

The background of the cover is a large, circular graphic filled with a dense arrangement of interlocking gears. The gears are rendered in various colors including gold, blue, purple, and grey, creating a complex, mechanical pattern. Overlaid on this are several concentric, semi-transparent dark blue circles that frame the central text.

Dementia Commission:

2023 Report



**NHS Innovation and
Life Sciences Commission**



Foreword

When they materialise, the advent of major health innovations can be overwhelming. The first instinct is excitement about the potential to change and even save lives, but that is swiftly followed by the dawning realisation of how many things need to change – and quickly – so that the innovation in question can reach the people who will benefit from it.

Nowhere in current medicine is this more true than in the field of dementia. After decades of false starts, we are finally on the cusp of therapeutic breakthroughs that will lead to disease-modifying therapies being regulated and reimbursed in the NHS. It was this exciting prospect that encouraged the Commission to focus on this field during the past year.

As our inquiry progressed, and while the excitement about treating and even preventing dementia has remained, it has become clear to us just how radically the way we diagnose, treat, and care for dementia patients must change. Almost no part of the care pathway, and the underlying infrastructure needed to support it, should remain untouched.

First, we must change our attitude – away from the disease whose grim progress is inevitable and toward one that can be ameliorated and eventually avoided. A problem to be solved, not a burden to be shouldered. Then, we need to leverage a range of technologies, some new and some old, to improve diagnosis and make it happen much earlier in the progression of the disease.

While we can all be excited by the innovations in new technologies that may modify the disease process, our commission also highlights some of the variation in diagnosis geographically and the impact this has on the utilisation of stretched clinical services. Additionally, the impact of the condition on carers and family members needs to be looked at through the level of support and training they can access, but also of the economic impact for them and society more generally. With the scale of the problem, investing in supporting families and carers should have a positive longer-term economic impact.

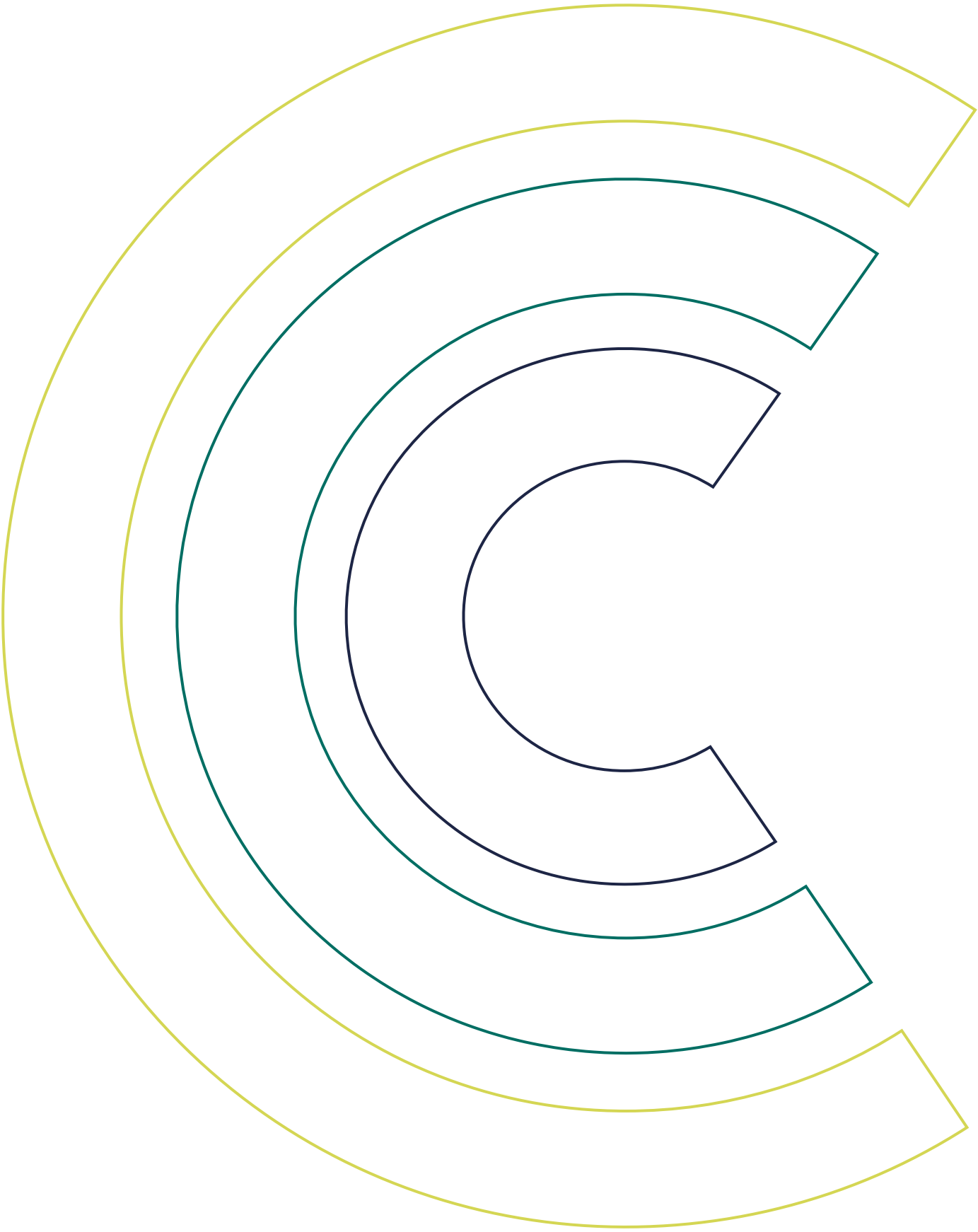
We need new models of care – designed for the various kinds of dementia that exist – a different kind of workforce, and a new compact with families and carers. All this needs to be underpinned by a comprehensive and usable digital layer and underwritten by innovative reimbursement models that will spread the cost of treatments over the same lifecycle as their benefits.

There is much to do, but hopefully, the recommendations of this report will help clarify and accelerate the change that needs to happen to realise the extraordinary opportunity facing us. It has been a collaborative effort, and we are grateful both to the Commission's sponsors and to the many people and organisations who have advised us so far. The hard work starts now.



**Lord James O'Shaughnessy
and Professor Mike Bewick
Co-Chairs NHS Innovation
and Life Sciences Commission**





Commissioners



**Lord James O'Shaughnessy
(Co-Chair)**

Co-Chairing this commission, James is one of the UK's leading policy advisors. He has operated at the highest levels of government, including as a Minister at the DHSC, as Director of the No.10 Policy Unit, and as an advisor to DHSC Ministers during the Covid-19 crisis.



**Professor Mike Bewick
(Co-Chair)**

Co-Chairing this commission, Mike is a former Deputy National Medical Director of NHS England and has wide-ranging experience including planning, commissioning, providing services, leading clinical and management teams on a local, regional and national basis, and advising on policy for NHS England to Secretaries of State and Government Ministers.



Richard Stubbs

Chief Executive Officer at Yorkshire and Humber Academic Health Science Network, Richard has over 20 year's experience working in national and international roles, working with partners across the country and globally to tackle health inequality, positively influence the diversity and inclusion of the health sector and bring about commercial and philanthropic opportunities for UK PLC in international healthcare markets.



Dr Harpreet Sood

Harpreet has worked at the intersection of technology and innovation and the impact of this on healthcare delivery and transformation. Harpreet's interest is in new models of primary care and the use of clinical data, innovation and AI enabled interventions in providing healthcare and diagnostics. The founder of two healthcare start-ups, Harpreet is a practising primary care doctor.



Professor Gillian Leng CBE

Former Chief Executive at NICE, Gill is a clinician by background, with experience in public health, healthcare, education, and social care. In her current and previous roles she developed close working relationships with the life science industries, patient organisations, professional societies, academia, plus local and national government across the United Kingdom.



Professor Ann Keen

Ann Keen was Labour MP for Brentford and Isleworth from 1997-2010. Ann served on the Health Select Committee and became Health Minister in 2007 under Gordon Brown. In 2009-2010, Keen led the Prime Minister's independent commission on the future of nursing and midwifery in England, which resulted in the report "Front Line Care". Ann is also a Fellow of the Queen's Nursing Institute, Fellow of the Royal College of Nursing and Chair of the Patients Association.



Dr Keith Ridge CBE

Keith is a former Chief Pharmaceutical Officer at NHS England and current visiting Professor at Imperial College London. While at NHS England, Keith was Senior Responsible Officer for reducing inappropriate prescribing of antimicrobial in the UK AMR Strategy, and led on issues such as medicines optimisation, digital medicines, pharmacy educational reform and transforming pharmacy practice in line with the NHS's Five Year Forward View.



Corinna Bull

Corinna is our primary policy consultant on this commission. She has over a decade of experience working in the life sciences and health tech sector with companies from start-ups to Fortune 500 organisations. She has a strong belief that policy is an important first step to effect change, but for lasting transformation there must be continued scrutiny, accountability, and learning.

Charity Partner



At **Alzheimer's Society** they are working towards a world where dementia no longer devastates lives. They do this by giving help to those living with dementia today, and providing hope for the future. As a Society, they are made up of people with dementia, carers, trusted experts, campaigners, researchers and clinicians. They are the UK's largest collective force of people with unparalleled knowledge and over 40 years of experience addressing the biggest challenges facing people living with dementia.

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The Commission has kindly been supported by our sponsored partners who have provided financial contributions to fund the research and report, and give input into the advisory board and the research programme.

The work and direction of the Commission is entirely independent and does not advocate on behalf of any external body.

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Executive Summary and Recommendations

Dementia represents one of the most significant and growing healthcare challenges of our time. As the world's population ages, the prevalence of dementia continues to rise, impacting individuals, families, and healthcare systems worldwide.

One in three people born in the UK today will develop the disease.¹ With one million people in the UK predicted to have dementia by 2025,² 700,000 unpaid dementia carers³, and a total cost to the UK of £25 billion per year⁴, dementia presents a significant financial, societal, and emotional burden.

During this inquiry, the Commissioners heard of the challenges faced by patients, carers, and the health system, but there were also some reasons for optimism. Ill health in old age is not inevitable and the UK population is living longer, healthier lives.⁵ 40 per cent of dementia cases can be prevented through lifestyle changes to reduce key risk factors.⁶ We stand on the cusp of revolutionary diagnostics and treatments that will improve people's experiences of old age by reducing the onset of disease and the proportion of life that people live with significant disability. This will not only offer significant benefits for individuals' lives; it will also reduce the overall burden of dementia and related conditions on the health system and wider society.

A Vision for Dementia Care

When reflecting on what dementia care should look like ten years hence, participants agreed on five crucial components that together, would allow those with cognitive impairment to live long, healthy lives, grounded in respect and dignity.

