northern Ireland (62%) were applied

Figure 15: Models for estimating undiagnosed dementia cases across the UK by 2040



Governments and health systems across the four nations of the UK should set out a long-term path to increase their dementia diagnosis rates. This could include introducing annual targets that look to deliver a year on year rise (such as a 1% increase) in the number of people being diagnosed each year. If adopted this model would see the diagnosis target in England for example move from two thirds to above the 80% stretch model set out above. The emergence of blood tests that could help diagnose dementia more quickly could also present a step-change opportunity for more quickly increasing the dementia diagnosis rate (see next section).¹⁰⁴

Embedding the prioritisation of increasing the dementia diagnosis rate within the system more widely will also be important. Reforms to the primary care incentives framework create an opportunity to incentivise dementia diagnosis improvements in primary care across the UK.¹⁰⁵ The dementia diagnosis target should also be re-included within the next Government mandate to NHS England.¹⁰⁶

Investing in service capacity and diagnostics

Investing in improved capacity and diagnostics will not only improve the rate of dementia diagnosis but also in the quality of diagnosis. There are over 200 subtypes of dementia but many patients currently only receive a generic diagnosis.¹⁰⁷ The most recent NICE guideline for dementia recommends the use of PET (Positron

¹⁰⁴ <https://www.alzheimers.org.uk/news/2023-11-07/blood-biomarker-challenge-dementia-diagnosis>

¹⁰⁵ <https://www.gov.uk/government/consultations/role-of-incentive-schemes-in-general-practice/role-of-incentive-schemes-in-general-practice>

¹⁰⁶ <https://www.gov.uk/government/publications/nhs-mandate-2023/the-governments-2023-mandate-to-nhs-england>

¹⁰⁷ <https://www.dementiauk.org/information-and-support/types-of-dementia/>

Emission Tomography) scans and lumbar punctures that sample CSF (Cerebrospinal Fluid) to support subtyping and improved patient management.¹⁰⁸ However the most recent National Dementia Audit found only 2.2% of patients had received such a specialist investigation.¹⁰⁹

Access to scanners is a major limitation. According to the most recent Life Science Competitiveness Indicators there are only 0.5 PET scanners per 1 million people in the UK. Ireland has the second lowest recorded ratio, of 1.8 scanners per 1 million people. Australia and Italy by contrast have 3.9 and 3.8 PET scanners per 1 million people respectively.¹¹⁰ The UK is also bottom of the sixteen country table for access to MRI scanners. The numbers per million population have though increased recently – by 25% and 10% for PET scanners and MRI scanners respectively since 2020.¹¹¹

Subtyping will become increasingly important as new treatments for dementia become available. The next group of treatments will be most effective during the early stages of disease progression for those with Mild Cognitive Impairment (MCI) and mild Alzheimer's disease and will not be suitable for people with late stage disease and other forms of dementia, such as vascular dementia.¹¹² Patients will also require access to MRI scanners for ongoing treatment monitoring.

Research from ARUK has estimated that a lack of access to diagnostics and the blockages in the system mean that just one in three services will be able to provide new disease modifying treatments within a year of market authorisation.¹¹³

Across the UK increasing access to dementia diagnostics is challenging. In a ARUK survey of old age psychiatrists published in 2021, just 6% said that psychiatry services were able to fully meet the current NICE guidelines regarding accessing further biomarker and diagnostic tests for Alzheimer's disease.¹¹⁴

In England one of the major barriers – beyond financing an expansion of scanners – is limits on health service estate space to install and operate them. The current NHS backlog maintenance bill is growing, putting pressure on services and now stands at £11.6 billion.¹¹⁵ Along with workforce expansion (see later section), services will also need the appropriate lab capacity to process any expansion in testing (such as CSF tests).

