Levelling up dementia diagnosis

Tackling variations in diagnosis rates in England

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During his time with the Secretary of State, Richard worked across Whitehall, the NHS and local government on major policy decisions including the NHS Long Term Plan, the creation of NHSX and the Prevention Green Paper. He also supported Ministers on global healthcare issues including preparations for the G7 and action on antimicrobial resistance. He has fifteen years' experience in public policy and healthcare, starting his career in Parliament before a successful career in public affairs where he led a team of 20 to the prestigious Communique Public Affairs Team of the Year Award.

Richard is undertaking his doctoral thesis in preventative healthcare systems at Liverpool University. He has a Masters Degree with Distinction from the University of Nottingham and a Bachelors Degree from the University of Durham.

About Future Health

Founded by former UK Government Special Adviser, Richard Sloggett, Future Health is a policy research centre with a mission to advance public policy thinking that improves the health and wealth of people, communities and nations.

Healthcare systems around the world are facing significant challenges of demographic, societal and technological change. The importance of prevention and the development of new technologies have long been seen as ways to transform health systems to improve patient outcomes and performance, but progress has often been slow. COVID-19 is an inflection point, demonstrating the need and opportunity of investing in and delivering more effective and efficient healthcare services in the future. In undertaking cutting edge public policy research across key areas such as prevention, technology and links between healthcare and the wider economy, Future Health is working to support such positive changes and deliver policy that improves health outcomes and tackles health inequalities.

This work, funded by Roche and in partnership with York Health Economics Consortium, on dementia diagnosis forms part of Future Health's work in prevention.

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About Roche, tide and Front of Mind

Roche is a pioneer in pharmaceuticals and diagnostics, focused on advancing science to improve people's lives. Roche is committed to rising to the global challenge of Alzheimer's disease through innovation and collaboration.

tide is a national involvement network for carers and former carers of people with dementia. tide believes that carers have the experience and knowledge to improve health and social care, research, and policy development throughout the UK.

Front of Mind is a joint campaign by Roche and tide (together in dementia everyday), calling for people with dementia and their carers to receive the recognition - and support - they deserve.

Executive Summary

More and more people are set to receive a dementia diagnosis in England, but many others will have the condition and either wait years for the news or never receive it. Before COVID-19 progress had been made to get dementia diagnosis rates up to the two thirds Government target. However, the impact of restrictions on access to services, deteriorations in population health and backlogs of care has seen this rate fall back sharply in the last two years.

A dementia diagnosis remains one of the most feared – amongst those over 65, 6 in 10 are most worried about receiving the news that they have dementia[1]. But for those who have the condition, their family and carers, a lack of an early, accurate diagnosis can have a significant negative impact leading to poorer outcomes and increased health and social care costs. A diagnosis opens up access to a range of critical help, care, treatment and support.

This report looks at the impact of the pandemic on dementia diagnosis rates, regional variations of performance, and wider socio-economic costs. It finds that less than 60% of people with dementia are currently diagnosed and rates across the country vary from 83% to 47%.

There are also health inequalities in accessing a timely diagnosis. People in rural areas and those from ethnic minorities face particular barriers and hurdles to access the services they need.

With the number of people with dementia set to increase to 1.6 million across the UK by 2040 and services struggling to recover following the impact of COVID-19, the Government is right to use this moment to develop a new national dementia strategy.

This strategy should be based on a policy framework that aims to improve and tackle variations in diagnosis rates. This will require investment in service recovery and future transformation, scaling new flexible workforce models, tackling stigma and placing dementia at the heart of the new planned integrated health and care system.

Learning from the success of past dementia strategies - setting clear targets for earlier and improved diagnosis with investment in the staff and equipment needed to deliver it - can help people access the appropriate care and support they need.

With a new generation of personalised treatments for dementia emerging, the importance of early, accurate and clear diagnoses – particularly subtyping – is going to become ever more critical to delivering high quality treatment and care that people with dementia and their families deserve.

Improving dementia diagnosis – recommendations and proposed policy framework

This report makes the following recommendations for improving and levelling-up dementia diagnosis rates. The recommendations are explored in more detail in Chapter 4.

AMBITION

Setting new targets for diagnosis rates and diagnosis subtyping

PUBLIC HEALTH

Tackling public attitudes and stigma to dementia through new public health campaigns on brain health

INCENTIVES

For improved primary care diagnosis through the Quality and Outcomes Framework (QOF)

INTEGRATION

Making dementia an exemplar for integrated care in Integrated Care Systems (ICSs) through the appointment of ICS dementia leads and the publication of dementia strategies

DATA

Building a National Dementia Observatory to improve transparency, tackle service variation and deliver quality improvement

WORKFORCE

Scaling flexible, integrated patient centred dementia care models and supporting primary care staff through education and training

INVESTMENT

In pandemic service recovery and in the future including new equipment and digital tools to support improvements in diagnosis rates

Introduction

What is dementia?

The word ‘dementia’ describes a set of symptoms that over time can affect brain function such as memory, problem-solving, language and behaviour. Dementia is caused by damage to the brain. Where this damage is within the brain, determines the type and extent of the symptoms which occur over time.

There are over 200 subtypes of dementia.

Alzheimer’s disease affects the brain through a build-up of abnormal proteins called ‘plaques’ and ‘tangles’, which disrupt nerve cell functions and, over time, cause nerve cells to die[2]. Alzheimer’s disease is the most common cause of dementia[3].

Other subtypes of dementia include Vascular Dementia, Frontotemporal Dementia and Creutzfeldt-Jakob disease[4]. Sometimes having another condition like a learning disability or HIV can increase a person’s chances of developing a certain form of dementia[5].

Prevalence and the importance of early, accurate diagnosis

The Alzheimer’s Society estimates that 1 in 14 people over the age of 65 have dementia, and the condition affects 1 in 6 people over 80[6].

Projections show that over one million people will be living with dementia in the UK by 2025. This is estimated to rise to almost 1.6million in 2040[7]. There is also growing evidence that lifestyle choices (smoking and excess drinking) and pre-existing conditions such as high-blood pressure and diabetes increase the chance of an individual developing the condition[8].

Within England in 2020-2021 430,000 people had a formal diagnosis of dementia. However, analysis by the York Health Economics Consortium (YHEC) estimates that 750,000 people were living with the condition in this same period – meaning over 4 in 10 people living with dementia did not have a diagnosis[9].

Early identification of Alzheimer’s disease – the most common form of dementia – is based on measuring relevant “biomarkers”, a distinctive biological indicator that may indicate the presence of the disease[10].

These biomarkers can be detected using analysis of cerebrospinal fluid (CSF) and positron emission tomography (PET) imaging. The presence of biomarkers alone – which in the future could be found through a blood test – can only detect those potentially at risk of developing Alzheimer’s disease, and cannot be used to diagnose the condition[11].

A clinical diagnosis of Alzheimer’s disease is only possible after cognitive symptoms have appeared[12]. A timely diagnosis is important for patients and their loved ones to access the care and support they need.

Looking ahead, as new Disease Modifying Therapies (DMTs) become available, accurate diagnosis that includes the patient’s underlying biology will be increasingly important so patients get early access to the treatment and care they need.

Economic cost of dementia

The Alzheimer's Society estimate the total cost of care for people with dementia in the UK to be around £34.7billion[13]. These costs include healthcare, social care and unpaid care costs. Social care needs account for 45% of these costs (£15.7bn)[14].

With rising numbers of people living with dementia, the overall cost of care for dementia is set to rise sharply to £94.1billion in 2040, with social care spending in particular expected to triple to £45.4billion[15]. Of the current cost burden for social care, 60% of the cost falls directly on families of those living with dementia (£8.3billion per year) with unpaid carers (often family or friends) providing care to a value of £13.9billion a year[16].

CHAPTER 1

The importance and challenges of diagnosing dementia

"Receiving a dementia diagnosis can be life-changing, and often leads to feelings of grief, loss, anger or helplessness. But a diagnosis is essential in supporting people to live well, even in the absence of a cure or drugs to slow the progression. It opens the door to emotional, practical, legal and financial advice and support[17]." Alzheimer's Society

Government and NHS action

With prevalence rates and costs associated with dementia rising, the Government and the NHS have taken active steps to improve diagnosis and care (summarised below).

Figure 1: Major Government commitments to improving dementia diagnosis

LIVING WELL WITH DEMENTIA (2009)	PRIME MINISTERIAL CHALLENGE 2015 (2012)	PRIME MINISTER'S CHALLENGE ON DEMENTIA 2020 (2015)
• Increased public and professional awareness and understanding • Improved early diagnosis and care pathway • Enabling better access to care, support and advice	• Driving improvements in health and care including establishing a diagnosis target by 2013 and financial rewards for care excellence • Creating dementia friendly communities • Increasing research funding	• Focus on prevention • Timely and equitible access to diagnosis (geographically and across ethinicity groups) • NICE guideline implementation • Metrics to assess progress • Better healthcare professional training

The first national dementia strategy, Living Well With Dementia, was published by the Labour Government in 2009[18]. This framework was focused on tackling stigma, improving diagnosis and the development of tailored services for those living with dementia.

In 2012, under the Coalition Government, the Prime Minister's Challenge on Dementia was published which announced ambitions to increase investment in dementia research and deliver major improvements in care by 2015[19]. This plan led to the first ever target to diagnose two-thirds of people living with dementia being announced in 2013[20].