- **Accurate Diagnostics:** simple, non-invasive, cost-effective diagnostic options effective prior to the onset of symptoms.
- **Therapeutic Choices:** a range of treatment options that can prevent or reverse the effects of dementia.
- **Personalised Care:** tailored not only to an individual's circumstances but also their phenotype and genotype.
- **Holistic Approach:** offering not only appropriate medical interventions, but also addressing the social, emotional, and psychological needs of the individual, their families, and their carers.
- **Supportive Environment:** dementia-friendly communities that reduce stigma and promote inclusivity.

A New Paradigm

Achieving this vision will require a substantial change in our approach to the diagnosis, treatment, and care of patients with dementia. It is increasingly clear that the current model, based in primary care, with limited therapeutic options and heavily reliant on informal care networks, is not fit for purpose. There will need to be a fundamental transformation in care pathways, new locations for care, and new economic models to bring innovations to market.

This new paradigm will need to be grounded in prevention and early diagnosis. Slowing cognitive decline should enable people to live independently for longer, reducing the burden on health and care systems. Integrated care systems (ICS) are best placed to drive this transformation, with their mandate to bring together local authorities, the NHS, and other partners to meet the health and well-being needs of citizens in their area. Better dementia care, clearer and more structured care pathways and, ultimately, improved outcomes should be considered as key indicators of the success of ICSs, with clear accountability and measurable objectives.

Underpinning this new paradigm for dementia care should be a common digital platform, such as the NHS app, through which patients, families, and their carers can access their medical records, navigate care pathways, be informed about suitable clinical trials, and receive information about local services. Without technological solutions joining up care, patients and their carers risk endlessly repeating their medical history to different providers within a fragmented treatment pathway, to the detriment of the patient and carer experience. Investment in digital solutions will also enable the development of a comprehensive, anonymised database for dementia research, based on the NHS Secure Data Environment framework.

This new paradigm needs to be a comprehensive shift in the way we address dementia. Without this change, we will not be able to achieve the vision for dementia care and we risk failing patients and their families.

Recommendations

After hours of conversation with thought leaders, experts, and those with lived experience of dementia, the Commissioners have concluded that the NHS needs to accelerate and expand its current planning for future dementia services. The Commission has identified ten key areas of focus, each with specific recommendations. These recommendations form the basis of an implementation plan, on which we can build towards the new dementia paradigm.

1) Enhance Early Detection and Prevention

Dementia is a complex and devastating condition, and prevention and early detection are critical components of effective dementia care. Raising public awareness about, and confidence in, the importance of early and accurate diagnosis is essential. There needs to be a more ambitious target for detection and diagnosis – backed by increased funding – to ensure that people with dementia receive the care and support they need as early as possible.

- Launch a nationwide public awareness campaign emphasising the importance of early dementia detection and the actions individuals can take to reduce their risk of cognitive decline.
- Increase the existing dementia diagnosis target from 66.7 per cent to 90 per cent by 2030.
- Provide increased funding for earlier detection and diagnosis, designed, and located in innovative, citizen-centric sites to enable increased uptake.

2) Strengthen Timely Diagnosis

Timely diagnosis is essential for ensuring that individuals with dementia receive appropriate care and support. General practice and community pharmacy must be strengthened to facilitate timely diagnosis, considering the complex needs of the ageing population affected by dementia. Dementia diagnosis should include an accurate subtype classification, allowing for more precise treatment and care planning.

- Enhance training programmes for primary care practitioners, including community pharmacists, focusing on dementia-specific symptoms and diagnostic methods.
- Introduce standardised protocols for dementia assessment in primary care settings.
- Allocate resources to support the implementation of advanced diagnostic technologies, such as brain imaging, blood tests, and new digital forms of cognitive testing, to facilitate accurate subtype classification.
- Expand access to diagnostics by investing in dementia diagnostics at community diagnostic centres.

3) Transform Dementia Care Pathways

Dementia patients deserve respect and dignity. Yet current treatment and care pathways are not fit for purpose and need fundamental transformation to ensure they meet patients' needs. Dementia care pathways must be transformed to involve patients and their carers in decision-making. Leveraging the social care workforce, integrating health and social services, and exploring technology-driven care solutions can enhance the overall quality of care and make the journey more patient-centric.

- Establish a task force comprising health and social care professionals, patients, and caregivers to review and redesign dementia care pathways
- Integrate patient and caregiver perspectives into decision-making processes – invest in technology-driven solutions, such as telehealth platforms, to enhance communication and coordination among different care providers.
- Individuals who go onto dementia pathways should be offered physical health checks to identify any physical health challenges that could exacerbate their cognitive decline or require additional treatment or support.

4) Bolster Post-diagnosis Support

Receiving a diagnosis of dementia can be a challenging period for both patients and their carers. There needs to be an expansion and improvement of support networks to provide emotional, informational, and practical assistance for patients and families coping with dementia. This support should include respite care for caregivers, uniform access to dementia support workers nationally, and tailored support based on a patient's needs.

- Expand existing support networks for dementia patients and their families.
- Develop and promote respite care programmes for caregivers.
- Standardise access to dementia support workers nationally, ensuring uniform coverage.

5) Build Trust and Ensure Equitable Engagement

Dementia affects everyone differently. There is evidence of a trust deficit as well as cultural and linguistic barriers in some communities. Lived experiences must be valued, and investment made in sustaining long-term engagement and ensuring that all communities receive the support they need, regardless of their cultural or ethnic background.

- Invest in cultural competence training for healthcare professionals.
- Establish community-specific outreach programmes to address trust deficits and cultural barriers.
- Implement measures to ensure equitable access to information and support, irrespective of cultural or ethnic background.

6) Promote Collaborative Integrated Care

To improve dementia care and raise public awareness, collaboration among healthcare providers, advocacy groups, communities, and policymakers is essential. ICSs are best placed to drive this transformation as they are grounded in their locality and bring together local authorities, NHS organisations, and other key local partners to meet local health and wellbeing needs. Dementia should be a priority for integrated care systems, supported by strong leadership from DHSC and NHSE.

- Integrate dementia care into the priorities of integrated care systems, with a named dementia lead.
- Establish 'Dementia Alliances' across each ICS, chaired by a patient representative but involving all the relevant stakeholders to ensure views are sought, listened to, and acted upon
- Invest in national dementia expertise at DHSC and NHSE to ensure strong national governance.

7) Invest in Health and Social Care Staff Training

Providing effective dementia care requires well-trained health and social care professionals. Training programmes should be expanded in line with the Dementia Training Standards Framework to equip health and social care professionals with the skills and knowledge necessary for delivering better dementia care.

- Expand existing dementia training programs for health and social care professionals based on the Dementia Training Standards Framework
- Develop continuous professional development opportunities to keep health and social care staff updated on the latest advancements in dementia care.
- Train volunteers to act in a support role, building on the Alzheimer's Society Dementia Friends initiative.

8) Prepare for New Technologies and Innovations

Innovators are on the cusp of delivering new innovations and technologies that will require the health system to transform dementia care if their benefits are to be maximised. The NHS needs to urgently plan for the likely impacts on existing pathways to ensure the existing services and budgets are not overwhelmed by demand and affordability. Work should start now to explore new economic models for innovative treatments that are fair and deliver value to patients, innovators, the health service, and taxpayers.

- Establish a task force to assess the potential impact of new innovations and technologies on existing dementia care pathways.
- Develop a roadmap for incorporating new treatments, ensuring that services and budgets are not overwhelmed and that the implementation requirements of transformation are fully resourced.
- Engage with innovators and stakeholders to explore new economic models for innovative treatments.

9) Foster Responsible AI Integration

Investing in artificial intelligence (AI) models for early prediction and detection of neurodegenerative diseases has the potential to revolutionise dementia diagnosis and treatment. However, it must be done responsibly, with a focus on fairness, privacy, transparency, and accountability. An expert panel should be convened, as part of the AI Safety Institute, to consider the impact of AI on those with cognitive impairment.

- Convene an expert panel, part of the AI Safety Institute, to assess the ethical implications of AI in dementia diagnosis and treatment.
- Develop guidelines for responsible AI integration, emphasising fairness, privacy, transparency, and accountability.
- Collaborate with AI developers to ensure responsible deployment in healthcare settings.

10) Implement Data Integration and Dynamic Care Records

There needs to be a common digital platform through which patients and their carers can access their medical records, be informed about suitable clinical trials, and receive information about local services. Data collection must be improved to understand the true burden of dementia across the UK and to improve service planning. Additionally, to recognise the crucial role of carers in dementia, it should be possible to have a named carer(s) in medical records and allow them to contribute directly to patients' written care plans.

- Develop a common digital platform, potentially through the NHS app.
- Invest in a comprehensive data collection system to gather accurate information on the prevalence, impact, and outcomes of dementia across the UK, based on the NHS Secure Data Environment framework.
- Modify medical record systems to include named carers and enable their direct contribution to patients' care plans.

Dementia is a pressing global challenge, affecting millions of individuals and their families. But there is hope. Novel diagnostic and treatment options, alongside technologies that allow patients to live independently for longer, offer new opportunities for those diagnosed with the condition. By enhancing early detection and prevention, transforming care pathways, bolstering post-diagnosis support, and promoting collaborative care, we can build a new paradigm, focused on a compassionate, patient-centred, and effective dementia care system.

Next Steps

To support the further development of these recommendations, the Life Sciences Commission is planning a 'Sprint Roundtable' in early 2024. This dynamic discussion is focused on developing actionable strategies for building the new dementia paradigm. Bringing together experts in the field of dementia, including policy and service delivery leads, the 'Sprint' approach will take participants on a rapid journey, identifying tangible actions that can drive process and promote collaboration and knowledge sharing and create a roadmap for delivery of these recommendations. The objective is to apply the recommendations to a dementia care pathway and design a system that will enable the most efficient delivery of new treatments to patients.

Acknowledgements

The Commissioners were inspired by the resilience of those living with dementia and the unwavering commitment of their carers, the healthcare professionals, and the campaigners who support them. We thank each of them for their participation and contribution.