¹⁰⁸ <https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109>

¹⁰⁹ https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/round-5/final-1608-nad-mas-national-report-2021.pdf?sfvrsn=dc5b5d40_8

¹¹⁰ <https://www.gov.uk/government/publications/life-sciences-sector-data-2023>

¹¹¹ <https://www.gov.uk/government/publications/life-sciences-sector-data-2023/life-sciences-competitiveness-indicators-2023>

¹¹² <https://www.alzheimersresearchuk.org/wp-content/uploads/2023/08/Tipping-Point-Report.pdf>

¹¹³ <https://www.alzheimersresearchuk.org/wp-content/uploads/2023/08/Tipping-Point-Report.pdf>

¹¹⁴ https://www.alzheimersresearchuk.org/wp-content/uploads/2021/05/ARUK-Are-we-ready-to-deliver-disease-modifying-treatments_25May21.pdf

¹¹⁵ <https://www.hfma.org.uk/articles/backlog-maintenance-increase-sparks-call-capital-boost>

Northern Ireland does not currently have access to an amyloid PET scanner which can identify amyloid in the brain and support a dementia diagnosis.¹¹⁶ There may be opportunities to work with the Republic of Ireland on possible access arrangements to their amyloid PET scanning equipment.¹¹⁷

In Wales a pilot project to tackle diagnostic access was established by the Aneurin Bevan University Health Board in late 2019. The project aimed to benefit patients in the Gwent area; increasing earlier diagnosis and diagnostic rates for dementia, achieving more reliable diagnosis of dementia subtype, enabling earlier disease-specific treatment and access to psychosocial support and reduction of the carer burden.¹¹⁸ 52 Fluorodeoxyglucose (FDG) PET scans were completed as part of the project and in 91% of cases the use of the scan changed clinical processes. There was a 100% confidence benefit recorded by clinicians in their decision making as a result of the scans.¹¹⁹ Following the pilot the Welsh Health Specialised Services Committee has commissioned FDG-PET scans for dementia nationally.

Governments and health systems with limited resources, particularly for capital spend will need to work out how best to scale patient access to dementia diagnostics. ARUK believe a £16 million investment could help significantly improve access to lumbar punctures when combined with workforce investment.¹²⁰

The NHS in England has already noted in its latest update on preparing the system for new dementia treatments that caution needs to be exercised in expanding access to PET scanners when this could be redundant in the future due to diagnostic innovation.¹²¹

Blood tests are being trialled internationally and ARUK and the Alzheimer's Society are running a £5 million programme with the National Institute for Health Research to pilot new blood tests in the NHS.¹²² These blood tests may well still require further diagnostic tests to fully confirm a diagnosis but they could help support efforts at faster and more accurate diagnoses across a wider range of healthcare settings.

Future Government Budgets should be used to announce capital investment funds that support increased investment in cost-effective dementia diagnostics – supporting the scaling of innovative pilot findings and evidence when they become available.

¹¹⁶ <https://www.rqia.org.uk/RQIA/files/6d/6da304fb-195b-4749-bd90-6385514b8320.pdf>

¹¹⁷ Northern Ireland expert interview

¹¹⁸ <https://www.rcpsych.ac.uk/members/devolved-nations/rcpsych-in-wales/increasing-dementia-diagnosis-in-wales>

¹¹⁹ <https://www.rcpsych.ac.uk/members/devolved-nations/rcpsych-in-wales/increasing-dementia-diagnosis-in-wales>

¹²⁰ <https://www.alzheimersresearchuk.org/wp-content/uploads/2023/08/Tipping-Point-Report.pdf>

¹²¹ <https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/>

¹²² <https://www.alzheimersresearchuk.org/blog/blood-biomarker-challenge-if-we-can-fix-dementia-diagnosis-we-open-the-door-for-a-cure/>

Re-designing services

Improvements in dementia diagnosis, treatment and care will not be achieved through improvements in diagnostics alone. The potential arrival of new treatments will require changes to the way services and pathways are designed. One such model being trialled in a number of geographic areas is the Brain Health Clinic/Service.