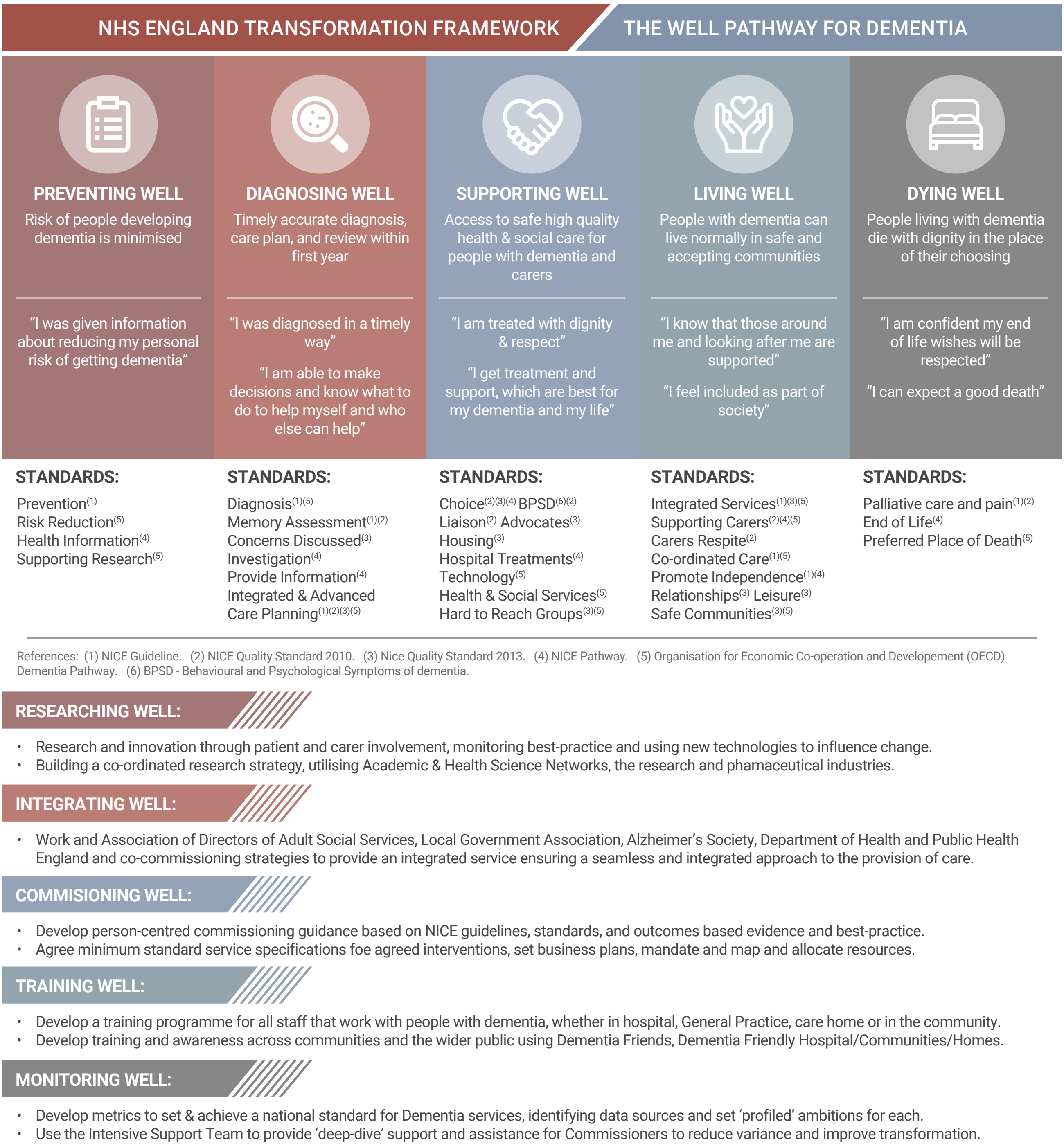
An updated strategy was published in 2015 – the Prime Minister's Challenge on Dementia 2020[21]. This document provided an update on progress and set ambitions for the UK to be the best place in the world for dementia care and research. This publication was followed by an implementation plan in 2016[22].

NHS commitments to improving dementia diagnosis and care

In 2014 the NHS England Five Year Forward View specifically called out the importance of dementia prevention and providing equitable standards of care for patients[23]. The NHS Long-Term Plan, published in 2019, reiterated the NHS commitment to prevention by setting out an ambition to prevent up to 150,000 heart attacks, strokes and dementia cases between 2019 and 2029[24]. Neither plan specifically focused on how the NHS will tackle levels of dementia underdiagnosis.

In 2016 the NHS published 'The Well Pathway for Dementia' which included a domain focused on diagnosing well with a commitment to 'timely accurate diagnosis, care plan and review within the first year[25]':

Figure 2: NHS England Transformation Framework – The Well Pathway for Dementia[26]



NHS ENGLAND TRANSFORMATION FRAMEWORK
THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
Risk of people developing dementia is minimised	Timely accurate diagnosis, care plan, and review within first year	Access to safe high quality health & social care for people with dementia and carers	People with dementia can live normally in safe and accepting communities	People living with dementia die with dignity in the place of their choosing
"I was given information about reducing my personal risk of getting dementia"	"I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help"	"I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life"	"I know that those around me and looking after me are supported" "I feel included as part of society"	"I am confident my end of life wishes will be respected" "I can expect a good death"
STANDARDS:	**STANDARDS:**	**STANDARDS:**	**STANDARDS:**	**STANDARDS:**
Prevention(1) Risk Reduction(5) Health Information(4) Supporting Research(5)	Diagnosis(1)(5) Memory Assessment(1)(2) Concerns Discussed(3) Investigation(4) Provide Information(4) Integrated & Advanced Care Planning(1)(2)(3)(5)	Choice(2)(3)(4) BPSD(6)(2) Liaison(2) Advocates(3) Housing(3) Hospital Treatments(4) Technology(5) Health & Social Services(5) Hard to Reach Groups(3)(5)	Integrated Services(1)(3)(5) Supporting Carers(2)(4)(5) Carers Respite(2) Co-ordinated Care(1)(5) Promote Independence(1)(4) Relationships(3) Leisure(3) Safe Communities(3)(5)	Palliative care and pain(1)(2) End of Life(4) Preferred Place of Death(5)

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) Nice Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Developement (OECD) Dementia Pathway. (6) BPSD - Behavioural and Psychological Symptoms of dementia.

RESEARCHING WELL:

- Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
- Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and phamaceutical industries.

INTEGRATING WELL:

- Work and Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England and co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

COMMISIONING WELL:

- Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
- Agree minimum standard service specifications foe agreed interventions, set business plans, mandate and map and allocate resources.

TRAINING WELL:

- Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
- Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospital/Communities/Homes.

MONITORING WELL:

- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.
- Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.

The Well Pathway for Dementia includes reference to clinical guidelines and tools developed by The National Institute for Health and Care Excellence (NICE) aimed at supporting improved dementia diagnosis:

- NICE Clinical Guideline (NG97) - The guideline *Dementia: assessment, management and support for people living with dementia and their carers* section 1.2 includes recommendations aimed at supporting a timely and effective diagnosis[27]
- NICE Quality Standard (QS184) – Statement 2 of the Standard updated in 2019 focused on diagnosis stating:

> “Referral to dementia specialist diagnostic services ensures that diagnosis is timely and accurate, and dementia subtypes, such as Alzheimer’s disease and dementia with Lewy bodies, can be identified. It also means that people can access support and treatment sooner. The benefits of a timely diagnosis include the person and their family and carers knowing what to expect so that they can consider future mental capacity and make plans early”[28]

Importance of diagnosis to patients and families

The Alzheimer’s Society on behalf of the Dementia Action Alliance asked people affected by dementia, and other key stakeholders, what type of care and support they would hope to receive in the future. This led to the development of the dementia statements which are rights enshrined in the Equality Act, Mental Capacity legislation, Health and Care legislation and International Human Rights Law. The statements include the following on diagnosis:

“We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live[29].”

Challenges of implementation

In their 2020 review of the dementia pathway the Alzheimer’s Society identified a number of challenges to improving dementia diagnosis rates:

- Challenges in diagnosing, especially in younger people and ethnic minorities, and reducing misdiagnosis
- The impact of GP consultation time and referral processes on effective diagnosis
- Barriers to diagnosis subtyping, doing this effectively, and whether people understand what their subtype means for their symptoms and prognosis
- The importance of case finding and actively searching for patients – and diagnosis in hospitals and care homes, and the interaction between primary, secondary and social care at this point of the pathway
- How to improve the diagnostic experience, particularly when delivering a diagnosis, to ensure people see their condition as positively as possible

Case study: Versha Patel, carer of mother with dementia

“In my community, the concept of dementia doesn’t really exist. When my mother was diagnosed, I thought ‘Will they understand? Will they not?’. For my broader family, I had to print off information about what dementia was in their language. I didn’t feel embarrassed, but I knew they weren’t going to understand; I thought they were going to think I was making it up.

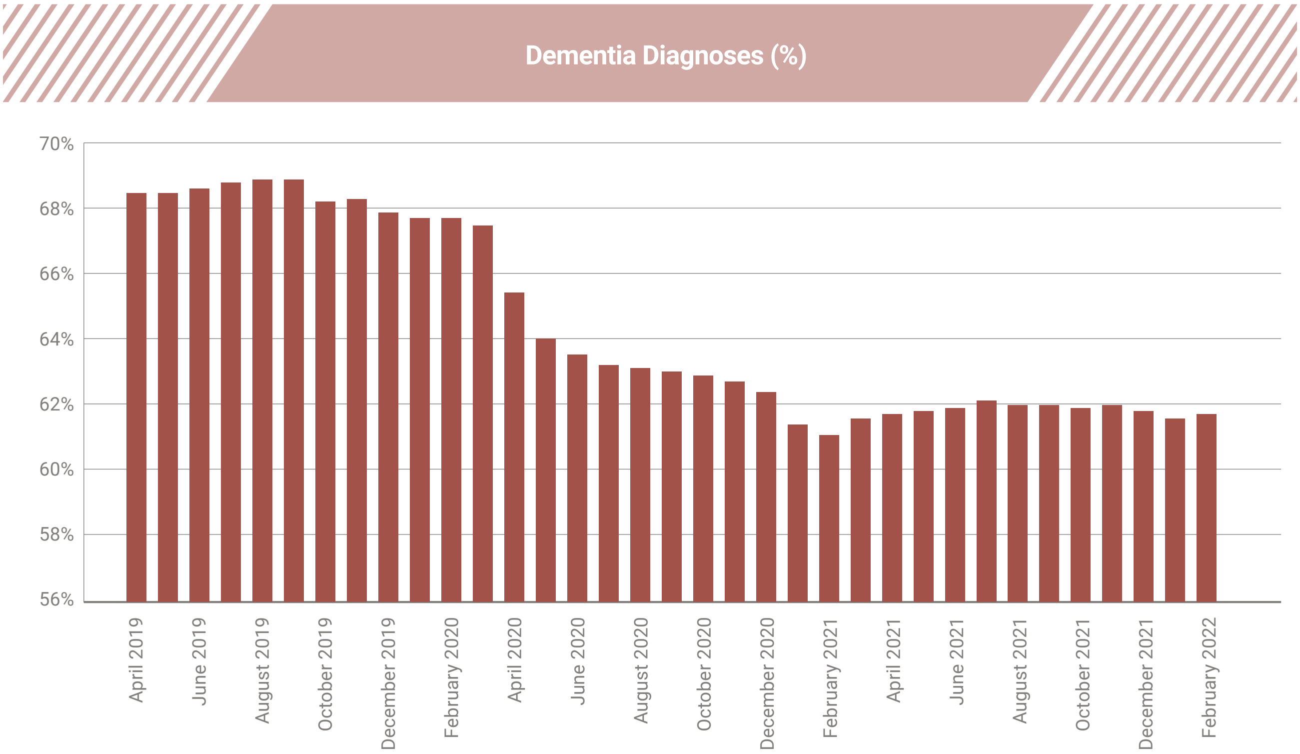
We know about cancer in our culture and people understand what it is, but when it comes to dementia there is just no understanding or awareness. It really does permeate every aspect of life – some people would not marry into families if there was a history of dementia, since mental health is such a stigmatised concept. This further entrenches the stigma surrounding the condition in my culture. A diagnosis unlocks a wealth of care and support to help people and their families live with the condition[37] .”