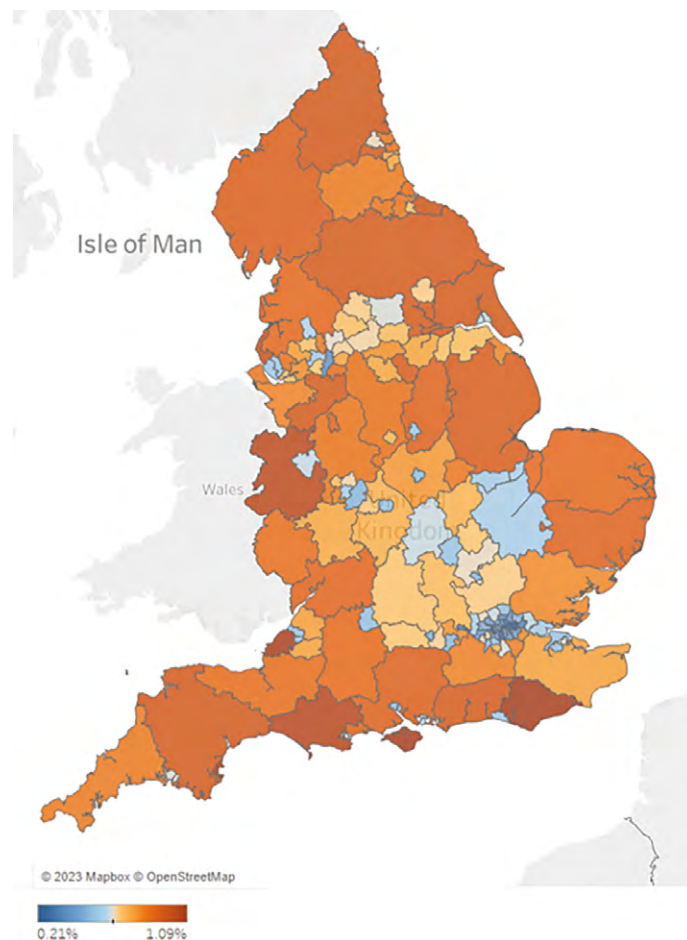
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- 1 <https://www.alzheimersresearchuk.org/blog/dementia-in-the-future/> Accessed 7.11.23
 - 2 <https://www.dementiauk.org/information-and-support/about-dementia/what-is-dementia/> Accessed 7.11.23
 - 3 <https://www.alzheimers.org.uk/news/2021-11-03/carers-uks-state-caring-2021-report-alzheimers-society-responds> Accessed 7.11.23
 - 4 <https://dementiastatistics.org/statistics/the-economic-impact-of-dementia/> Accessed 7.11.23
 - 5 Chief Medical Officer's Annual Report 2023, Health in an Ageing Society, <https://assets.publishing.service.gov.uk/media/654ccbf2c0e068000e1b2ca5/cmo-annual-report-2023-executive-summary-and-recommendations.pdf> Accessed 14.11.23
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DEMENTIA PREVALANCE

Dementia Prevalence by Local Authority

(proportion of GP-registered patients on the Dementia register, i.e. diagnosed)



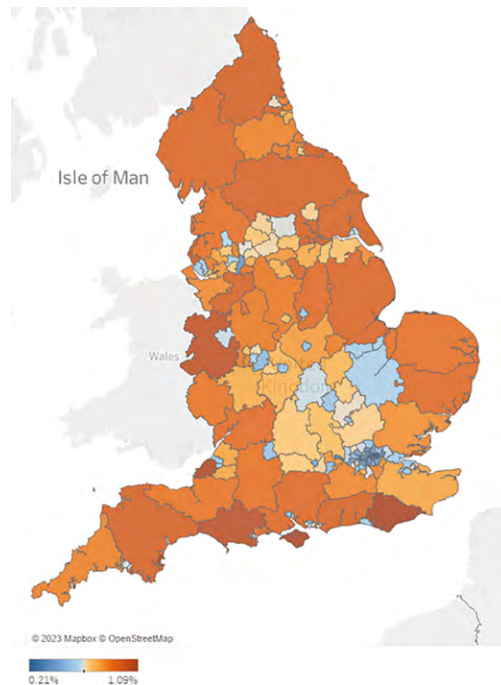
Local Authority Map of Dementia QOF prevalence (all ages) 2021/22

This visualisation shows dementia prevalence by local authority footprint.

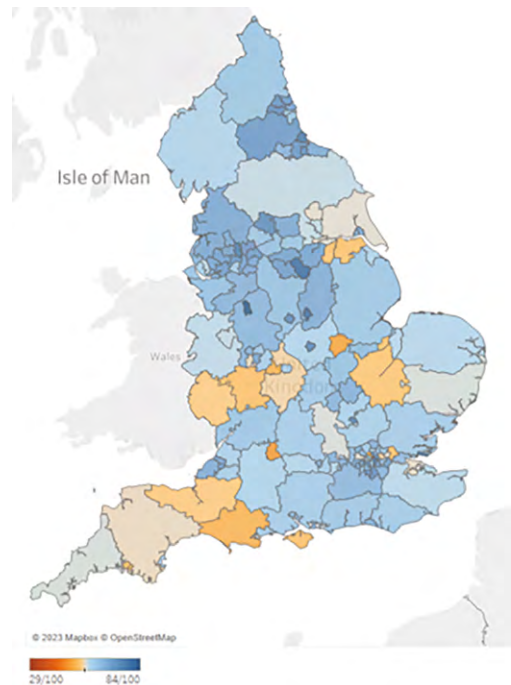
Across England we can see variation in the prevalence of dementia, with levels in the highest areas five times that of the lowest.

Whilst we can see variation and perhaps begin to form some hypothesis as to why this might be the case, in reality, this high-level view, which is typically the primary analysis available, does not give us any level of understanding as to why we may have these levels of variation.

An example of this is that we do not typically see the lowest levels of dementia in the areas of highest urban deprivation, where typically life expectancy is much lower, so likelihood of dementia is lower. However, whilst these geographies typically have fewer over 65s per 100,000 residents, these areas typically have much higher population densities, so we may see one offsetting the other.



Local Authority Map of Dementia QOF prevalence (all ages) 2021/22

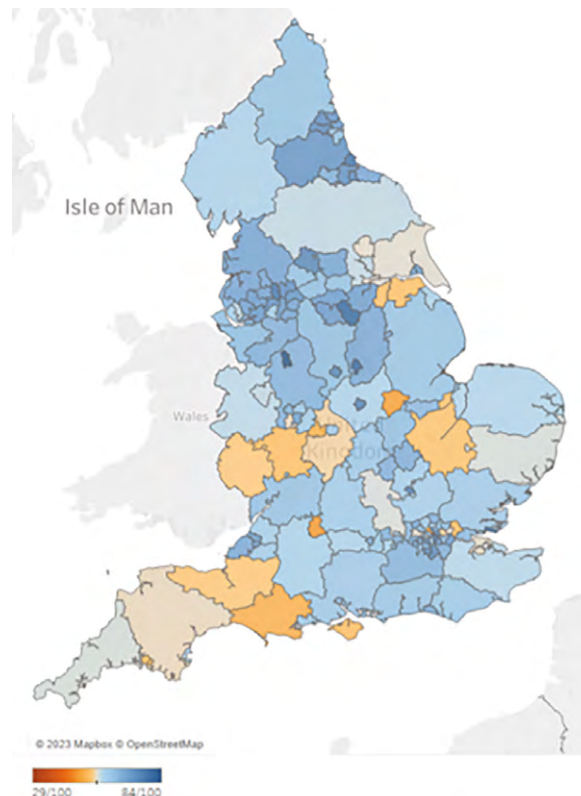


Local Authority Map of Estimated dementia diagnosis rate (aged 65 and older)

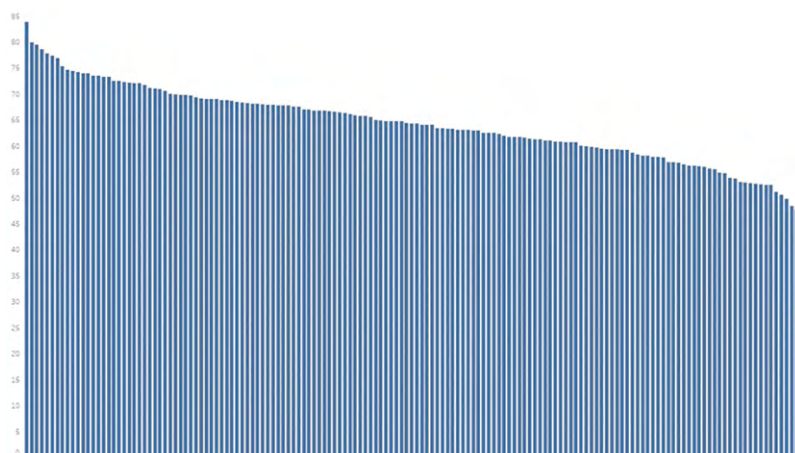
This visualisation shows dementia prevalence vs diagnosis variation. Diagnosis variation is the Government measure of the level of diagnosed dementia vs the level they would expect to see based on demographic, with the blue areas being the highest levels of diagnosed prevalence. With these two visualisations side by side, we can clearly see that there is evidence of under diagnosis driving overall prevalence which, in turn, could mean we do not fully understand the amount of symptomatic dementia sufferers there are.

Variation in Diagnosis Rate

(the estimated proportion of sufferers who have had a dementia diagnosis)



Local Authority Map of Estimated dementia diagnosis rate (aged 65 and older)