The Oxford Clinic provides patients with an advanced brain health assessment that includes:

- An MRI scan instead of a CT scan, providing clinicians with more detailed information about brain pathology
- An additional neuropsychological assessment, supplementing the brief cognitive assessment completed at the memory clinic
- Clinical questionnaires covering depression, sleep, activity, alcohol use and long-term conditions
- An interview with the person accompanying the patient, including questions about changes in the patient's cognition, behaviour and general function¹²³

Scotland launched its first Brain Health Service in Aberdeen in December 2023.¹²⁴ The Service has three principles: accurate risk profiling, a personalised action plan and early disease detection.¹²⁵ Alzheimer's Scotland and Brain Health Scotland, supported by the Scottish Government have developed a guideline for setting up a Brain Health Service which was published in 2023.¹²⁶ Figure 16 sets out the brain health pathway based on the work of the Brain Health Service.¹²⁷

¹²³ <https://oxfordhealthbrc.nihr.ac.uk/our-work/brain-health-centre/>

¹²⁴ <https://www.nhsgrampian.org/your-health/brain-health/>

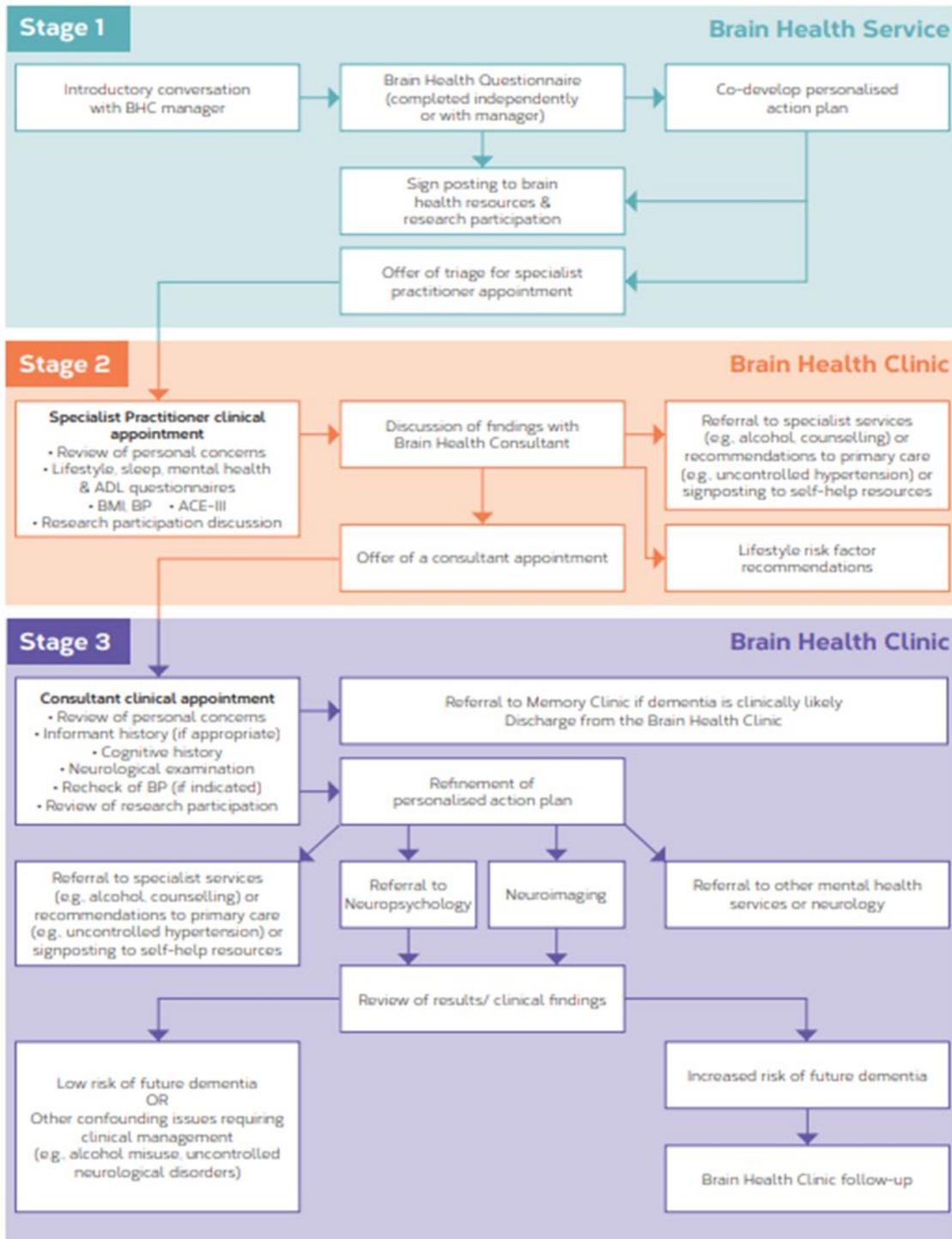
¹²⁵ <https://www.brainhealth.scot/brainhealthservices>