COVID-19 impact on people with dementia and dementia diagnosis

The pandemic has had a particularly significant impact on people with dementia and their families.

Dementia was the most common pre-existing condition for those who died from COVID-19[30]. People living with dementia who survived COVID-19 suffered increased isolation and a reduction in access to services and support[31]. 82% of people surveyed by the Alzheimer's Society (which included carers as well as those living with dementia), reported a deterioration in symptoms[32]. In February 2020 diagnosis rates for dementia fell below two thirds – the official Government target and have remained well below this target since[33].

Figure 3: National recorded dementia diagnoses as a percentage of overall dementia diagnoses[34]



In response, the Government made £17m available to NHS England and NHS Improvement in the 2021-22 financial year, to increase diagnoses, support memory services and tackle the backlog of appointments caused by the pandemic[35].

The most recent Government Mandate (2022-23) to the NHS includes a focus on the restoration of services for people with dementia, as well as action on the prevention of the disease[36]. However, it does not include specific ambitions around diagnoses.

CHAPTER 2 Dementia diagnosis rates in England

Prevalence of dementia

Across England rates of dementia vary. An analysis of the QOF data-set 2020/21 reveals an average national prevalence rate at Clinical Commissioning Group (CCG) level of 0.71%[38].

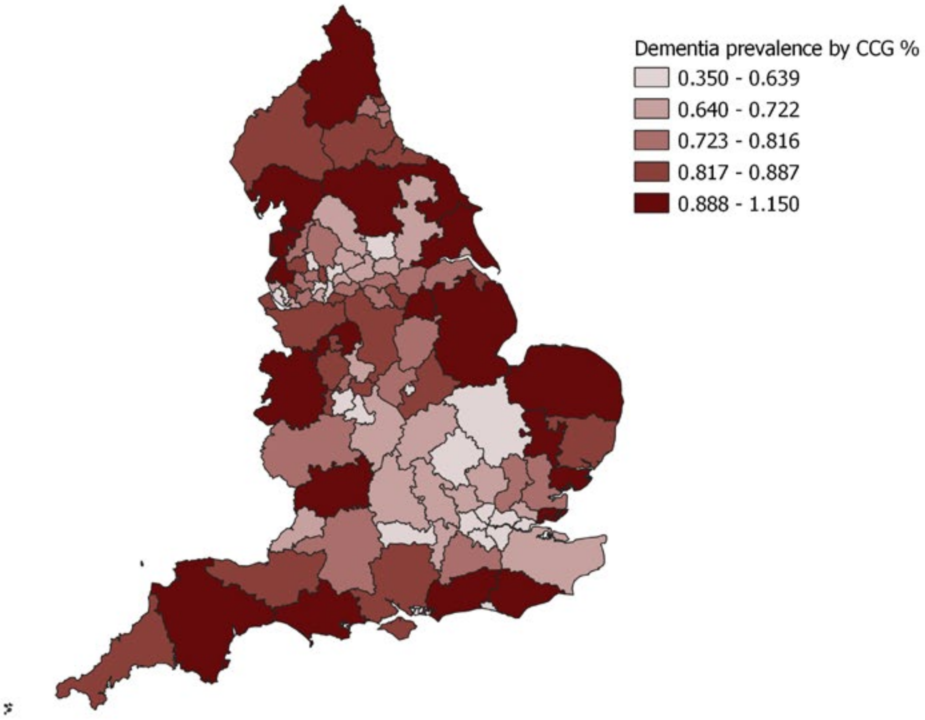
Table 1 below shows the extent of the variation. The proportion of people with dementia in London, 0.46%, was considerably lower than the average for England (0.71%), with the South West having highest prevalence (0.84%).

Table 1: Dementia prevalence by region compared to England average

Region name	Number of practices	List size	Register	Prevalence (%)	England equivalent prevalence (0.71%)	Difference
East of England	665	6,997,910	51,651	0.74	49,659	-1,992
London	1,195	10,359,317	48,052	0.46	73,512	25,460
Midlands	1,296	11,270,175	82,430	0.73	79,976	-2,454
North East and Yorkshire	1,009	9,077,155	70,084	0.77	64,414	-5,670
North West	991	7,620,875	56,393	0.74	54,080	-2,313
South East	848	9,465,121	72,313	0.76	67,167	-5,146
South West	567	5,925,691	49,934	0.84	42,050	-7,884
Total	**6,571**	**60,716,244**	**430,857**	**0.71**	**430,857**	**-**

The following map shows the regional variation in dementia prevalence.

Figure 4: Map of England showing variation in dementia prevalence, based on QOF 2020-21 data[39]



In the London region all CCGs have a lower prevalence of dementia compared with the national average. The CCGs with the highest rates of reported dementia prevalence for the last full year of data are set out in the table below. These CCGs have reported prevalence rates of 0.89% or more.

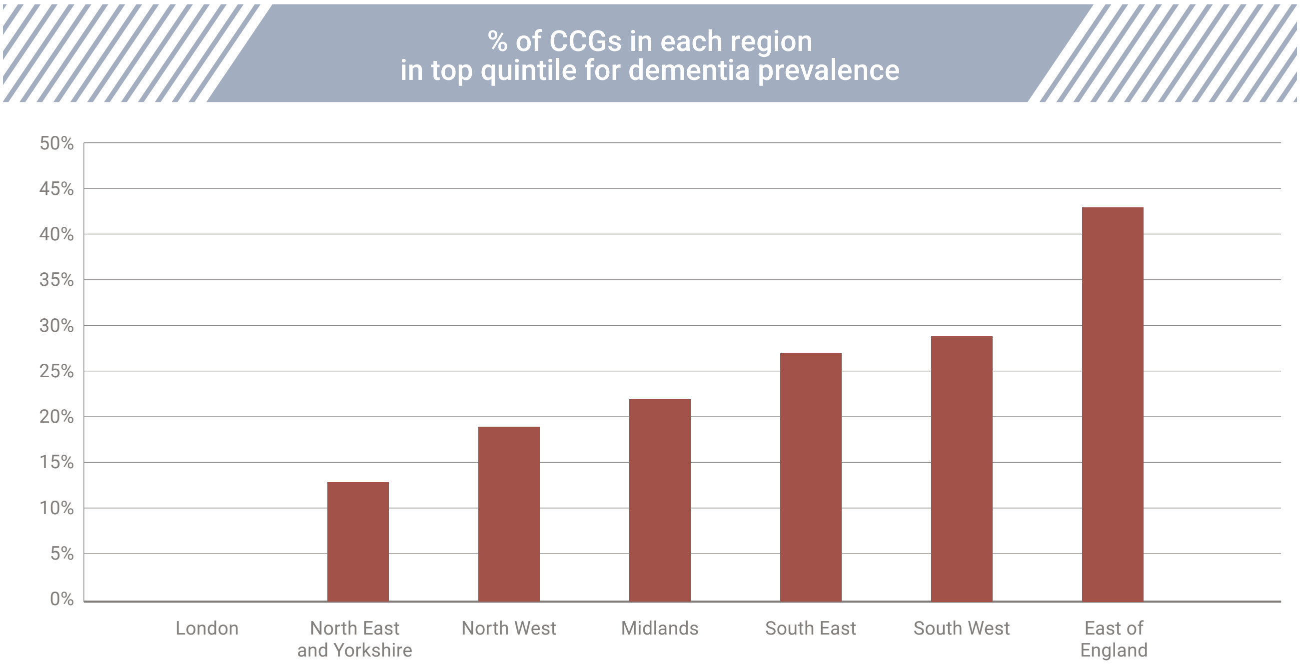
Table 2: CCGs in upper quintile of dementia prevalence

CCG	Prevalence (%)
NHS Southport and Formby CCG	1.15
NHS Fylde and Wyre CCG	1.13
NHS East Sussex CCG	1.08
NHS Morecambe Bay CCG	0.99
NHS East Riding of Yorkshire CCG	0.98
NHS North Staffordshire CCG	0.98
NHS Bassetlaw CCG	0.97
NHS Dorset CCG	0.96
NHS North East Essex CCG	0.95
NHS Castle Point and Rochford CCG	0.95
NHS North Yorkshire CCG	0.95
NHS Blackpool CCG	0.94
NHS Northumberland CCG	0.93
NHS Southend CCG	0.93
NHS West Lancashire CCG	0.92
NHS Lincolnshire CCG	0.92
NHS West Sussex CCG	0.92
NHS Devon CCG	0.90
NHS Shropshire, Telford and Wrekin CCG	0.89
NHS Norfolk and Waveney CCG	0.89
NHS West Suffolk CCG	0.89
NHS Gloucestershire CCG	0.89
NHS Stoke on Trent CCG	0.89

Within the upper quintile for dementia prevalence, the East of England has the highest representation of CCGs with 6 of its 14 (43%) included. The South West has 2 of its 7 CCGs (29%), Devon and Dorset, in the list.

London unsurprisingly has no CCGs in the top quintile. The North East and Yorkshire has only 3 of its 24 CCGs in the top quintile (13%) and the North West similarly has 5 of its 27 CCGs (19%) in the list.

Figure 5: Percentage of CCGs in each region within top quintile for dementia prevalence



Underdiagnosis of dementia

There is evidence that a substantial number of people with the symptoms of dementia are undiagnosed at any given time in England. In a study, Walker et al found that diagnosis of dementia in England is only 41% of what it would be expected to be[40]. In their work, Ford et al identified the types of symptoms that can be attributed to dementia but which may remain undiagnosed, including disorientation and wandering; behaviour change; schizophrenia and self-neglect[41].

This is an additional issue of concern in relation to potential inequalities associated with the diagnosis and treatment of dementia as there may be a higher burden of underdiagnosis of dementia across different areas of England.