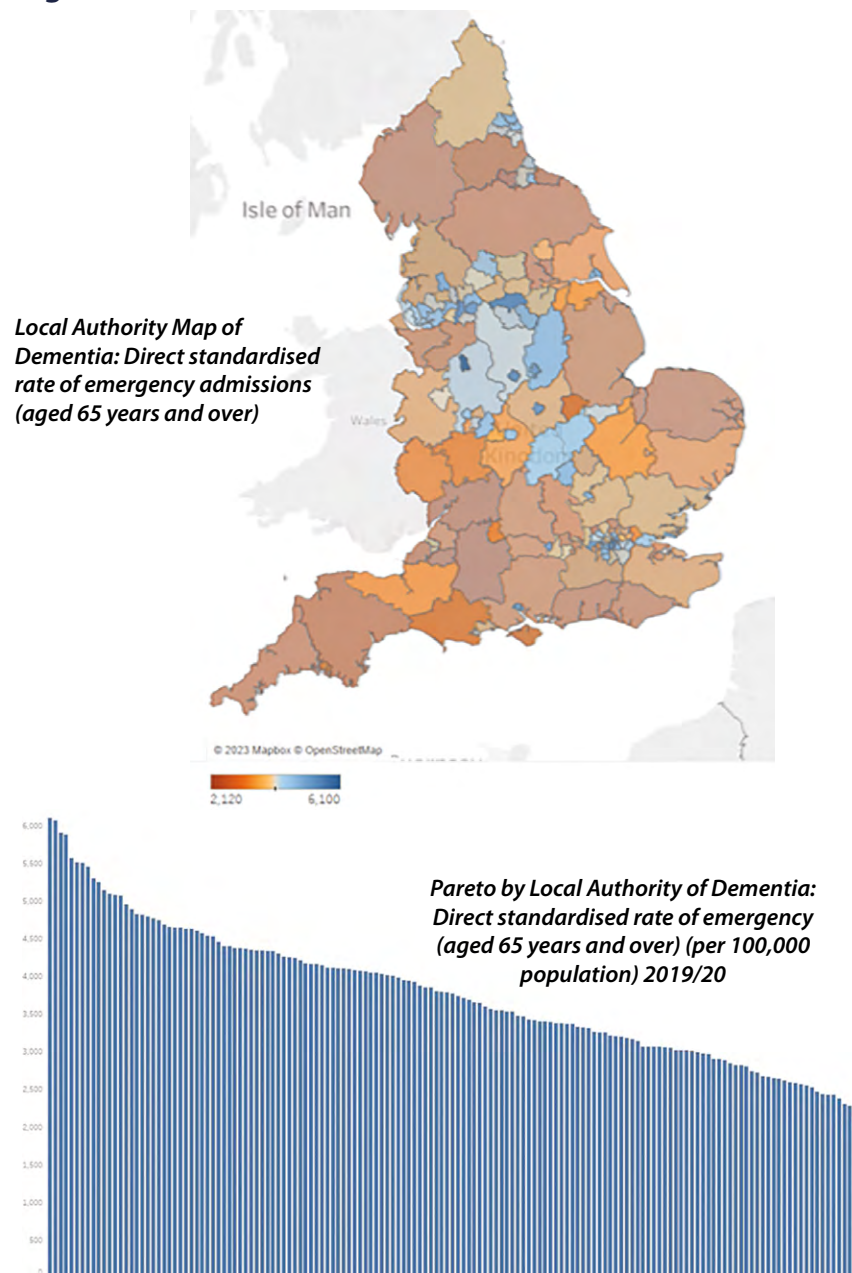


Pareto by Local Authority of Estimated dementia diagnosis rate (aged 65 and older) 2023

This next visualisation builds on the previous one and shows that the variation of expected vs actual diagnosis of dementia across local authorities varies hugely, from above 80% to below 30% with many local authorities diagnosing less than two thirds of their expected dementia cohorts.

Dementia and Emergency Hospital Admissions

(number of emergency admissions per 100,000 where patient coded as suffering from dementia)

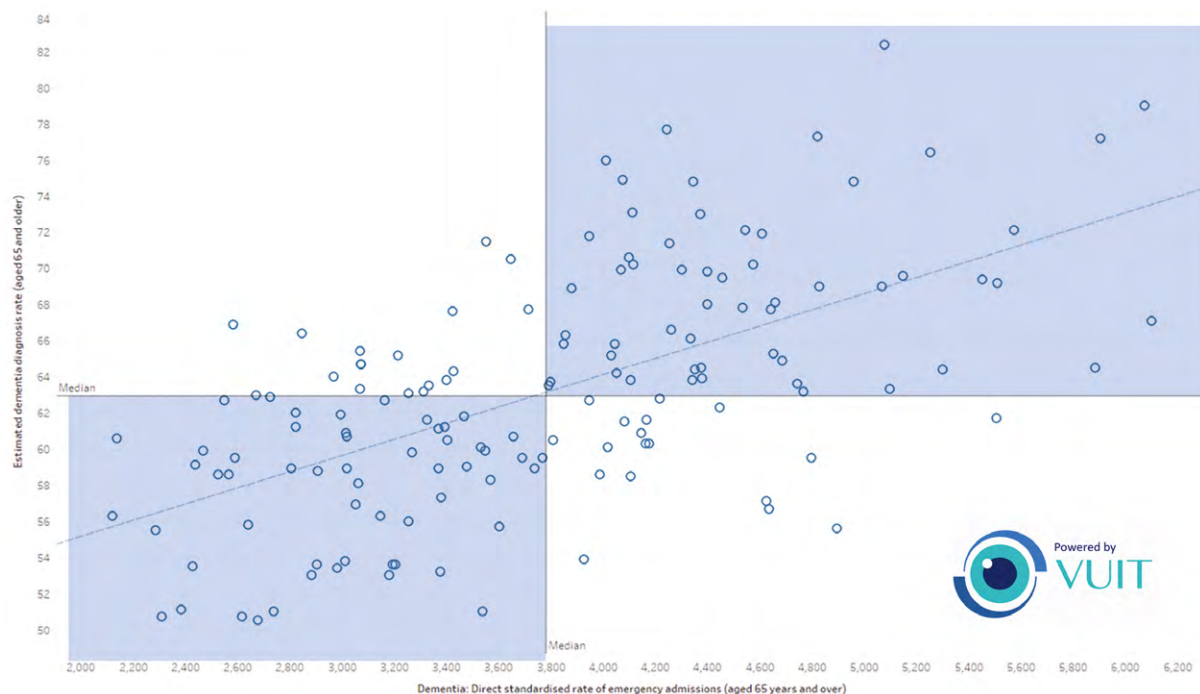


Here we see some of the impact of this underdiagnosis of Dementia on acute hospitals.

Whilst many of the hospitals who receive high levels of undiagnosed dementia will go on to diagnose this as part of the care pathway, the risk of patients being diagnosed with delirium rather than dementia is high and the ability to care for patients in appropriate wards is hampered when people in emergency pathways are not clearly pre-diagnosed.

Diagnosis Rate Versus Level of Emergency Hospital Admissions

(the estimated proportion of sufferers who have had a dementia diagnosis)

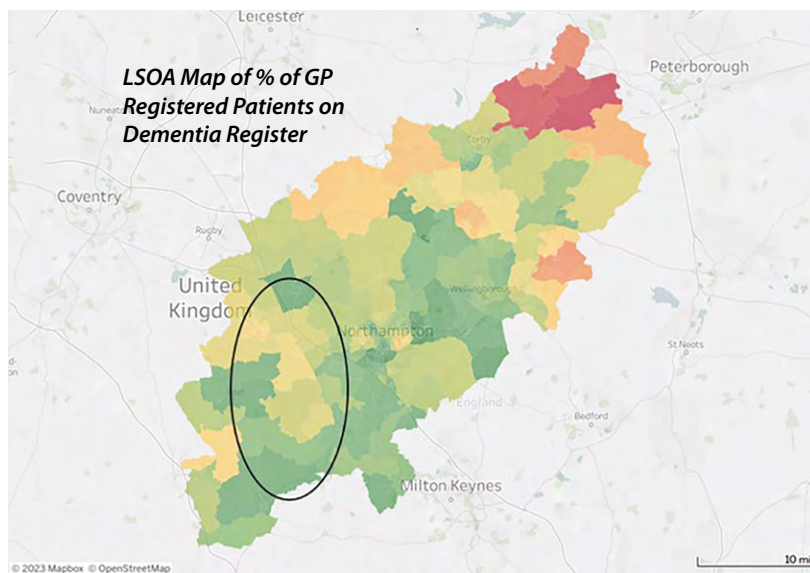
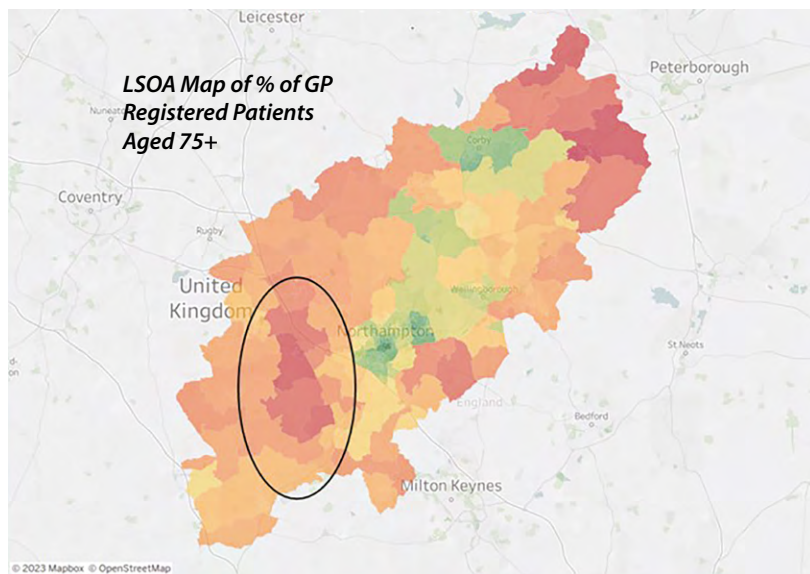


Scatter plot of Estimated dementia diagnosis rate (aged 65 and older) Versus Dementia: Direct standardised rate of emergency admissions (aged 65 years and over)

The impact of undiagnosed dementia on emergency pathways is further reinforced here, where the scatter plot shows two clear groupings. We can see those with higher diagnosis rates presenting higher (standardised) presentations at emergency department with pre-diagnosed dementia and the inverse where primary care diagnosis is lower.

Whilst this is probably expected, we can reasonably extrapolate out that more dementia diagnoses in primary care would lead to fewer emergency attendances for those without a dementia diagnosis, which would significantly improve the acute outcomes for those people by allowing the acute hospital to deliver the correct pathways and care more often and avoid misdiagnosis of delirium when dementia is present.