¹²⁶ https://www.brainhealth.scot/_files/ugd/d90149_e7dd0c41f0a040d0ba07f37a4a9c0739.pdf?index=true

¹²⁷ https://www.brainhealth.scot/_files/ugd/d90149_e7dd0c41f0a040d0ba07f37a4a9c0739.pdf?index=true

Figure 16: Brain Health Care Pathway for Brain Health Service in Scotland¹²⁸

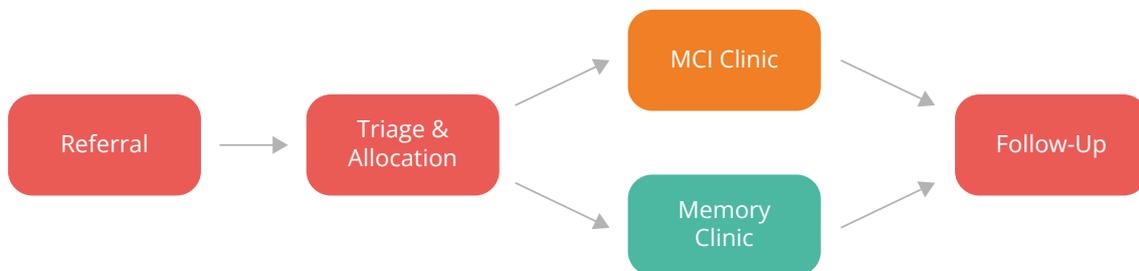
Brain Health Care Pathway Flowchart



¹²⁸ <https://link.springer.com/article/10.14283/jpad.2021.63>

In Wales the Aneurin University Health Board have created a new Mild Cognitive Impairment (MCI) clinic aimed at diagnosing people with dementia earlier. Those with mild symptoms are referred to the clinic. The threshold for referral is low although capacity is limited. The criteria for referral include those under 65 years old with memory concerns; patients of any age with memory concerns and high cognitive scores; those with good functional ability.¹²⁹ A pre clinic assessment form is performed by a research nurse. The appointment at the clinic is a 75 minute appointment which includes a focused neurological examination and medication review. The clinic is held jointly between psychiatry and neurology and a plan is developed for the patient. The plan could include further imaging, lifestyle interventions and a mental health plan.¹³⁰ This service sits alongside the memory assessment clinic, within the Newport Memory Assessment Service, which is focused on later diagnosis.

Figure 17: Newport Memory Assessment Service¹³¹



Patient feedback on these services has been positive. For example the Oxford Clinic reports that 98% of patients were satisfied with the pre-appointment information and 97% agreed that they were well informed about next steps and given the opportunity to ask questions which were answered adequately.¹³²

One of the challenges with many of these new models has been the lack of funding available. Manchester's Brain Health Clinic for example has used research grants, innovation pots, partnership funding and other sources to build the services.¹³³

More sustainable, longer-term funding will be required to ensure that people across the country can be assessed for a dementia diagnosis and possible treatment following a referral. Services are already under pressure and patient access to care is variable. For health commissioners new funding will be critical to delivering an enhanced dementia service. This service will need to blend and coordinate local knowledge, relationships and insights through the existing MAS and the Brain Health Clinics (where they operate) with regional specialisms found at tertiary centres.¹³⁴

¹²⁹ https://www.brainhealth.scot/_files/ugd/d90149_84e47c771a144ca5bff0dcbb28b62f67.pdf?index=true

¹³⁰ https://www.brainhealth.scot/_files/ugd/d90149_84e47c771a144ca5bff0dcbb28b62f67.pdf?index=true

¹³¹ https://www.brainhealth.scot/_files/ugd/d90149_84e47c771a144ca5bff0dcbb28b62f67.pdf?index=true