To assess levels of underdiagnosis, a total estimated rate of prevalence based on age sex consensus was calculated by York Health Economics for each CCG. The QOF registered number of people with dementia (2020-2021) was then subtracted from the consensus calculated value to give a potential estimate of the number of undiagnosed people with dementia for each CCG, with the percentage rate of diagnosis compared with consensus estimate values being reported.

There were around 430,000 people with diagnosed dementia on the QOF register but as table 3 below shows the consensus values estimate dementia prevalence at around 750,000 in 2020-21[42]:

Table 3: Estimates of numbers of people with undiagnosed dementia in England 2020-21

Region name	Register	Consensus estimates	Estimated undiagnosed	Rate of diagnosis v consensus estimates
East of England	51,651	94,969	43,318	54%
London	48,052	80,277	32,225	60%
Midlands	82,430	144,867	62,437	57%
North East and Yorkshire	70,084	118,568	48,484	59%
North West	56,393	92,764	36,371	61%
South East	72,313	132,147	59,834	55%
South West	49,934	93,127	43,193	54%
Total	**430,857**	**756,719**	**325,862**	**57%**

The regional variation and extent of underdiagnosis is demonstrated through the graph and map below.

Figure 6: Regional variation in number of undiagnosed people with dementia

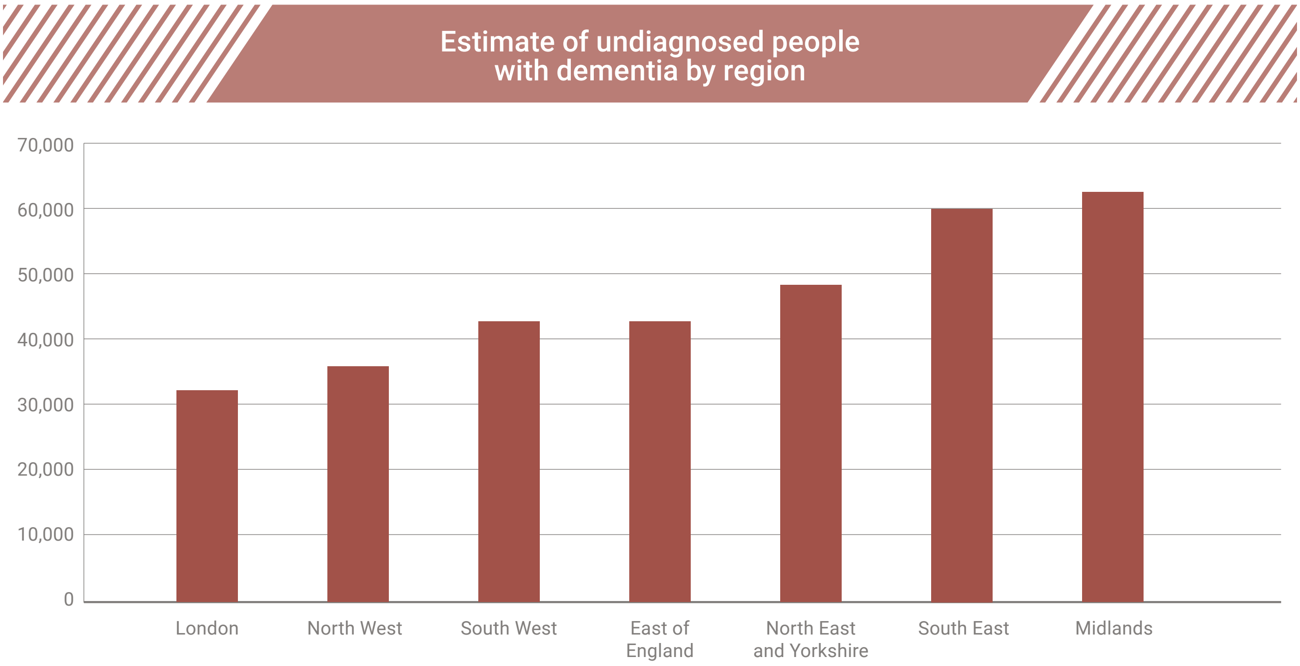
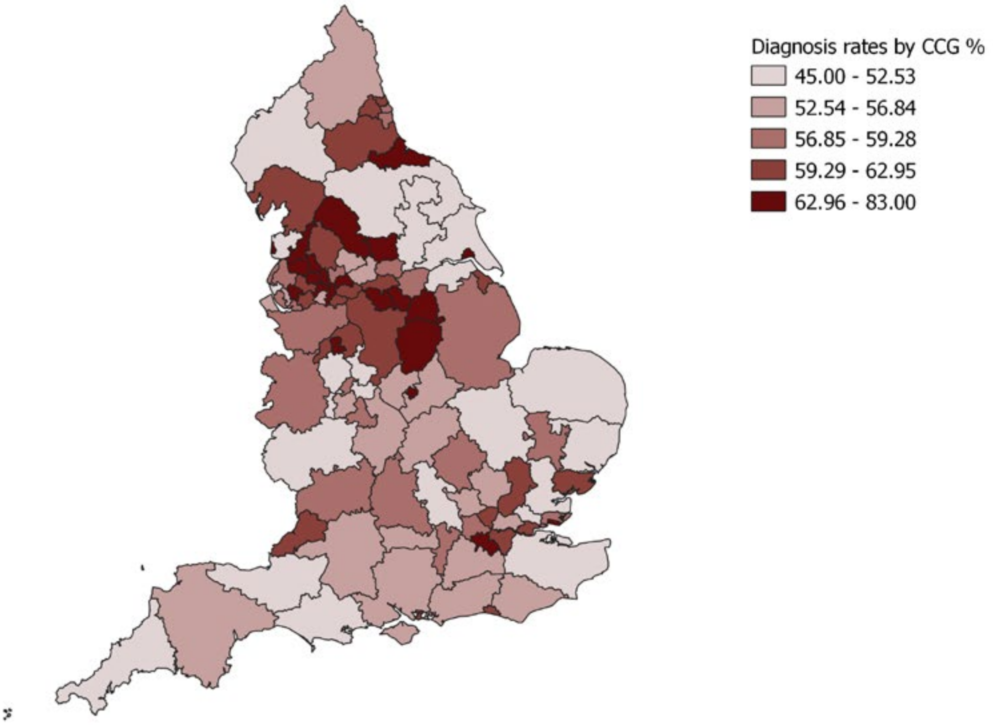


Figure 7: Regional variation in rates of dementia diagnosis by CCG based on YHEC analysis[43]



The Midlands has the largest number of undiagnosed people with dementia with over 60,000 people with the condition not yet diagnosed. The South East has just under 60,000 (59,834) undiagnosed. London (32,225) and the North West (36,371) both have less than 40,000 people undiagnosed.

Underdiagnosis of dementia was estimated for all CCG areas. Compared with consensus values, on average 57% of people with dementia are diagnosed and included on the QOF register. The proportion of those diagnosed ranged from 47% to 83% across different CCGs.

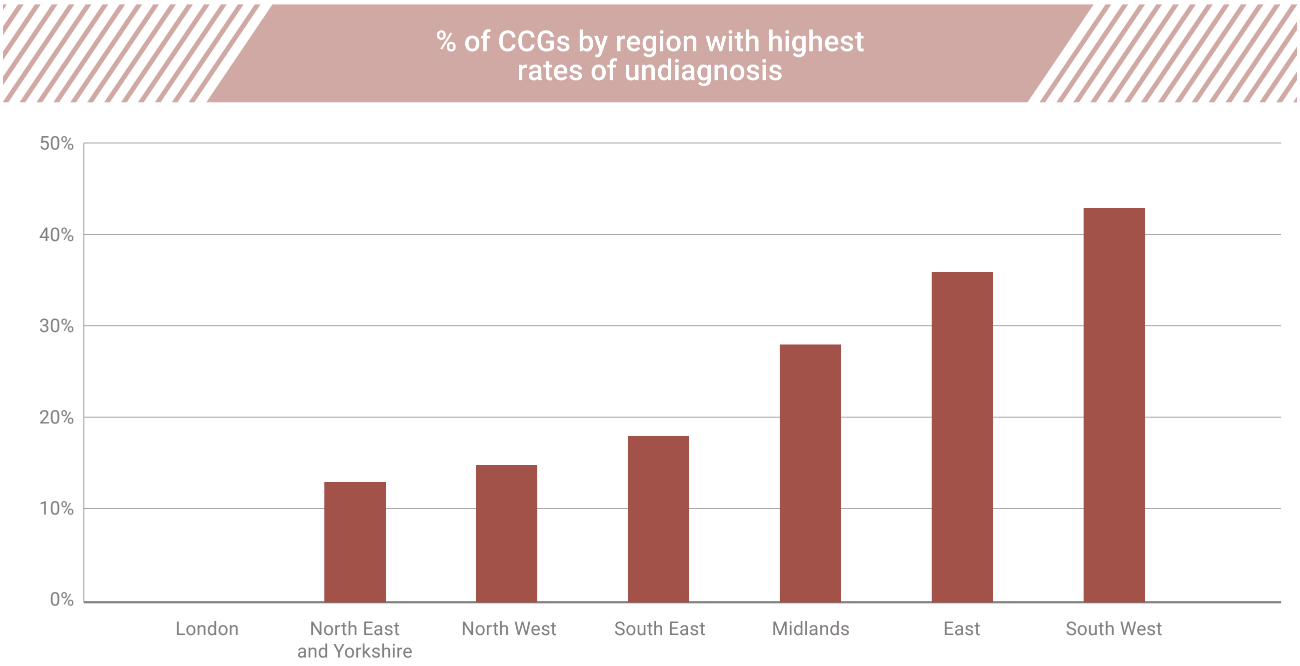
The following are the CCGs in the upper quintile for rates of undiagnosed dementia. These CCGs have estimated undiagnosed rates of between 47% and 54%:

Table 4: CCGs with highest rates of undiagnosed dementia

NHS Mid Essex CCG	NHS East Riding of Yorkshire CCG
NHS Norfolk and Waveney CCG	NHS North Yorkshire CCG
NHS Ipswich and East Suffolk CCG	NHS South Sefton CCG
NHS Cambridgeshire and Peterborough CCG	NHS Fylde and Wyre CCG
NHS Basildon and Brentwood CCG	NHS North Cumbria CCG
NHS Herefordshire and Worcestershire CCG	NHS Knowsley CCG
NHS Stafford and Surrounds CCG	NHS Kent and Medway CCG
NHS South East Staffordshire and Seisdon Peninsula CCG	NHS Buckinghamshire CCG
NHS North Lincolnshire CCG	NHS Kernow CCG
NHS East Staffordshire CCG	NHS Somerset CCG
NHS Vale of York CCG	NHS Dorset CCG

The following graph shows the proportion of CCGs by region with the lowest recorded rates of diagnosis:

Figure 8: CCGs with highest undiagnosed dementia rates by region



Nearly half of the South West's 7 CCGs (3 of 7) are in the upper quintile for undiagnosed dementia. The East of England (5 of 14) and Midlands (5 of 18) both have 5 CCGs in the list.