Variation in Diagnosis Rate – Practical solutions

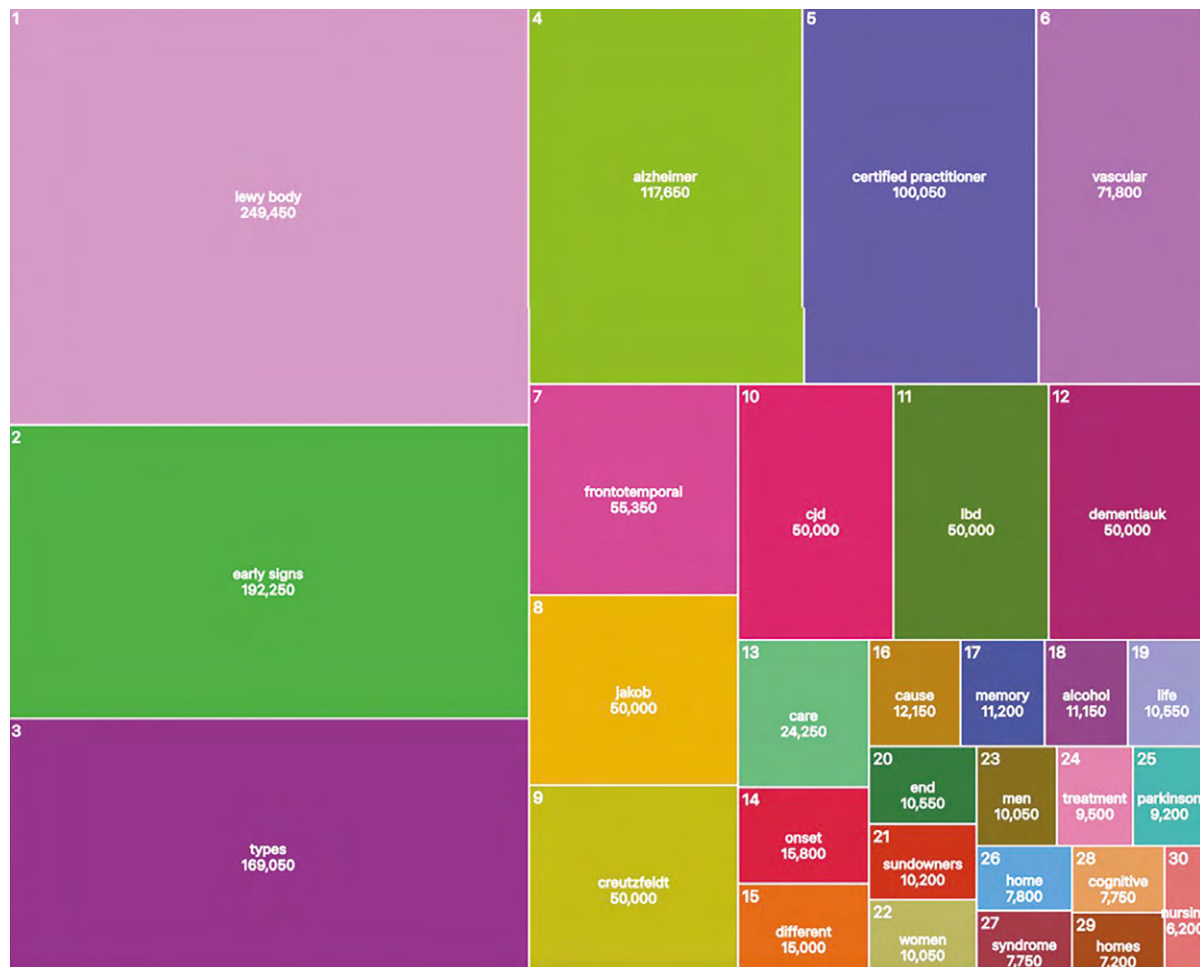


Whilst highlighting this challenge of under-diagnosis is useful, without practical solutions, it counts for nothing. This is why the ability to easily highlight areas with high numbers of over 65 populations and lower-than-expected dementia diagnoses at a geographical level that can be addressed sensibly is key.

The map opposite shows an example of the granular analysis that VUIT can produce to enable a detailed understanding of small geographic areas where the likelihood of prevalence and actual diagnosis are different

VUIT is working extensively with multiple ICS teams to enable them to see these geographies, highlight the GP practices that would most benefit from a targeted resource of support and staffing and, as a direct result, reduce unwarranted presentation of undiagnosed dementia on the health and social care system but, critically, improve the outcomes of those affected by dementia

Un-Met Need – What the Voice of The Patient is Telling Us



Whilst there continues to be unwarranted variation in diagnosis and support for dementia sufferers, they, and their loved ones, will seek out answers for themselves.

This unique analysis, conducted by EGG Insights, looks at the topics that are searched for most commonly around the over-arching topic of dementia. Understanding the second and third (and fourth and fifth) levels of search being undertaken allows us to get a real understanding of the things that people would want to know and the support they would potentially need if their needs were to be met.

Correlating this data with the geographic 'hotspots' of underdiagnosis offers an incredibly detailed insight into the types and geography of solutions that could be delivered.

Un-met Need – What The Voice of The Patient is Telling Us ‘Hot Topics’

“Certified Dementia Practitioner”

A Deep Dive

	Text	Stakeholder	Journey Point	Monthly Volume	3 Month Change	12 Month Change
1	Emergency dementia respite care	Unknown	Unknown	500	900%	900%
2	frontotemporal dementia prognosis	Unknown	Unknown	500	900%	900%
3	Hearing loss and dementia	Unknown	Unknown	500	900%	900%

Like all unfulfilled requirements, addressing some of these needs may reveal new challenges, emerging as the latest unanswered questions.

Further ‘deep dive’ analysis of the voice highlights, under each topic, what the fastest growing areas of unmet need are.

Each of these separate emerging subjects indicates areas where solutions that answer these articulated needs could and should be implemented.

This distinctive method of analysing individuals' thought processes, coupled with its unscripted revelation of insights, minimises the risk of comprehending accurate answers to inaccurate questions. This approach mitigates the potential for cognitive bias and avoids the common scenario in other qualitative diagnostics where questions are posed based on our capability to meet existing needs rather than illuminating needs that remain unaddressed.



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A full-page background image with a blue tint. It shows a person in a white lab coat and white gloves interacting with a computer monitor. The monitor displays a DNA double helix and some data. In the foreground, there is a round-bottom flask with liquid on a desk, and a computer keyboard is partially visible. The overall scene is a laboratory or research environment.

FUTURE TECHNOLOGIES



Co-chaired by Lord James O'Shaughnessy and Professor Mike Bewick, the first inquiry session of the NHS Innovation and Life Sciences Commission's dementia programme took place on 22nd May. This session focused on diagnostics and future technologies for dementia patients, bringing together the recommendations of leaders in the NHS and life sciences industry.

Session One: Diagnostics and Diagnosis

The first half of this inquiry session focused on current and future developments in diagnostics and improving early diagnoses for patients with dementia. The panel for this session were:

- **Professor John O'Brien – National Speciality Lead of Dementia, NIHR**
- **Professor Matt Brown – Chief Scientific Officer, Genomics England**
- **Professor Nadeem Sarwar – Global Head, Genomics Strategies, Eisai EMEA**
- **Dr Sasha Bozeat – Global External Engagement and Scientific Collaboration Lead, Roche**

Future vision and ambition

Lord O'Shaughnessy opened the inquiry session by asking the panellists for their vision of dementia diagnostics, treatments, and technologies in the next ten years. Dr Sasha Bozeat expressed her desire for individuals to receive a timely diagnosis, considering the individual's readiness for the diagnosis. Dr Bozeat noted that patients should have the choice to be diagnosed in the early symptomatic phase of these diseases or later, based on their specific circumstances, such as family history or increased risk. She emphasised the need for a streamlined diagnostic process to reduce the anxiety and confusion often experienced by individuals seeking a diagnosis. Dr Bozeat also suggested moving away from using the term "dementia" due to its stigmatising nature, proposing that diagnoses should focus on identifying the underlying cause of symptoms. She stressed that the term "dementia" itself is misleading in the same way that cancer is a catch-all phrase. Dr Bozeat recommended more awareness of the differentiation of neurodegenerative conditions. Additionally, she stressed the importance of prevention through lifestyle modifications and early education.

Professor Nadeem Sarwar envisioned a shift from developing medications for specific types of dementia to targeting mechanisms that underlie various neurodegenerative diseases. He noted the parallels with cancer treatment, where medicines are designed for specific causal driver pathologies. Professor Sarwar expressed optimism about the current and upcoming pharmacological toolbox, including monoclonal antibodies, antisense oligonucleotides, small molecules, gene therapies, and RNA targeting therapies. He emphasised the potential for mechanism-based, multimodality therapeutics that can address the causes of the disease.

On prediction and prevention, Professor Sarwar highlighted the need to leverage scalable technologies, particularly digital technologies combined with advanced analytics. He suggested creatively utilising these tools to improve access to imaging, cerebrospinal fluid analysis, and other diagnostic technologies, including daily monitoring technology such as wearables. Professor Sarwar believes in intervening not only pharmacologically but also through lifestyle, societal, and digital interventions. He envisions a future where accurate prediction of the disease is possible and prevention is more viable.

Professor Matt Brown focused on the aspect of early diagnosis. He discussed the transition in genomics from being a research tool to becoming more widely used in studying the population. He mentioned Genomics England's pilot project involving sequencing newborns, with the potential for newborn sequencing to become a routine service in the NHS. Professor Brown also envisions the future of whole genome sequencing in older populations, allowing for pharmacogenomics and polygenic risk scores to diagnose and predict the early onset of various common diseases, including different forms of dementia. He mentioned the rapidly declining costs of whole genome sequencing, from \$200 to \$100–\$50 within five years, making it financially feasible to screen the entire population affordably. This could lead to identifying individuals with high-risk genetic variants associated with severe diseases, like APOE4 or specific genes related to frontotemporal dementia. Professor Brown contemplated the ethical implications of disclosing genetic risk for dementia without effective treatments or interventions. He theorised that there would be effective treatments within ten years, thus removing the ethical concern of disclosing a genetic risk.

Professor John O'Brien emphasised the need for expanding prevention strategies beyond the established vascular risk factors. While managing conditions like hypertension, diabetes, and obesity are important, he believes there should be a greater emphasis on dementia-specific prevention. He suggested considering environmental factors like hearing loss as potential contributors to dementia. Ideally, the development of a statin-like treatment for lowering amyloid, as research has shown that dementia, especially Alzheimer's disease, is not a disease of late life but rather mid-life as it is a disease that develops over several decades. Professor O'Brien believes that focusing on preventive measures during this period could help reduce the number of cases. However, he acknowledged that despite prevention efforts, there will still be a considerable number of dementia cases due to increasing longevity. Professor O'Brien also expressed concern about the lack of investment and interest in symptomatic treatments for Alzheimer's disease and emphasised the need to improve the quality of life for both patients and caregivers. Professor O'Brien also noted that there is a large disparity between services' use of diagnostic tools. He cited that diagnostic imaging varies between 0 per cent to 97 per cent while 56 per cent of services did not have access to cerebrospinal fluid (CSF) biomarkers. He suggested services should be brought up to an equal threshold for better diagnostic services across the nation.



Advancements in dementia diagnostics

Dr Keith Ridge asked the participants to discuss the advancements that researchers and innovators should prioritise. Professor O'Brien began by stating that current diagnostics are not yet at the desired level. He highlighted the importance of studying biomarker performance in real-world scenarios, particularly emphasising the potential of blood-based biomarkers due to their ease of sampling and cost-effectiveness. He also mentioned promising advancements in alpha nucleus assays for Parkinson's disease and Lewy body dementia, stressing the need to diagnose and develop therapeutics for non-Alzheimer's dementias as well. Professor O'Brien suggested the importance of validation and implementation in these areas.

Professor Brown emphasised the significance of genetics as a biomarker for early detection and prediction of diseases like Alzheimer's. He noted that genetics offered the possibility of low-cost, easily accessible testing using saliva or blood samples. In addition, he noted that genetic screening would test for risk for other diseases and so is beneficial for the prevention of a wide range of conditions. Professor Brown called for further research to improve the subclassification of diverse types of dementia and address the issue of ancestry in genetic testing. He also suggested that combining genetics with other biomarkers and imaging techniques could lead to more accurate diagnoses.