¹³² <https://oxfordhealthbrc.nihr.ac.uk/our-work/brain-health-centre/>

¹³³ Interview with Manchester Brain Health Clinic

¹³⁴ https://www.alzheimersresearchuk.org/wp-content/uploads/2021/05/ARUK-Are-we-ready-to-deliver-disease-modifying-treatments_25May21.pdf

Investing in and training the dementia workforce

Improving the earlier identification, diagnosis and treatment of dementia has significant implications for the healthcare workforce. Currently there are shortages in a number of important areas including psychiatry, neurology and radiology.

The Royal College of Psychiatrists estimates that there is a shortfall in England of 690 psychiatrists. Numbers have only increased by 5.8% in the last ten years despite record referral rates to specialist mental health services.¹³⁵

Neurologists will be important for subtyping dementia diagnosis. The UK has fewer neurologists proportionately than other countries. Data from the latest Royal College of Physicians consultant survey in 2022 reveals that the number of neurologists was 1.8 per 100,000 population across the UK.¹³⁶ In France and Germany there are estimated to be 1 per less than 25,000 people.¹³⁷ MASs currently delivering research trials for new treatments will often have neurologists embedded but many others will not, likely leading to challenges in particular parts of the country in delivering new treatments quickly if they become available.

The Royal College of Radiologists has estimated that there is a 29% shortfall in radiologists across the UK.¹³⁸ Radiologists will be critical for both dementia diagnosis and the ongoing monitoring of patients on new treatments.

The future projections of the NHS Workforce Plan in England do include population health projections for major conditions including dementia.¹³⁹ However there are no clear commitments on specifically expanding the number of psychiatrists, neurologists or radiologists.

Within primary care the mix of skills across primary care networks and community care is leading to new models of care being rolled out for people diagnosed with dementia. Examples include the use of dementia care navigators in Gateshead who spend time with people newly diagnosed, helping to tackle issues of social isolation and also connecting people with voluntary groups and handling particular requests (such as prescriptions). In Barnsley a 'trio' Memory Assessment and Support Service brings together a band 6 nurse, band 5 nurse and a band 3 Memory Support Worker to support GP practices in delivering co-ordinated and timely care for people diagnosed with dementia.¹⁴⁰

¹³⁵ <https://www.rcpsych.ac.uk/news-and-features/latest-news/detail/2023/05/25/royal-college-of-psychiatrists-calls-for-urgent-publication-of-nhs-workforce-plan-as-psychiatrist-numbers-stagnate#:~:text=25%20May%202023&text=These%20issues%20stem%20from%20working,the%20current%20consultant%20psychiatrist%20workforce>

¹³⁶ <https://www.rcplondon.ac.uk/projects/outputs/uk-2022-census-consultant-physicians>

¹³⁷ https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf

¹³⁸ https://www.rcr.ac.uk/media/30dhjeh2/clinical_radiology_census_report_2021.pdf

¹³⁹ <https://www.england.nhs.uk/wp-content/uploads/2023/06/nhs-long-term-workforce-plan-v1.2.pdf>

¹⁴⁰ https://www.futurehealth-research.com/site/wp-content/uploads/2022/05/220505_Levelling-Up-Dementia-Diagnosis-Web-.pdf

However access to post diagnostic support is highly variable across the UK with great variation in provision. A survey by Frost et al found that the voluntary sector and local authorities played a large role in providing information, caregiver support and services to aid living well in the community; with some commissioning areas reporting multiple providers delivering the same service, with services rarely consistently delivered by the same provider.¹⁴¹

The Scottish Government has guaranteed a year of post diagnostic support for people diagnosed with dementia. The five pillars of post diagnostic support include:

- Understanding the illness and managing patient symptoms
- Supporting people's community connections
- Having the chance for people with dementia to meet other people with dementia, their partners and families
- Planning for future decision making
- Planning future support¹⁴²