London which has the lowest rates of dementia prevalence nationally has no CCGs in this quintile. The North East and Yorkshire (3 of 24) and North West (4 of 27) both have less than 15% of CCGs with the worst diagnosis rates

Three CCGs are found in the upper quintile for prevalence and the upper quintile for under-diagnosis. They are:

- Dorset
- Norfolk and Waveney
- Fylde and Wyre

It would appear that with high rates of prevalence and under-diagnosis there is a particular need in these areas to make efforts to improve diagnosis.

Variations in diagnosis rates within regions

With the NHS moving towards ICSs and the expected imminent abolition of CCGs, it is worth exploring variations within regions as these new entities commence their work.

In a number of areas CCGs have already evolved to become a single organisation within the ICS, but in others a number of CCGs constitute an ICS footprint.

The following ICSs have the largest variation in diagnosis rates across their geographies:

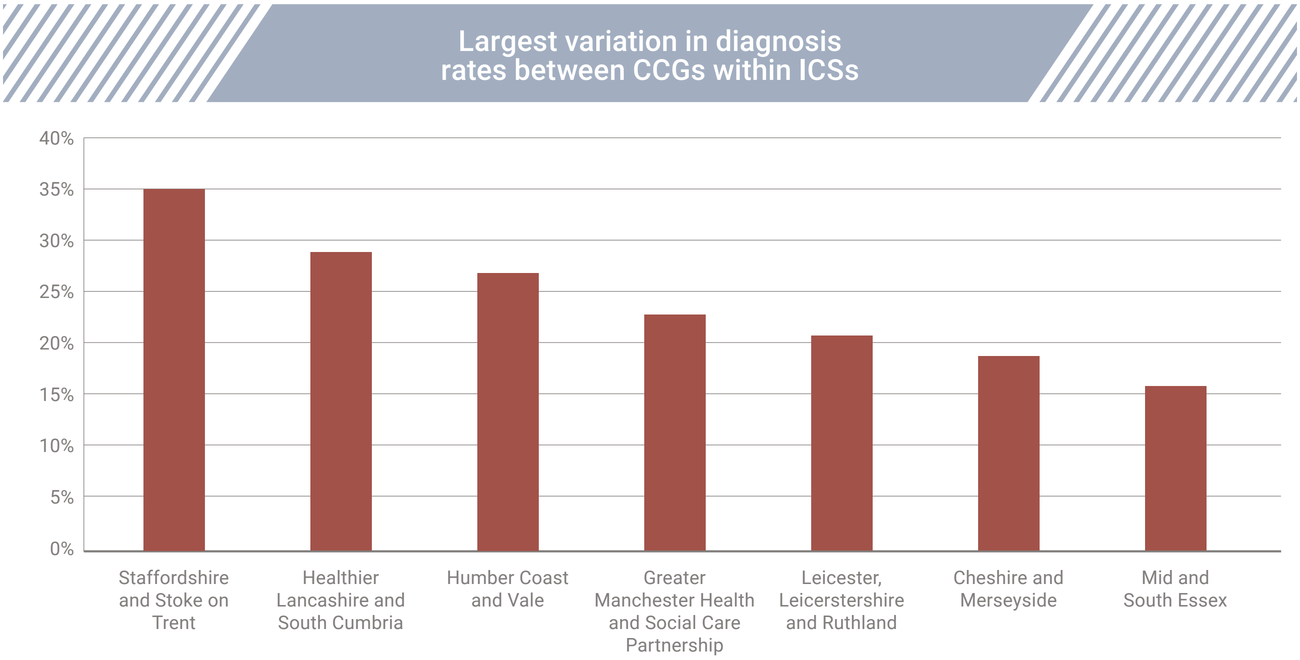
Table 5: Largest variation in diagnosis rates by CCGs within the same ICS

ICS	CCG	Estimated diagnosis rate vs consensus estimate	Variation
Staffordshire and Stoke on Trent	Stoke on Trent	83%	35%
	Stafford and Surrounds	48%	
Healthier Lancashire and South Cumbria	Blackpool	80%	29%
	Fylde and Wyre	51%	
Humber Coast and Vale	Hull	74%	27%
	Vale of York	47%	
Greater Manchester Health and Social Care Partnership	Manchester	77%	23%
	Trafford	54%	
Leicester, Leicestershire and Rutland	Leicester City	75%	21%
	East Leicestershire and Rutland	54%	
Cheshire and Merseyside	St Helens	66%	19%
	South Sefton	47%	
Mid and South Essex	Southend	65%	16%
	Mid Essex	49%	

The largest variation on this analysis is seen within Staffordshire and Stoke on Trent ICS, with Stoke on Trent CCG recording an 83% diagnosis rate but Stafford and Surrounds only recording a 48% rate. Four other ICSs had rates of variation over 20% including Healthier Lancashire and South Cumbria (29%) and Humber Coast and Vale (27%).

Tackling such variation through better service integration and co-ordination should be a priority for ICSs in regards to dementia as they begin their formal work this summer.

Figure 9: Variation between dementia diagnosis rates between CCGs within ICS footprints



CHAPTER 3

Dementia health inequalities and wider socio-economic costs

Dementia and health inequalities

The pandemic has demonstrated the extent of health inequalities across the country. These inequalities had been highlighted before COVID-19 particularly through two reviews conducted by Sir Michael Marmot in 2010 and 2020[44].

There is a range of evidence of people with dementia experiencing inequalities in access to treatment and support in living well.

A 2016 UK study looking at the relationship between deprivation and the prescribing of drugs targeting the symptoms of dementia found that deprived patients were 25% less likely to be initiated on the drugs than the least-deprived patients[45]. The study concluded that there was no evidence that the English National Dementia Strategy's key objective of reducing treatment inequalities was being achieved.

A more recent UK study on the same topic found that the least-deprived areas had approximately twice the rate of prescribing of drugs targeting the symptoms of dementia compared to the most-deprived areas. The observed inequality was increased by a threefold rise in the number of prescription items for drugs targeting the symptoms of dementia over the ten-year period (2009-2019). The study concluded that further analysis was needed to establish whether higher rates of prescribing in the least-deprived areas may be reflective of better and early diagnoses and access to treatments[46].

A 2018 study in Great Britain found that there were inequalities in living well with dementia according to levels of deprivation, and that additional resources were needed to improve care in highly deprived areas and support for those without an informal carer[47].

Rurality and dementia diagnosis

Accessing healthcare services in rural areas, where 10 million people in England live, can be challenging. Rural populations are also getting older. A 2019 report by Public Health England (PHE) into inequalities in older people living in coastal and rural communities noted that: “older people comprise a large and growing segment of the population of rural and coastal areas. The population aged 65+ will grow by around 50% in rural areas by 2039[48].”

A paper from the Local Government Association and PHE identified a range of health risks related to rural areas, summarised in the box below.

Health risks in rural areas

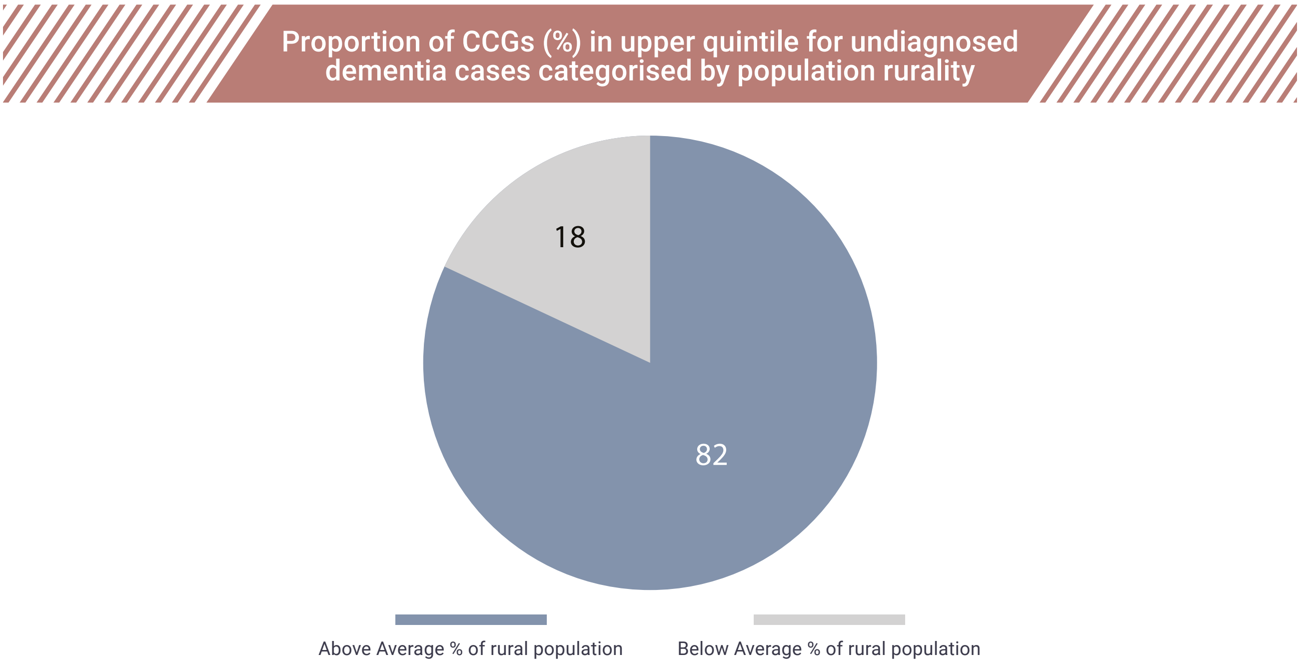
- Changing population demographics
- Infrastructure – in particular sparsity of transport links
- Digital access and exclusion
- Access to health services and longer travel distances
- Worsening air quality
- Increased risk of social isolation and loneliness
- Lack of affordable, good quality housing and fuel poverty
- Limited employment opportunities[49]

Rural populations in the UK are generally older and research suggests that getting a diagnosis of dementia, particularly in the early stages of the condition, in rural areas is challenging[50]. A study of health inequalities in Scotland found that such inequalities amongst the over 65s were greater in remote rural areas than urban areas for both males and females[51].