Professor Sarwar took a practical approach, considering what approaches could be successful and scalable in diagnostics. He envisions an accelerated diagnostics funnel that includes genomics, blood-based measurements, and digital technologies, with the goal of achieving accurate and scalable testing in people's homes. He explained that not only does home testing accelerate diagnostics, but it also prevents the need for the potentially traumatic experience of hospital testing

and is more accessible to the public. Professor Sarwar acknowledged that these methods might not initially match the accuracy of more advanced techniques involving imaging, but they could still effectively identify individuals who could then be prioritised for further testing. He also foresees that technology could lead to the advancement of clinical trials being conducted remotely and a lower screen failure for clinical trial participants. He emphasised the importance of understanding the underlying mechanisms involved in neurodegenerative diseases and suggested focusing on key mechanisms like beta-amyloid, tau, neurofilament light, alpha-synuclein, TDP-43, and microglia for diagnostic and therapeutic purposes.

Sasha Bozeat agreed with the vision of utilising technology to triage individuals through the diagnostic pathway. She mentioned the potential of wearables and passive monitoring of changes in gait and eye movement. While these technologies are not fully developed yet, blood-based biomarkers are available and should be properly validated. Sasha emphasised the importance of using blood-based biomarkers early in the diagnostic pathway, along with digital at-home monitoring, to guide individuals in seeking healthcare advice. This approach could help reduce the need for invasive and expensive procedures.

Strategies and collaboration for future technologies

Professor Gillian Leng began the discussion on the strategies and collaborations the UK should pursue to achieve the vision of early diagnosis and personalised treatments for dementia. Professor Sarwar emphasised the importance of multisector partnerships, bringing together government, industry, clinical practice, pharmaceutical technology, and other companies. He drew inspiration from the successful COVID-19 mission and stressed the need to build trust by clearly and transparently articulating how people's data would be used and what solutions would emerge from it.

Dr Bozeat continued by emphasising the need to collaborate on validating existing and novel technologies, particularly blood-based biomarkers, in clinical cohorts. She also highlighted the importance of developing clear guidelines for the clinical management of dementia and mild cognitive impairment, as healthcare professionals often follow guidelines. Professor Leng acknowledged the significance of guidelines and suggested supporting guideline developers for more rapid updates.

Professor O'Brien emphasised the need for international collaboration and mentioned the importance of filling gaps in scientific knowledge and cohorts. He highlighted existing collaborations such as the Dementia Platform UK and the Dementia Translational Research Collaboration. He also stressed the importance of changing the terminology from "dementia" to "type of dementia" and developing guidelines specifically for Alzheimer's disease and mild cognitive impairment. Professor O'Brien noted the lack of mid-life cohorts in clinical trials and stressed the importance of their inclusion. He explained that this age range is when the first indicators of the disease can be identified, and more research needs to be done to identify risk factors.

Professor Brown proposed a collaboration focused on combining omics and genomic markers at a community level in the UK. He mentioned the Our Future Health programme, studying five million Britons, including dementia research, and suggested integrating it with other large-scale omics programmes to advance multi-omic diagnosis.

Lord O'Shaughnessy emphasised the importance of not only preparing for future advancements but also making existing interventions more widely accessible and equitable across the country.

Professor O'Brien responded by mentioning the existence of brain health clinics and their state-of-the-art approach. However, he believed that this alone would not solve the problem because there was a lack of dissemination and spread of knowledge. He pointed out that dementia services are currently delivered separately by mental health and acute hospital trusts, creating a commissioning failure. Professor O'Brien suggested that a joint commissioning approach involving health and social care, as well as acute and mental health trusts, is necessary to ensure access to validated biomarkers and diagnostics. This would help in offering appropriate treatments to individuals based on their specific disease. He is concerned that access to appropriate diagnostics is a postcode lottery and he suggested that services across the nation should be brought up to an equal standard.

Strategies for the implementation of treatments and technologies

Lord O'Shaughnessy asked the panellists to provide any ideas they would like to see included in future commitments to service change.

Dr Bozeat mentioned the Davos Alzheimer's Collaborative as an example of successful healthcare system preparedness. She suggested that demonstrating the effectiveness of new processes or methodologies through practical examples was important. However, she noted that scaling the new processes to the nation at large would be a challenge. Dr Bozeat also highlighted the Brain Health Scotland initiative, which aimed to alleviate pressure on general practitioners by creating a walk-in centre where people could seek cognitive health information and access services for diagnosis. Dr Bozeat suggested that keeping neurodegenerative disease on the agenda and setting targets should feature in party manifestoes for the upcoming General Election. She emphasised the need for updated guidelines and routine implementation of biomarkers to streamline the diagnostic pathway and prepare for upcoming treatments.

Professor Brown, although not directly involved in dementia clinical care, suggested looking at the cancer field as a model for driving forward dementia research and outcomes. He mentioned the improvement in cancer outcomes through early diagnosis, better diagnostic centres, and expanded clinical trial programmes.

Nadeem Sarwar reflected on the practical ideas discussed and suggested that the UK should pioneer a scalable at-home diagnostics approach using its expertise in genomics, data sciences, and digital technologies. He believes that such an approach could make the UK stand out as a pioneer on a nationwide scale, attracting investment, company creation, and research opportunities.

Lord O'Shaughnessy concluded the discussion, thanking the panellists for their insights.





Session Two: Treatment and Care

The second half of this inquiry session focused on the future of treatment and care for patients with dementia. The panel for this session were:

- **Hilary Evans – Chief Executive, Alzheimer’s Research UK**
- **Professor Nick Fox – Director of the Dementia Research Centre and Group Leader at UK DRI, UCL**
- **Professor Michael Hornberger – Professor of Applied Dementia Research, Norwich Medical School**

What will be the state of dementia healthcare in ten years?

Professor Bewick opened the session by posing a question to the panel, asking them about their vision for the state of diagnostics, treatment, and care in ten years’ time.

Professor Michael Hornberger responded by stating that he believed blood tests would likely be available, although the form they will take remains uncertain. He emphasised the need to determine when to profile individuals for increased risk and expressed his belief that in a decade, people will be using these tests. Michael also highlighted the importance of early identification and implementing treatments. Additionally, he mentioned the significance of raising awareness about preventing dementia and reducing the risk, particularly in terms of manifestos, arthritis, education, and care. He noted that with technological advancement, there would need to be regulation to provide safe guidelines and standardised measures for treatment and care.

Hilary Evans, representing Alzheimer's Research UK, presented their vision for the next ten years. Evans stated that they have the potential to completely transform the lives of individuals with dementia with disease-modifying. The regulatory approval for which, is close. However, she noted that preparedness is an issue as only a third of memory clinics are ready to offer new treatments. Evans further explained that due to the new treatment pathway, more of the public would seek diagnosis, putting pressure on an already overwhelmed system. She emphasised the importance of changing public perceptions of dementia and dispelling the notion that it is an inevitable part of ageing. Evans highlighted the need for conversations across all stages of life regarding dementia and the actions individuals can take to reduce their risk. She envisioned a future where people in early and midlife understand the measures they can take to mitigate their chances of developing dementia. Evans also stressed the significance of early detection, identifying higher-risk individuals, facilitating their participation in research, and improving the infrastructure for clinical trials in the UK. The ultimate goal, according to Evans, is to establish a system where individuals receive timely and accurate diagnoses and have access to medications that can alter the course of their disease.

Subsequently, Professor Nick Fox shared his vision for the future. Drawing a comparison with cancer, he highlighted the need for a fundamental shift in the diagnostic process for dementia. Professor Fox stressed that timely diagnoses are crucial and expressed the desire for a shift in attitude, similar to how cancer diagnoses are treated urgently. He emphasised the importance of making specific diagnoses rather than just detecting dementia, allowing for targeted treatments, and understanding the underlying causes. Professor Fox advocated for earlier interventions, new criteria for determining treatment initiation and discontinuation, and improved, person-centred care that supports families and caregivers. He also called for a re-evaluation of end-of-life care, empowering individuals to be involved in decisions regarding their care and treatment preferences. Professor Fox also encouraged the changing of public perceptions, particularly around the nihilism and stigmata associated with dementia. He predicts that once an effective treatment is available, this perception will change, similarly to the change of opinion that occurred regarding cancer. Professor Fox explained that currently, there is a strong emphasis among clinicians to diagnose cancer early, whereas the opposite is true regarding dementia. As there is currently no effective treatment for dementia, clinicians feel that diagnosis is a burden to the patient. Professor Fox predicts that this will change once there are effective treatment options and clinicians will move to an earlier diagnosis focus. He would like to see a rethinking of end-of-life care so that patients are able to choose how long they would like to live with a lower quality of life.

Throughout the conversation, the participants discussed their visions for the future state of diagnostics, treatment, and care in the context of dementia. They highlighted the potential for advancements in technology, raising awareness, early detection, research participation, and the need for comprehensive and person-centred approaches to improve the lives of individuals with dementia and their families.

Barriers that hinder treatments and technologies

Keith Ridge opened the discussion by addressing the primary barriers that may hinder the access and adoption of various biopharmaceutical treatments and technologies. He mentioned factors such as funding, regulation, professional and clinical behaviours, and integration. He specifically asked if these barriers could impede the implementation of initiatives like the mission and if they were sufficiently connected to those responsible for implementation.



Professor Fox acknowledged that there were multiple barriers to consider. He started by highlighting the need for increased funding, emphasizing that detection, diagnosis, delivery of new therapies, and monitoring would all require more resources. He also mentioned the importance of additional training and proposed a more innovative approach to multidisciplinary teams, recognising that certain tasks traditionally performed only by doctors could be delegated to other healthcare professionals. He used the example of a nurse running a successful cerebrospinal fluid (CSF) clinic, demonstrating how capacity barriers could be overcome. Professor Fox further discussed the barriers related to regulation, professional and clinical behaviours, and integration. He suggested that individuals should have certain rights, such as not having to wait for years to receive a diagnosis. He proposed a minimum assessment period, during which treatment options could be evaluated. He stressed the importance of ensuring that healthcare systems are properly connected to facilitate seamless care. In particular, the need for better diagnostic imaging and triaging, and ensuring that all data is captured.

Professor Fox identified that many patients' home carers are not professionals and feel overwhelmed and isolated. He believes more needs to be done to support patients and their carers in their homes on an as-needed basis. Professor Fox stated that there often appears to be a gap between research and practical application. He emphasised the need for strategies to accelerate the adoption and implementation of new advancements. Professor Fox admitted that he was uncertain where the investment would come from but praised the NHS and the UK's previous success in cost and risk sharing for new therapies. He suggested starting the implementation of disease-modifying therapies in specialist centres to establish safe delivery and monitoring systems. He also emphasised the importance of efficient imaging, triaging, and comprehensive data collection within the NHS to create a robust real-life clinical trial setting. Professor Fox explained that while dementia costs the UK economy billions, the research spending on dementia is minuscule in comparison. He highlighted the need to focus on improving quality of life rather than solely extending lifespan. Professor Fox emphasised the importance of supporting informal carers to prevent emergency crisis admissions. He mentioned the high prevalence of cognitive impairment or dementia among individuals in residential care and the need to invest in supporting people in their homes to reduce the reliance on such care. Professor Fox also highlighted the significance of providing well-being, support, and knowledge to individuals to help them navigate the system and access the necessary help. He emphasised that no one should be denied support and care due to their inability to fill in forms or manage the system.