This support is provided by Alzheimer's Scotland or NHS Staff depending on the region patients and families are in. The programme of work is underpinned by an evidence based pilot which supported people and their families with information, advice, signposting, and emotional and practical support to understand and come to terms with living with dementia. People with dementia and their families/ supporters felt better informed and better equipped to manage their dementia, through the provision of 1:1 information and participation in workshops. They were also able to make contact with, and benefit from the support of, other people with dementia and their families, through dementia cafés, workshops and occasional social events.¹⁴³

More widely, efforts have been made across the UK to train and increase awareness of the signs and symptoms of dementia amongst healthcare staff. In England the most recent dementia strategy included a commitment that all NHS staff would receive dementia training appropriate to their role.¹⁴⁴ Such efforts were combined with the opportunity for members of the public to be trained as 'dementia friends' to be able to better understand and engage with people with dementia.¹⁴⁵

In Wales a Dementia Learning and Development Framework was published in 2016 with the aim of helping the health and social care workforce in understanding the issues involved in high quality dementia care and support.¹⁴⁶ Scotland's

¹⁴¹ <https://research.ncl.ac.uk/media/sites/researchwebsites/pridem/Frost%202020%20-%20e-survey%20June%202020.pdf>

¹⁴² <https://www.alzscot.org/pds>

¹⁴³ <https://www.alzscot.org/sites/default/files/2019-07/Facing-dementia-together-post-diagnostic-support-pilot.pdf>

¹⁴⁴ <https://assets.publishing.service.gov.uk/media/5a80d3ce40f0b62302695b8c/pm-dementia2020.pdf>

¹⁴⁵ <https://www.dementiafriends.org.uk/>

¹⁴⁶ <https://socialcare.wales/cms-assets/documents/Good-Work-Dementia-Learning-And-Development-Framework.pdf>

new dementia strategy includes, as part of its vision, that it wants people to ‘be supported by a skilled and knowledgeable workforce that accesses the highest quality dementia specialist education and training, and implements evidence-based, including trauma-informed, practice.’¹⁴⁷

Improving dementia health system data

Data on dementia is patchy and variable across the UK. In some countries diagnosis rates are not routinely published or available country-wide making an assessment of health system performance challenging. Audits such as those of MAS discussed above are not comprehensive. There are an estimated 222 MAS in England and 25 in Wales. 138 services across England and Wales participated in the audit. Only 53 services submitted patient feedback from 251 patient and carers.¹⁴⁸ The NHS in England has developed a dashboard to help commissioners and providers to assess their service performance but the data is not published publicly.¹⁴⁹ Table 2 seeks to provide a summary of the dementia data published by each UK nation.

Table 2: Dementia data collection and publication by UK nation

	Prevalence data	Diagnosis data	Service data
England	Yes including at regional level	Yes including at regional level	In part, dashboard developed by NHS England to support commissioners and providers in monitoring performance but data is not publicly available Royal College of Physicians (RCP) clinical audit of MAS covers services in England but is not comprehensive
Scotland	In part, but commitment in dementia strategy to improve data collection	No, but commitment in dementia strategy to improve data collection	No, but commitment in dementia strategy to improve data collection ¹⁵⁰

¹⁴⁷ <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2023/05/new-dementia-strategy-scotland-everyones-story/documents/dementia-scotland-everyones-story/dementia-scotland-everyones-story/govscot%3Adocument/dementia-scotland-everyones-story.pdf>

¹⁴⁸ https://www.hqip.org.uk/wp-content/uploads/2022/08/Ref-317-NAD-Memory-Assessment-Services-Spotlight-Audit-2021_FINAL.pdf

¹⁴⁹ <https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/>

¹⁵⁰ <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2023/05/new-dementia-strategy-scotland-everyones-story/documents/dementia-scotland-everyones-story/dementia-scotland-everyones-story/govscot%3Adocument/dementia-scotland-everyones-story.pdf>

	Prevalence data	Diagnosis data	Service data
Wales	Yes including at regional level, though most recent data is for 2021-22	Yes including at regional level, though most recent data is for 2021-22	In part, RCP audit of MAS includes services in Wales but is not comprehensive Alzheimer's Cymru has called for better data collection and publication ¹⁵¹
Northern Ireland	Yes including at regional level	No	No, a review of mental health services by the Northern Ireland Audit Office found variation on the collection of waiting times data including dementia data ¹⁵²