When examining links between rurality and dementia diagnosis rates, the data does appear to support a connection between above average levels of rural living and rates of under-diagnosis.

An analysis of CCGs in the upper quintile for proportions of people undiagnosed (see table 4) reveals that 4 of the 22 CCGs (18%) have lower than average numbers of people living in rural settings. Meanwhile the remaining 18 all have higher than average proportions of their population living in rural areas[52].

Figure 10: Proportion of CCGs (%) in upper quintile for undiagnosed dementia cases categorised by population rurality



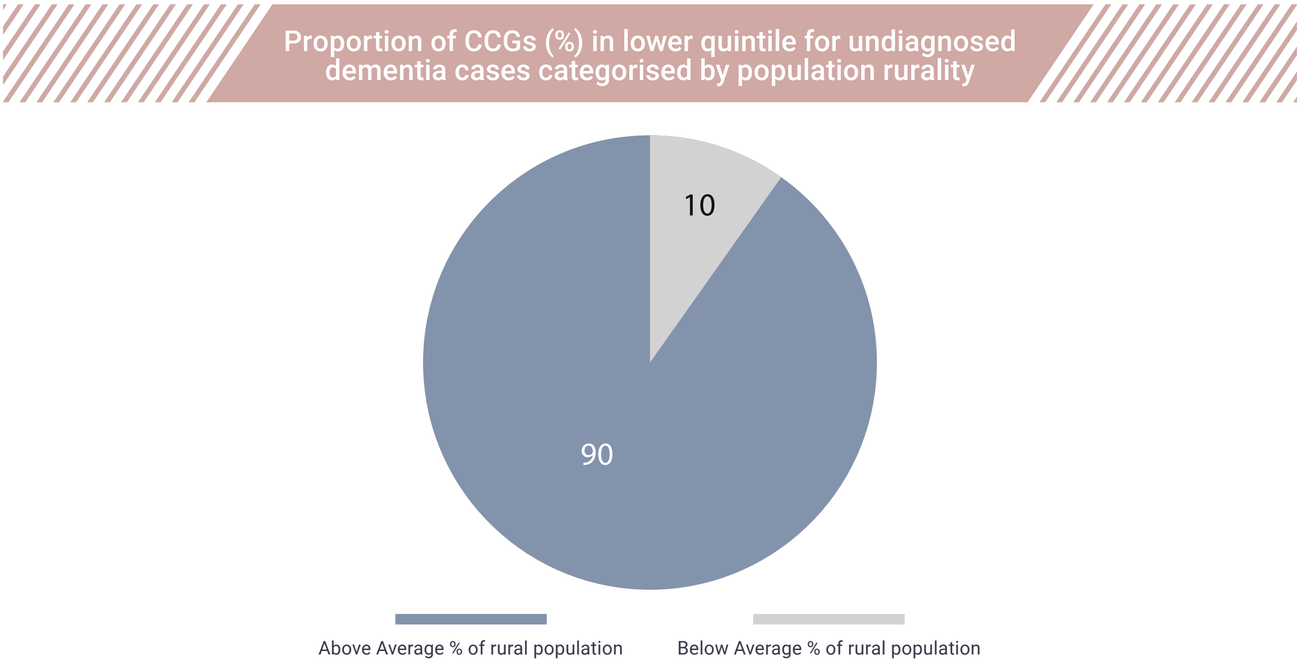
The following CCGs are in the lowest quintile for underdiagnosis; and have the highest diagnosis rates.

Table 6: CCGs with lowest rates of dementia underdiagnosis

NHS Salford CCG	NHS Bradford District and Craven CCG
NHS Rotherham CCG	NHS Oldham CCG
NHS Bassetlaw CCG	NHS Bolton CCG
NHS Nottingham and Nottinghamshire CCG	NHS Bury CCG
NHS Leeds CCG	NHS Hull CCG
NHS South West London CCG	NHS Leicester City CCG
NHS Tees Valley CCG	NHS Manchester CCG
NHS Southend CCG	NHS Blackburn with Darwen CCG
NHS Chorley and South Ribble CCG	NHS Blackpool CCG
NHS Sheffield CCG	NHS Stoke on Trent CCG
NHS St Helens CCG	

In contrast to those CCGs in the upper quintile, these CCGs have lower rural populations, with an average of under 5% of their populations classed as rural dwellers. Only 2 of the 21 have above the national CCG average rural population, while 19 (90%) have fewer than the average, with many in major towns and cities (such as Leeds, London, Nottingham and Stoke).

Figure 11: Proportion of CCGs (%) in the lower quintile for undiagnosed dementia cases categorised by population rurality



The above data snapshot would appear to confirm disparities in dementia diagnoses between urban and rural communities. Tackling these disparities should be a focus for ensuring diagnosis rates are returned to pre-pandemic levels.

Dementia and wider socio-economic costs

As highlighted earlier, the wider costs of dementia across health and social care are substantial. Not getting an accurate diagnosis can lead to greater costs as people do not get the treatment, care and support they need. This can be seen in the rising hospital costs associated with dementia[53].

A 2012 economic evaluation found that early assessment of dementia patients leads to savings or is highly cost-effective in the majority of cases through reduced health and social care resource use, and in producing better patient outcomes in terms of improved quality of life and extended life[54].

Table 7 details the lifetime estimated net cost savings (and equivalent 2021 values) for early assessment and treatment with donepezil 10mg for dementia versus no early assessment or treatment.

Table 7: Lifetime estimated net cost savings from early assessment and treatment for dementia

	2007 value	2021 value*
Direct lifetime cost savings	£3,593	£4,407
Indirect lifetime cost savings	£4,148	£5,087
Total lifetime cost savings	**£7,741**	**£9,494**

* The NHS cost inflation index (NHSCII) – taken from PSSRU Unit Costs of Health and Social Care 2021[55]

Direct care costs consist of medical costs (inpatient care, outpatient care, day hospitals and medication), community health costs, social care costs (day centres, social care, respite care), and costs of accommodation for institutionalised patients. Indirect costs were those associated with caregiver time by patients' primary caregivers.

Based on the estimates of people with undiagnosed dementia (as reported in Table 7 above), Table 8 shows the estimated cost savings using the findings of this study.

Table 8: Estimates of cost savings for people with undiagnosed dementia in England if early assessment and treatment was provided

Region name	Direct savings (£m)	Indirect savings (£m)	Total savings (£m)
East of England	190.9	220.4	411.3
London	142.0	163.9	305.9
Midlands	275.1	317.6	592.8
North East and Yorkshire	213.6	246.6	460.3
North West	160.3	185.0	345.3
South East	263.7	304.4	568.1
South West	190.3	219.7	410.1
Total	**1,435.9**	**1,657.7**	**3,093.7**

If the estimated numbers of people with undiagnosed dementia are accurate and if those people were assessed early and provided with treatment then the health and social care system could save £1.436 billion over their lifetime. Indirect, or societal benefits would be approximately an additional £1.658 billion for the same people.

CHAPTER 4

Opportunities and recommendations for improving dementia diagnosis rates

To explore opportunities for new action on improving diagnosis rates Future Health conducted a series of expert interviews and held a roundtable discussion with representatives from Government, the NHS, clinicians, professional bodies, academics and patient groups.

With a new dementia strategy expected shortly, there is now a real chance to make new progress on improving diagnosis rates and tackling regional variations.

Recommendation 1: Investment to support service recovery and future transformation

The pandemic has reversed some of the progress made in diagnosing dementia in recent years, restricted access to services and seen a wider deterioration in population health. There has been a reduction in primary care referrals to memory assessment clinics[56]. Ambitions within the Prime Minister's 2020 Dementia Challenge for a six week timeline from GP referral to assessment have not been met[57].

The Government's investment of an additional £17m in Memory Assessment Services to support recovery is highly welcome; but the Alzheimer's Society estimate that an investment of £70m is needed to recover services[58].

Investment in these services will be realised elsewhere in health and social care systems. Alzheimer's Research UK has estimated that the cost of dementia for hospitals has increased from £1.2bn in 2010/11 to £2.7bn in 2017/18. The number of people being admitted to hospital with dementia increased by 93% from 210,000 in 2010/11 to 405,000 in 2017/18. Underlying causes of admission for people with dementia included admissions for potentially preventable conditions such as pneumonia, sepsis, urinary system disorders, and leg fractures[59].

Looking ahead there is a need to develop a future NHS investment plan for dementia that goes beyond the diagnosis rates seen before the pandemic. A two-thirds diagnosis rate was a significant achievement for the NHS, but should not be seen as a set benchmark – a higher overall diagnosis rate in the future should be the ambition.

This investment plan will need to consider:

- How to ensure patients diagnosed with Mild Cognitive Impairment (MCI) – impairment that is greater than that associated with normal ageing, but not as marked as someone with early-stage dementia – are able to request further investigation into the underlying case, including CSF testing
- How to unlock the benefits of new digital tools to support better screening and monitoring of people at risk of dementia
- How to support primary care in particular to support timely referrals for assessments

Recommendation 2: New targets on diagnosis and the importance of recording diagnosis subtype

Additional investment should be used to support an updated ambition around dementia diagnosis within the new dementia strategy and NHS Long-Term Plan refresh. This should not just focus on numbers diagnosed, but also aim to achieve improved levels of the recording of diagnosis subtype across the country.

Despite the number of subtypes of dementia, patients often find themselves with a generic diagnosis. Evidence shows that the needs of dementia patients vary depending on the type of dementia they have[60]. A lack of subtype diagnosis hinders health and social care professionals from tailoring a treatment and care package around a patient's needs. As new, more personalised, treatments for dementia become available, effective diagnosis subtyping will become ever more important.

At present there is a shortage and uneven distribution of diagnostic equipment to deliver this. This equipment is often accessible if a patient lives near a teaching hospital which will have the necessary equipment to provide a PET scan and lumbar puncture. However, it becomes more difficult for patients living further away from these facilities such as in rural areas.

There are also challenges regarding the access of memory clinics to the Picture Archiving and Communication System (PACS) system for imaging, which makes accurate and subtyping diagnosis difficult.

If all those living with dementia are to receive the same standards of care and treatment then there must be substantial investment in diagnostic equipment such as PET scanners and CSF testing that is more evenly distributed across the country, tackling these geographic inequalities.