Professor Hornberger then addressed the barriers from his perspective. He concurred with Professor Fox's earlier point about the critical need for funding. He emphasised the importance of allocating funds towards the care side of dementia, as opposed to primarily focusing on diagnosis and treatment. Michael noted that the evidence base for care practices is often lacking and could be significantly improved. He highlighted the potential challenge of accommodating disease-modifying therapies, which would extend the time individuals spend living with the disease. Professor Hornberger also addressed barriers related to technologies, such as the need for a robust evidence base, privacy concerns, and data protection. He expressed the difficulty in striking a balance between individual autonomy and ensuring safety, particularly when patients transition from hospitals to the community. Additionally, he emphasised the importance of integration within the NHS and with other services, including social care. He suggested the implementation of computerised decision support systems to help clinicians make better diagnostic decisions.

Hilary Evans expressed her agreement with Nick's point and connected it to the question at hand. She stressed the importance of regulators considering the societal and social care costs associated with dementia treatment. Evans emphasised the need for timely decision-making to ensure patients have access to safe and effective drugs. She discussed the significance of cross-party support, leadership, and continued funding for the long-term mission. Evans acknowledged the challenges in changing existing systems and integrating new diagnostic pathways into an overwhelmed NHS. She highlighted the opportunity to leverage the UK's wealth of data and emphasised the need for buy-in and adequate funding. Evans expressed concern that the lack of access to new treatments would generate anger among charities and the wider society. She highlighted the groundwork done by her charity in policy development and engagement with NHS leaders. Evans welcomed discussions about expanding the mission's role in delivery and securing additional investment beyond the initial funding.

Professor Hornberger shared his thoughts on the support needed to implement these pathways effectively. Professor Hornberger acknowledged the significance of consistency and integration in health and social care services. He highlighted the need for computerised decision support systems to leverage the vast amount of data available and provide the best possible care. He also raised the question of involving informal carers in these pathways and addressing their confusion and challenges in navigating the healthcare system.

Evans shared her thoughts on the new pathway in dementia care. She discussed the need for scaling up brain health clinics and reaching the hardest-to-reach individuals, including those who are alone or overwhelmed as carers. Evans mentioned the importance of involving patients and carers in the co-design of pathways to ensure they work effectively for everyone. She also emphasised the uniqueness of dementia compared to other conditions and the need for clear understanding and detection in the initial stages. Evans stated that raising awareness and breaking down stigma is crucial in changing public perception and enabling progress in dementia care. She was asked if the new integrated care systems (ICS) bodies would be better positioned to address these challenges and involve various community members, not just traditional healthcare professionals. Evans responded positively, mentioning the need to think beyond current structures and learn from the experiences and networks developed during the COVID-19 pandemic. She also referred to her conversations with Kate Bingham regarding applying those learnings to dementia care.

Strategies to raise awareness

Moving on to the next question, Gillian Leng asked the panel about the strategies required to raise awareness, educate, and empower people about dementia and its potential for change.

Evans started by discussing the progress made in the last ten years by raising awareness, breaking down stigma, and encouraging conversations around dementia. She mentioned the importance of public understanding to support fundraising for medical research and emphasised the need to address the misconception that dementia is an inevitable part of ageing. Evans highlighted the impact of campaigns, public figures, and celebrities sharing their experiences with dementia, leading to increased awareness, and understanding. She also mentioned the ongoing challenge of getting families to openly discuss dementia and the need for honest conversations about the devastating effects of the condition. Evans confirmed that their organisation tracks public awareness trends through the Dementia Attitudes Monitor, which provides valuable insights into public perception.

Professor Fox echoed Evans' sentiments, emphasising that few medical conditions have the same societal impact as dementia. He mentioned how HIV, cancer, and COVID-19 became part of public discourse and how the availability of treatments changed the perception and reduced stigma. In the same way that cancer is now identified publicly as a bucket term for various cancers, he suggests that the public should be made aware of the diverse types of dementia and neurodegenerative conditions. Professor Fox suggested focusing on pathways, clinical trials, and providing tools for reducing risk as positive aspects to discuss. He warned that the system would need to be ready for the swell of people wanting early diagnosis.

Suggestions for political party manifestoes

To conclude, Professor Bewick asked the participants if they could briefly summarise what they would like to see in the political party manifestoes regarding dementia. Evans advocated a recommitment to the dementia mission and increased funding. She believes that the next government should ensure everyone is able to have a timely diagnosis and access to treatment. Great Britain could become the first nation to have a full diagnostic pathway for dementias. Professor Hornberger added that the political parties should promote greater awareness of dementias and increase funding, especially in the research into care. Professor Fox concluded that a commitment to timely and specific diagnoses and ensuring that patients and carers do not feel dismissed should be a priority to the political parties.





POPULATION HEALTH AND ENGAGEMENT



Co-chair of the NHS Innovation and Life Sciences Commission's Dementia Program, Lord James O'Shaughnessy, welcomed attendees to the inquiry session, highlighting the importance of addressing the health crisis posed by dementia. The program aims to explore the challenges of dementia and the potential for innovation and change.

The session focussed on population health, patient engagement, and tackling stigma. The format included introductions by speakers followed by a question-and-answer session. The below report outlines a summary of the key topics of discussion.

Session One: Earlier or More Timely Diagnosis in the Community, a Population/ Preventative Approach to Dementia

The speakers for the first session of the inquiry were

- **Professor Lynne Corner – Chief Operating Officer, National Innovation Centre for Ageing**
- **Alexis Chappell – Strategic Director of Adult Care and Wellbeing, Sheffield City Council**
- **Dr Sebastian Walsh – NIHR Doctoral Fellow, University of Cambridge, and Public Health Specialty Registrar**

Professor Lynne Corner began by emphasising the need to prioritise prevention and innovation in dementia care. She underscored the urgency of shifting to a prevention mindset and investing in a connected organisation ecosystem that addresses the challenges faced by both current and future populations. She cited the incredulity of members of the public regarding the lack of data communication between various branches of the health network.

“ Shifting our focus towards prevention and investing in a connected ecosystem is not just about addressing the challenges faced by today's population, but also about creating a brighter and healthier future for generations to come.”

- Professor Lynne Corner

Professor Corner addressed concerns related to waste, lack of data integration, and the potential of AI solutions. Additionally, she explored the significance of investing in brain health, promoting intergenerational engagement, improving health literacy, and personalising care for individuals with dementia. Professor Corner drew attention to the stagnation of life expectancy in the UK, the US, and other countries, alongside the significant expenditure on treating chronic conditions after diagnosis. Surprisingly, only 40 per cent of resources are allocated to preventable conditions. Within the UK, a fifth of citizens experience poor health, and there exists a notable 20-year difference in life expectancy. Notably, the issue is particularly prominent in the northeast region. To address these challenges effectively, Professor Corner emphasised the imperative to shift focus towards proactive prevention in healthcare provision rather than solely concentrating on diagnosis and post-treatment approaches.

Professor Corner highlighted the critically important need to address waste, duplication, and the lack of data integration within the healthcare system. By prioritising the effective joining up and coordination of key organisations and resources, progress can be accelerated. Specifically, the failure of data integration, such as the inability of primary care systems to connect, presents significant obstacles in both dementia diagnosis and post-treatment care. However, the report also recognises the exciting potential of AI solutions to address these challenges and improve outcomes.

To prevent dementia effectively, Professor Corner stressed the importance of investing in brain health and brain capital throughout an individual's lifespan. Understanding behavioural aspects and nurturing brain health upstream can significantly contribute to reducing the occurrence of cardiovascular-related dementia. This area of focus resonates strongly with citizens who express a keen interest in leveraging technologies, mobilising brain capital, and promoting intergenerational engagement. Furthermore, the presentation highlighted the need to democratise access to information and improve health literacy, including digital health literacy, to ensure that the benefits of prevention are accessible to all individuals.

Professor Corner noted that despite challenges and barriers, public interest in the prevention of dementia remains high. However, she cautioned that confidence in the investment and ability to achieve prevention goals is mixed. Professor Corner highlighted the importance of addressing concerns surrounding confidence levels and the necessity for continued collaboration and dialogue among stakeholders to build consensus and ensure the effective implementation of prevention strategies.

Minority community outreach and social care

Alexis Chappell emphasised three key points. The first point focused on involving people and ensuring that their views and voices are central to achieving early diagnosis. Chappell highlighted the importance of reaching out to communities that are seldom heard, such as the Black, Asian, and Minority Ethnic (BAME) communities, and shared an example of launching videos in Arabic to raise awareness about dementia. Furthermore, she stressed the need to value the voices of those already living with dementia, particularly in developing policy.

Chappell's second point stressed the value of utilising the social care workforce to identify early signs of dementia. She mentioned the re-commissioning of home care services and the development of personal assistant supports in Sheffield to prioritise early detection and symptom recognition. The third point emphasised the need for integrated working between health and care services. Chappell highlighted the importance of joining conversations and promoting multidisciplinary collaboration to identify early signs of concern and provide support at a practical level. In Sheffield, efforts were made to align primary care, healthcare, and social care services to establish a unified approach for individuals. Chappell also highlighted the potential of technology-enabled care in promoting early diagnosis, facilitating early intervention, and enabling independent living.

"Our journey toward effective dementia care must be anchored in involving people, integrating services, and harnessing technology. It's about forging a path that values early detection, embraces collaborative care and empowers individuals to lead dignified lives." Alexis Chappell

Population prevention and policy

Dr Sebastian Walsh focused on population prevention and highlighted the need for policy-level changes to effectively reduce the prevalence of dementia. He explained that there is a mismatch between prevention strategies and the evidence suggesting policy-level changes. While individual risk reduction strategies are important, he claimed they do not address the larger picture and the evidence suggests that policy changes and population-level risk factor modifications are the key avenues for dementia prevention. Dr Walsh emphasised the role of improved public health measures, better cardiovascular health, increased education, and reduced smoking as factors contributing to this decline. He cited studies focusing on cognitive function and ageing, which showed a decline in dementia prevalence over time.

Dr Walsh stressed that policy changes not only have the potential to impact a larger population but also address issues of equity, ensuring that the benefits of prevention efforts are accessible to all socioeconomic groups. He stated that encouraging lifestyle changes without changing social determinants will only benefit the most affluent and would widen health inequality. Dr Walsh highlighted the need to focus on interventions that consider social determinants and create an environment conducive to behaviour change. The ongoing efforts of his research team aim to gather and consolidate evidence on effective interventions and their aims.