As a first step each nation should commit within two years to publish:

- At least annual prevalence data on dementia at a regional and national level
- Monthly or quarterly data on dementia diagnosis rates at a regional and national level
- Quality and outcomes data on dementia services (such as waiting times and patient experience data)

All nations should also commit to improve the accuracy in the way they calculate their dementia diagnosis rates. The dementia diagnosis rate is currently calculated by dividing the number of people diagnosed by baseline dementia prevalence. Baseline prevalence is calculated through age and sex profiling of a population, but does not take into account the wider health of the population and the modifiable risk factors. Applying these population health indicators to dementia diagnosis rates provides the potential to more accurately calculate the dementia diagnosis rate of a health system.¹⁵³

¹⁵¹ <https://business.senedd.wales/documents/s122259/WT%2029%20-%20Alzheimers%20Society%20Cymru.pdf>

¹⁵² https://www.niauditoffice.gov.uk/files/niauditoffice/documents/2023-05/00293490%20-%20Mental%20Health%20Report_WEB.pdf

¹⁵³ <https://www.futurehealth-research.com/site/wp-content/uploads/2023/01/FH-Dementia-Report-Hi-Res.pdf>

CONCLUSION: GETTING HEALTH SYSTEMS DEMENTIA READY

Dementia is a major challenge for health systems across the UK here and now. Not enough people are getting a timely dementia diagnosis and access to the high quality care and treatment they need. In cancer, patients are expected to be diagnosed within 28 days, in dementia following a referral it is 18 weeks and in some parts of the country much longer.¹⁵⁴¹⁵⁵ Diagnosis rates for dementia vary across the four nations of the UK, and whilst data is variable and irregularly published, hundreds of thousands of people have the condition but are currently undiagnosed.

The challenge of diagnosing, treating and supporting people with dementia is set to increase dramatically in the next two decades. Business as usual will not deliver what people with dementia and their families need. Meeting current diagnosis targets of two-thirds, coupled with an older population and increased prevalence will see the numbers of people undiagnosed soar by 200,000, to over half a million, with clear implications for patients and health systems.

The current approach of each of the UK nations to improving dementia diagnosis and care is highly variable. There are gaps in national leadership, strategic planning, commissioning policies and clinical guidelines. Diagnosis target ambitions are modest and still being missed. Diagnostic equipment and workforce distribution is inadequate and uneven. New innovative service models, such as Brain Health Clinics are being trialled locally, but often do not have significant central funding and support to scale. Central planning for potential new treatments has started in certain countries but not all, and readiness plans for treatment rollout are yet to be published. Data on diagnosis rates and service performance is patchy, making it difficult to assess progress.

To rise to the dementia challenge will require a significant strengthening of the dementia policy framework in each nation. New public health campaigns, coupled with cross-government action on the modifiable risk factors for dementia will be needed to support greater efforts on prevention. Diagnostics and innovations will require investment to benefit patients. Workforce plans will need to ensure the expansion of specialist and non-specialist roles to deliver co-ordinated care. New service models will need to blend local and regional specialisms. Greater ambitions will need to be set on diagnosis rates and access to post diagnostic support.

¹⁵⁴ <https://www.england.nhs.uk/2023/08/widespread-clinical-support-for-reforming-nhs-cancer-standards-to-speed-up-diagnosis-for-patients/#:~:text=the%2028-Day%20Faster%20Diagnosis,ruled%20out%20within%2028%20days>

¹⁵⁵ <https://www.dementiani.org/news/dementia-ni-member-calls-for-clear-action-on-long-waiting-times-for-a-diagnosis-in-the-western-trust> ; https://www.niauditoffice.gov.uk/files/niauditoffice/documents/2023-05/00293490%20-%20Mental%20Health%20Report_WEB.pdf

Advances in treatment provide hope for improving dementia outcomes; but without the right structures and policy building blocks in place many who may be eligible will not benefit. All four Governments of the UK should work to address this and in 2024 commit to publish a system readiness plan for new treatments that looks to address the gaps in the policy framework set out within this report.



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