Case study: National Memory Service Audit

In 2019 the London Dementia Clinical Network conducted a national audit of memory services. The audit was voluntary and 85 of 215 centres participated. The audit found:

- Variation in the percentage of people referred for diagnostic neuropsychology, suggestive of under provision in some services and possible over-referral in others, along with a lack of standardised criteria for which patients should be referred
- 60% of memory services are unable to view brain images as they do not have access to PACS (picture archiving and communication system). These images are helpful for subtyping diagnosis
- A quarter of services offered everyone a scan who had not previously had one, while some services were offering very few patients a scan. The NICE dementia guideline states that structural imaging should be offered to rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established and the subtype is clear

The report made a series of recommendations for further action including the improvement of access to the PACs service to support the subtyping of diagnosis[61]. The Royal College of Psychiatrists is currently running an updated audit of memory services[62].

Recommendation 3: Introducing incentives for primary care

Primary care will be critical to improving dementia services and the right incentive structure is needed to support the improvements in diagnosis rates. There are question marks about the long term future of the QOF; but whilst this remains the primary lever for quality improvement in primary care, there are opportunities to use the framework to better incentivise improvements in diagnosis. The past inclusion of case finding and dementia diagnosis as a Direct Enhanced Service (DES) was seen as important in delivering past acceleration in diagnosis rates[63].

It will be important that any such incentives align with ambitions for more holistic and person-centred care. Patients with dementia often have other conditions (e.g. diabetes, hypertension) and dementia can impact on their ability to manage these, worsening outcomes and raising costs. Co-ordination and proper auditing and monitoring of patient records in particularly relevant settings – such as in care homes – can ensure that care is holistic and effective[64].

For certain populations the revised and more technologically enabled NHS Health Check presents a further opportunity to deliver this more rounded approach to care[65]. The Health Check should be used to inform those aged 40- to 64-year-olds about how to improve their brain health by stopping smoking, improving physical activity and diet and reducing alcohol consumption.

Recommendation 4: Dementia as an exemplar for delivering more integrated care

Dementia has often been seen as a mental health issue within the NHS or as a social care problem. The new dementia strategy presents an opportunity for the NHS to place a new focus on the condition and to work with a range of partners to properly tackle the growing challenge it poses.

Regionally, ICSs should appoint a designated dementia lead and in those systems with widespread variation, highlighted above, plans should be developed and published to bring down the level of variation within the geographic boundary. There may be a supportive role for Academic Health Science Networks (AHSNs) here with experience of working across geographical boundaries on sharing good and innovative service practice.

Case study: Surrey County Council and the NHS, joint dementia strategy

In December 2021 Surrey County Council and the NHS published a health and care dementia strategy. The document seeks to bring together those involved in the commissioning and delivery of dementia services to improve the quality of life for those with dementia and their families. The strategy notes the reduction in diagnosis rates during the pandemic and sets out a plan for service recovery based on re-designing services to increase capacity:

“In the restoration and recovery phase the focus is on increasing the memory assessment clinics capacity and, for those who continue to require more stringent social distancing, encouraging virtual assessment where appropriate. To increase capacity, we support the introduction of memory assessment within our developing integrated hubs utilising the skills of clinicians with a special interest in Dementia. The post diagnostic support will be provided through Admiral Nurses (Guildford & Waverley) /Enhanced Care practitioners (East Surrey) / Dementia Nurse specialist (Northwest Surrey and Mid Surrey) to prevent crisis, reduce emergency acute and psychiatric admissions that have seen recent increase in the placed based areas/localities. These schemes will utilise the additional Dementia diagnosis and post diagnostic resources allocated to Surrey. The roles in each place are slightly different due to different pathways in the placed based areas[66].”

Recommendation 5: Establish a National Dementia Observatory to compile data and share good practice across the NHS and social care system

The national audit of memory services noted above is a helpful and important exercise in assessing service quality. However not all services participate and there is no clear, overall assessment of whether NICE guidelines and standards are being followed consistently across the country.

The establishment of a National Dementia Observatory would help national quality improvement efforts and support identifying areas of good practice that can be shared more widely.

Alongside national improvement, at a regional and local level, efforts for improved population health management by new integrated systems will only be successful if data is available at a highly localised level. This granularity of data can support better case finding and more focused interventions for particular populations and communities, particularly those more at risk of dementia.

Recommendation 6: Build and train a workforce to support improvements in dementia diagnosis rates and earlier diagnosis

The impact of the pandemic and backlogs of care are likely to mean significant pressures on health and care staff for a long time. GPs will be central to supporting the recovery of diagnosis rates through timely referrals. New digital tools that have greater accuracy than current cognitive screening instruments will need to be invested in to support this along with training on the diagnostic pathway.

The opportunities of more integrated and multi-disciplinary models of working through primary care networks and ICSs present opportunities for working differently and flexibly. Examples of such practice include working with Admiral Nurses and care navigators to support dementia patients and their carers. There are also models emerging to more closely co-ordinate the work of neurologists, who are important for subtyping dementia diagnosis, within the community to support better dementia diagnosis and referrals.

Any future national workforce plan such as that being developed by Health Education England, will need to take into account the rising prevalence of dementia and the multi-disciplinary teams needed to support those with the condition and their families. Efforts will be needed as part of this to increase the number of neurologists. The UK has only 1 neurologist per 83,000 people. In the EU and the USA there are 1 per 15,000 and 1 per 19,000 respectively. Neurologists are unevenly distributed, with “about 25% of neurologists working in inner London where there is one consultant per 37,000 people compared with figures of between 1 per 71,000 and 1 per 106,000 in the rest of the country[67].”

Case study: Barnsley ‘Trio’ Memory Assessment and Support Service

The Barnsley Memory Assessment and Support Service (MASS) delivers a comprehensive, one-stop service through a hub and spoke model. It is located within the Older Person’s Community Mental Health Team, which enables collaborative working. The model aims to address variation between GP practices in the identification of patients with suspected memory problems, by integrating MASS workforce within Primary Care Networks. This is achieved by providing a ‘trio’ service, comprising a band 6 nurse, a band 5 nurse and a band 3 Memory Support Worker who are attached to each practice, building relationships and providing continuity with primary care colleagues. The Memory Support Workers maintain links with dementia champions in each GP practice, while the band 5 nurses maintain a community role in the review and assessment of patients known to the service. This mix of skills enables the trio to meet patients’ complex needs. Primary care colleagues can also ask the trio for advice and to facilitate clinical case discussion. This offers a robust assessment and referral process for those referred into MASS. In some practices, the trio offer a pre-referral assessment clinic. Individual GP practices report that the service is accessible and quick to react, and that GPs know who to contact for advice or discussion about individual patients[68].

Case study: Dementia care navigators in Gateshead

Two GP healthcare assistants received online training and peer support to help understand dementia and ways of providing non-medical support to people with dementia and their carers.

For each new patient, they spend time getting to know the patient and their carers, identifying unmet needs and connecting them with sources of support. Common issues include social isolation and inactivity, and the navigators have built an extensive knowledge of the voluntary and community groups that can help. The navigators also act as a first port of call for nursing homes, handling issues such as prescription requests, visit requests and post-discharge coordination of services.

The navigators provide some direct support to patients and carers themselves, through regular fortnightly contact via telephone or a home visit, open invitations to the surgery for a “catch up and cuppa” and regular “getting to know you” events to meet with other people in similar situations.

An evaluation by Deloitte reported that, in the first three months the navigators supported the GPs at the practice with screening 117 patients for dementia, agreeing 396 care plans with patients and connecting 43 carers and 20 veterans with local services. They undertook post-discharge support, coordination of services and medication for 86 patients, removing the need for a GP appointment. Hospital admissions fell, by as much as 80%, for patients in contact with the navigators[69].

Recommendation 7: Launch a new public health campaign to improve brain health and tackle stigma associated with dementia

49% of UK adults say that dementia is the condition that they fear most about getting in the future, with this rising to 60% of over 65s. Nearly a third (31%) incorrectly believe there are medicines available on prescription on the NHS that can slow the underlying causes of the disease[70].

There are particular challenges regarding the stigma of dementia in certain communities. According to the Alzheimer’s Society, stigma may be more common in Asian and Eastern European communities as well as African Caribbean and Irish communities. As a result, some families may conceal or ignore early signs of dementia and delay seeking support, resulting in difficulty accessing a diagnosis[71].

More positively 40% of people would adopt a healthier lifestyle to reduce their risk of developing dementia[72].

The World Health Organisation’s public health dementia roadmap to 2025 notes the importance of public engagement to tackle stigma regarding dementia: “increasing public awareness, acceptance and understanding of dementia and making the societal environment dementia-friendly will enable people with dementia to participate in the community and maximize their autonomy through improved social participation[73].”

With the creation of the Office for Health Improvement and Disparities and a forthcoming white paper on health disparities there is an opportunity to use this moment to launch a new public health campaign on dementia to reduce stigma and encourage improvements in brain health.

Case study: Canadian dementia public awareness campaign

In January 2022 Canada's Public Health Agency (PHAC) launched its first national dementia awareness campaign to reduce negative perceptions about dementia and the people living with the condition. The agency has partnered with author, broadcaster and science communicator Jay Ingram, for the campaign, who wrote the book The End of Memory: a natural history of Alzheimer's and Aging, based on his personal and professional observations of the impact of dementia[74].

The campaign aims to support the implementation of Canada's first national dementia strategy. One of the objectives of the strategy is to eliminate stigma and promote measures that create supportive and safe dementia-inclusive communities[75].

Conclusion

Good progress had been made before the pandemic in increasing rates of dementia diagnosis. A diagnosis opens up access to a range of support and help for patients and their families. However, the impact of the pandemic in restricting access to services and subsequent backlogs of care across the NHS, has seen diagnosis rates fall significantly.

Looking ahead there is now an urgent need for the NHS to get back on track with diagnosing dementia, tackling variations regionally and ensuring more patients get access to the treatment and care they need.

To deliver on this, a multi-faceted approach across public health, the NHS and care services, will be required. Stigma will need to be properly addressed, public health campaigns launched, memory services invested in, incentives implemented, better data collected and new workforce models scaled and built for the future.

People with dementia and their families were some of the worst impacted by COVID-19; improving dementia diagnosis and care should now become a central mission of the NHS recovery.

This policy framework if implemented will not only see dementia diagnosis rates recover but continue to improve beyond pre-pandemic levels. This – alongside better diagnosis subtyping – will ensure people can access the personalised and tailored treatment and care they need.

Annex: Methodology note

YHEC methodology for estimating dementia diagnosis rates

YHEC developed an estimate of the potential extent of underdiagnosis of dementia in England by using Office of National Statistics (ONS) sex and age populations for each CCG and applying age sex standardised consensus estimates of the population prevalence (%) of late-onset dementia[76]. Consensus estimates on prevalence were obtained from the report compiled by Prince et al (2014) for the Alzheimer's Society[77].

The ONS data were grouped by age for both males and females in 5-year age bands from 60 through to 90+. The prevalence estimates shown in the table below were multiplied by the relevant populations for each age band by sex. Although the consensus estimates banding is split into 90 to 94 and 95+, ONS data only band people into age 90+, so the age 90 to 94 estimates were used for the whole population over the age of 90. The consensus estimates on prevalence are shown in the following table.

Consensus estimates on dementia prevalence in the UK in 2014

Age in years	Current estimates (Dementia UK 2014)		
	Female	Male	Total
60 to 64	0.9	0.9	**0.9**
65 to 69	1.8	1.5	**1.7**
70 to 74	3.0	3.1	**3.0**
75 to 79	6.6	5.3	**6.0**
80 to 84	11.7	10.3	**11.1**
85 to 89	20.2	15.1	**18.3**
90 to 94	33.0	22.6	**29.9**
95+	44.2	28.8	**41.1**

A total estimated rate of prevalence based on age sex consensus was calculated for each CCG. The QOF registered number of people with dementia was then subtracted from the consensus calculated value to give a potential estimate of the number of undiagnosed people with dementia for each CCG, with the percentage rate of diagnosis compared with consensus estimate values being reported.

Compared with the QOF registered patients, the estimate of the number of people with dementia was much greater using the consensus calculated prevalence values. There are around 430,000 people with diagnosed dementia on the QOF register but the consensus values estimate dementia prevalence at around 750,000. Underdiagnosis of dementia was estimated for all CCG areas. Compared with consensus values, on average 57% of people with dementia are diagnosed and included on the QOF register. This ranged from 47% to 83% across different CCGs.

References

All accessed May 2022 unless otherwise stated.

1 https://www.dementiastatistics.org/statistics/perceptions-of-dementia/

2 https://www.nhs.uk/conditions/Alzheimer's-disease/causes/

3 https://www.Alzheimer's.org.uk/blog/difference-between-dementia-Alzheimer's-disease

4 https://www.Alzheimer's.org.uk/about-dementia/types-dementia

5 https://www.Alzheimer's.org.uk/about-dementia/types-dementia

6 https://www.Alzheimer's.org.uk/about-dementia/types-dementia/what-is-dementia

7 https://www.Alzheimer's.org.uk/blog/how-many-people-have-dementia-uk

8 Dementia 2020 Challenge: 2018 Review Phase 1 (p.5)

9 York Health Economics Consortium, Roche data on file, M-GB-00006845

10 https://www.merriam-webster.com/dictionary/biomarker

11 https://www.sciencedirect.com/science/article/pii/S1474442221000661?via%3Dihub

12 https://alzres.biomedcentral.com/articles/10.1186/s13195-017-0312-4

13 https://www.Alzheimer's.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers

14 https://www.Alzheimer's.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers

15 https://www.Alzheimer's.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers

16 https://www.Alzheimer's.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers

17 https://www.Alzheimer's.org.uk/blog/why-spotting-early-signs-dementia-important

18 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

19 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf

20 https://www.gov.uk/government/news/dementia-diagnosis-to-be-overhauled

21 https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020

22 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf

23 https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf (p.10 and p.15)

24 https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf (p.63)

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

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

27 https://www.nice.org.uk/guidance/ng97

28 https://www.nice.org.uk/guidance/qs184/chapter/Quality-statement-2-Diagnosis

29 https://www.Alzheimer's.org.uk/about-us/policy-and-influencing/what-we-think/dementia-statements-and-rights

30 https://www.Alzheimer's.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf (p6)

31 https://www.Alzheimer's.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf (p6-7)

32 https://www.Alzheimer's.org.uk/news/2020-07-30/lockdown-isolation-causes-shocking-levels-decline-people-dementia-who-are-rapidly

33 https://www.Alzheimer's.org.uk/blog/how-many-people-have-dementia-uk

34 https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses#latest-statistics

35 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/973936/covid-19-mental-health-and-wellbeing-recovery-action-plan.pdf (p52)

36 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1065713/2022-to-2023-nhs-england-mandate.pdf (p.12 and p.17)

37 https://www.alzheimers.org.uk/sites/default/files/2021-09/ethinic_minorities_increasing_access_to_diagnosis.pdf (p.14-15)

38 Roche data on file, original source: https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/quality-outcomes-framework-qof

39 Future Health mapping of YHEC QOF analysis. Map Source: Office for National Statistics licensed under the Open Government Licence v.3.0, Contains OS data © Crown copyright and database right [2021]

40 Walker, I., Lord, P., & Farragher, T. (2017). Variations in dementia diagnosis in England and association with general practice characteristics. Primary Health Care Research & Development, 18(3), 235-241. doi:10.1017/S146342361700007X

41 Ford, E., Rooney, P., Oliver, S. et al. Identifying undetected dementia in UK primary care patients: a retrospective case-control study comparing machine-learning and standard epidemiological approaches. BMC Med Inform Decis Mak 19, 248 (2019). https://doi.org/10.1186/s12911-019-0991-9

42 Roche data on file, analysis undertaken by York Health Economics Consortium. Source: Clinical commissioning group population estimates (National Statistics) - Office for National Statistics (ons.gov.uk) Methodology: Consensus estimates on prevalence were obtained from the report compiled by Prince et al (2014) for the Alzheimer’s Society. The ONS data were grouped by age for both males and females in 5-year age bands from 60 through to 90+. The prevalence estimates were multiplied by the relevant populations for each age band by sex. Although the consensus estimates banding is split into 90 to 94 and 95+, ONS data only band people into age 90+, so the age 90 to 94 estimates were used for the whole population over the age of 90.

43 Future Health analysis of YHEC data. Map Source: Office for National Statistics licensed under the Open Government Licence v.3.0, Contains OS data © Crown copyright and database right [2021]

44 https://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review; https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on

45 Cooper C, Lodwick R, Walters K, Raine R, Manthorpe J, Iliffe S, Petersen I. Observational cohort study: deprivation and access to anti-dementia drugs in the UK. Age and ageing. 2016 Jan 1;45(1):148-54.

46 Vohra N, Hadi MA, Khanal S, Kurmi OP, Paudyal V. Impact of deprivation, dementia prevalence and regional demography on prescribing of antidementia drugs in England: A time trend analysis. British Journal of Clinical Pharmacology. 2021 Oct;87(10):3747-55.

47 Wu YT, Clare L, Jones IR, Martyr A, Nelis SM, Quinn C, Victor CR, Lamont RA, Rippon I, Matthews FE, Improving the experience of Dementia and Enhancing Active Life (IDEAL) study. Inequalities in living well with dementia—The impact of deprivation on well-being, quality of life and life satisfaction: Results from the improving the experience of dementia and enhancing active life study. International journal of geriatric psychiatry. 2018 Dec;33(12):1736-42.

48 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/824723/Health_Inequalities_in_Ageing_in_Rural_and_Coastal_Areas-Full_report.pdf (p4)

49 https://www.local.gov.uk/sites/default/files/documents/1.39_Health%20in%20rural%20areas_WEB.pdf (p8)

50 https://www.Alzheimer's.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf (p34)

51 Levin, K.A. and A.H. Leyland, A comparison of health inequalities in urban and rural Scotland. Social science & medicine (1982), 2006. 62(6): p. 1457-1464. https://pubmed.ncbi.nlm.nih.gov/16182421/

52 Future Health used the Rural Urban Classification (RUC) of CCGs from the ONS to determine the average rurality of CCG populations and calculate a national average: https://geoportal.statistics.gov.uk/datasets/ons::rural-urban-classification-2011-of-ccgs-including-population-in-england/about

CCG boundaries and associated data were merged where needed to align the 2011 data of RUC with the current CCG footprints

53 https://www.Alzheimer'sresearchuk.org/cost-of-dementia-hospitals-england-doubles/#:~:text=Alzheimer’s%20Research%20UK%20reveals%20the,1.2bn%20in%202010%2F11.

54 Getsios, D., Blume, S., Ishak, K.J., Maclaine, G. and Hernández, L. (2012), An economic evaluation of early assessment for Alzheimer’s disease in the United Kingdom. Alzheimer’s & Dementia, 8: 22-30. https://doi.org/10.1016/j.jalz.2010.07.001

55 Jones, K. & Burns, A. (2021) Unit Costs of Health and Social Care 2021, Personal Social Services Research Unit, University of Kent, Canterbury. DOI: 10.22024/UniKent/01.02.9234

56 https://www.Alzheimer's.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf (p.8)

57 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf (p31)

58 Alzheimer’s Society presentation to Future Health roundtable 5 April 2022

59 https://www.Alzheimer'sresearchuk.org/cost-of-dementia-hospitals-england-doubles/

60 https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-018-1135-2

61 https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf (p.20)

62 https://www.rcpsych.ac.uk/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/fifth-round-of-audit

63 https://www.Alzheimer's.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf (p13)

64 https://www.psi-napse.com/cms/resources/dementiadiagnosticchallenges2017.pdf (p.4)

65 https://www.gov.uk/government/publications/nhs-health-check-programme-review/preventing-illness-and-improving-health-for-all-a-review-of-the-nhs-health-check-programme-and-recommendations

66 https://www.surreysays.co.uk/adult-social-care-and-public-health/dementia-strategy-survey/user_uploads/dementia-strategy-for-consultation-dec-2021.pdf (p.11)

67 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6616178/#:~:text=Unfortunately%2C%20the%20UK%20has%20too,neurologists%20are%20extremely%20unevenly%20distributed.

68 https://www.Alzheimer's.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf (p.24)

69 https://www.england.nhs.uk/gp/case-studies/primary-care-navigators/

70 https://www.dementiastatistics.org/statistics/perceptions-of-dementia/

71 https://www.Alzheimer's.org.uk/sites/default/files/2021-09/ethinic_minorities_increasing_access_to_diagnosis.pdf (p13)

72 https://www.dementiastatistics.org/statistics/perceptions-of-dementia/

73 https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1 (p14)

74 https://www.newswire.ca/news-releases/the-public-health-agency-of-canada-launches-a-national-dementia-awareness-campaign-to-help-reduce-stigma-819945226.html

75 https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/National%20Dementia%20Strategy_ENG.pdf (p.17)

76 Clinical commissioning group population estimates (National Statistics) - Office for National Statistics (ons.gov.uk)

77 https://www.Alzheimer's.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf (xii); Prevalence of early-onset dementia, as with late-onset dementia, increases exponentially with increasing age, roughly doubling every five years. The 60–64 age group has been included in the late-onset dementia consensus, as there is more evidence available to estimate prevalence for this age band.

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