Widening public awareness of dementia

Gillian Leng invited the participants to discuss how public awareness of dementia can be widened and what strategies would be most effective to do so. Professor Corner emphasised that early diagnosis of dementia is crucial, but it should be accompanied by adequate post-diagnosis support. She explained that currently, there is a lack of support services in many places, particularly psychologically, leading to a sense of despondency among families after receiving a diagnosis. Professor Corner noted significant challenges in connecting healthcare and social care services, resulting in fragmented support for individuals and their families. She advocated that investment in data integration is essential to leverage existing assets and improve patient and caregiver experiences.

Dr Walsh highlighted that the focus should be on timely diagnosis rather than early diagnosis. He stressed that although the population affected by dementia is primarily in their 80s, an earlier diagnosis around age 65 would be preferable. The emphasis should be on meeting the needs of individuals and caregivers, regardless of the specific dementia diagnosis. Dr Walsh questioned the feasibility of moving dementia diagnosis from memory clinics to primary care settings. While it is recognised as a potential solution, he is concerned about the capacity and pressures within the current healthcare system. He stressed the need to design a service around the system that is in place currently and what that will develop into in the next five years, rather than an ideal system that is unfeasible.



Training and resources to empower healthcare providers in community settings

Professor Mike Bewick asked the participants to recommend what training and resources would be necessary to empower healthcare providers in community settings to diagnose and treat more effectively. Dr Walsh raised the importance of training healthcare staff to recognise and diagnose dementia early. He celebrated the existing training programs aimed at improving awareness and equipping healthcare professionals with the skills to provide better support for individuals with dementia.

Professor Corner stressed the importance of training to enable clinicians to recognise that patients often deal with comorbidities alongside neurodegenerative diseases. She advocated a holistic approach to accommodate these comorbidities and highlighted that all healthcare staff, especially primary clinicians, need to be trained in this way. Professor Corner noted that other healthcare professionals such as dentists and pharmacists are fundamental to early diagnoses as they are more likely to notice changes first. However, she explained that these professionals are uncertain of the referral pathways for dementia and that if trained, they would become great assets for timely diagnosis.

Chappell believes that the social care workforce is a prime example of an area of investment as they are an untapped workforce already placed in the community. She identified a practical solution to utilise social care as an early warning system – they are likely to notice changes in behaviour earlier. Chappell continued to say that similarly, the voluntary sector is also embedded in the community and would be more likely to notice an early change in individual presentation.



Session Two: Improving Population Health Through Innovation

- **Geraint Lewis – Director of Population Health, Microsoft**
- **Professor Zoe Kourtzi – Professor of Experimental Psychology, University of Cambridge**

Professor Bewick invited the panel members to begin with an opening statement on their view on improving the health of the population through innovation. Geraint Lewis, in his introductory comments, highlighted the tremendous opportunities presented by technology, specifically AI, in the prevention, diagnosis, and treatment of dementia. However, he stressed that caution must be exercised to avoid unintended consequences and adhere to established guidelines. Lewis considered the potential limitations of technology and applying responsible AI frameworks and that it is possible to harness the transformative power of technology while prioritising patient safety, privacy, and well-being in dementia care. Lewis expressed enthusiasm about the role of technology, specifically AI, in dementia care. He highlighted the emergence of new diagnostic technologies that are less subjective, more accurate, and efficient compared to traditional diagnostic methods. He also mentioned the potential for technology to enable diagnoses in community centres and even within smart home environments, leveraging smart devices and detector devices.

Lewis discussed the concept of virtual wards, which could provide treatment at home for conditions traditionally requiring hospital admissions. He advocated that the approach has the potential to enhance the quality of care while reducing the burden on healthcare facilities. Lewis highlighted the utilisation of data analysis as an opportunity to detect gaps in care and ensure that preventive care and appropriate treatments for dementia are provided. He explained that analysing data can offer valuable insights into areas where improvements are needed and optimise the overall care experience for individuals with dementia.

Lewis acknowledged the significant burden that dementia places on society, particularly affecting disadvantaged groups. However, he emphasised the potential opportunities for intervention. He mentioned that there is a clinically silent phase of dementia that can last up to 20 years. During this phase, tackling risk factors like obesity and hypertension may potentially reduce the incidence of dementia-related conditions, such as diabetes, by 40 per cent. To mitigate risks associated with the use of AI, Lewis stressed the importance of applying responsible AI frameworks. He noted that Microsoft has a Responsible AI framework that covers factors such as fairness, reliability, privacy and security, inclusiveness, transparency, and accountability. Lewis suggested implementing such frameworks can ensure ethical and responsible use of AI technology in dementia care.

Developing predictive models for dementia

Professor Zoe Kourtzi set out the potential of AI and technology to revolutionise dementia care while emphasising the need for caution, clinical relevance, and global applicability of the models developed. Professor Kourtzi outlined that models built for early prediction and detection of neurodegenerative diseases, specifically dementia, need to be clinically relevant and biologically informed. She explained this ensures that the predictions generalise across different populations and are not biased toward specific groups. Professor Kourtzi stressed it is essential to develop models that are interpretable, meaning the factors driving the model's decisions in predicting dementia can be understood, this helps in reducing misdiagnosis and minimising false positives and false negatives. Professor Kourtzi emphasised that dementia is a global problem, and therefore, the models developed should provide global solutions and be interoperable. Her work focuses on early detection and prediction of dementia, as by identifying the causes of dementia in the brain up to 10 to 15 years before symptoms occur, interventions and preventive measures can be implemented to potentially prevent the onset of dementia or delay its progression.

Professor Kourtzi highlighted early detection enables the possibility of changing the clinical and diagnostic pathways for patients with dementia. She stated that this can lead to less invasive and costly procedures, reduced anxiety for patients, and the implementation of personalised treatment plans, considering the potential of new treatments. She explained that the models developed have the advantage of analysing large amounts of patient data from diverse sources worldwide and can process multimodal data, combining different types of information, which contributes to their power and accuracy. Professor Kourtzi asserted that models assist in reducing misdiagnosis by distinguishing between individuals who will remain stable over time and those who may experience slow or rapid progression of dementia. She emphasised this allows for appropriate allocation of resources and tailored treatment pathways for different patient groups, utilising real-world data to make this decision. In her view, the aim of AI and technology in dementia care is to support clinicians rather than replace them. In Professor Kourtzi's view, the goal is to assign patients to the right diagnostic and treatment pathways, improving patient well-being, reducing costs for healthcare systems, and facilitating drug discovery by stratifying patients more precisely.

The use of artificial intelligence to identify warning signs of dementia

Gillian Leng posed the question of how AI can be used to identify warning signs in individuals prior to a diagnosis of dementia. Lewis emphasised the potential of AI in improving early diagnosis, personalised care, and preventive measures for dementia, while also highlighting the need for careful consideration of ethics, governance, and access to ensure equitable implementation. He emphasised that the amount of data wearable and personal devices is substantial and leveraging this data can provide a wide variety of health monitoring measures. He cited examples including device cameras that can measure vital signs through a video and wearables that can analyse gait and fall risk. Lewis stressed the importance of accurate diagnosis and giving people the right prognosis. He acknowledged that there is currently a mismatch in this area and that it is crucial to address it. Lewis did however caution that there is an inverse equity in technological health monitoring as those most likely to benefit are those least likely to have access. Lewis concluded with a suggestion that data analysis be considered part of a multidisciplinary strategy to tackle dementia.

Professor Kourtzi indicated that the use of AI would vary depending on whether the aim was to diagnose or to notify of potential indicators of dementia. She suggested that AI could be used to alert individuals to changes in their cognitive abilities and enable early intervention. Professor Kourtzi explored how AI could be practically implemented and suggested that individuals might choose to enable AI alerts on their personal devices or that there could be an NHS-wide solution via the NHS app. Furthermore, she advocated that wearable device data should be integrated with clinical data for a holistic model of diagnosis. She summarised that AI is important for the development of future diagnostic pathways and would reduce the need for invasive and costly diagnostic tools.

The use of technology in personalising care

Next, Corinna Bull asked the panel to suggest how technology can be used to personalise care. Professor Kourtzi highlighted the potential of AI and technology in personalising dementia care. She suggested that

wearable devices and other technologies could provide data that can inform personalised interventions and preventive measures, such as addressing comorbidities like cardiovascular disease and hearing loss. She highlighted that many regions do not have access to preventative diagnosis and thus, using technology to allow for home diagnosis would be a great benefit to a new diagnostic pathway. Professor Kourtzi suggested that technology can also provide early warning signs of dementia that would then refer patients to a GP for accurate diagnosis and to identify comorbidities.

Lewis stressed that although data is precise, clinical practitioners are often too overwhelmed to utilise it effectively. He suggested the use of technology to bring clinicians back on track by detecting gaps in care and deviation from the expected care standard. Lewis explained that the software would then suggest the best action to get back on track. Furthermore, he cited that there is evidence for home-based treatments using technology to prevent or treat dementia, such as cognitive training.

Gaps and challenges in dementia research

The next topic was outlined by Dr Keith Ridge, who asked the panel what they considered the current gaps and challenges in dementia research, specifically in relation to AI and early diagnosis. Professor Kourtzi began by explaining that there is not enough data on dementia prior to symptoms, though there are a few ongoing studies in this area. She stressed that there need to be predictive models that can outline how dementia develops in the initial stages and identify preventative methodology. Professor Kourtzi advocated paired studies involving groups of healthy individuals alongside dementia patients to accurately compare the progression of dementia. She noted that there is already substantial health data available, which could be utilised in research in the NHS system already. However, this would need to be used safely and be compliant with data legislation. Professor Kourtzi emphasised that AI would be essential in the analysis of this data and should include data obtained from clinical trials. She explained that it would be time-consuming to integrate data and algorithms to create an early prediction model that combines wearable device data and existing biomarker data.

Lewis highlighted that there are five key types of prevention in public health

- Primordial – this deals with social and environmental factors including policy setting
- Primary – reducing risk factors to the individual to reduce the occurrence of dementia
- Secondary – screening programmes to identify genetic markers of dementia
- Tertiary – how to improve the life quality of those diagnosed with dementia
- Quaternary – preventing or reducing over-medicalisation for individuals

He stated that whilst secondary prevention receives a lot of attention, the other types are just as worthy of focus and research.

Commissioning and assessing technology with equality in mind

Lord James O'Shaughnessy highlighted the concern that technological adoption can be unequal and asked the panel how they would assess and commission technology in a way that overcomes inequality. Professor Kourtzi emphasised that personal technology is not necessarily the most effective method for diagnosis, but it can provide early warning signals for dementia and provide excellent data for developing predictive models. She explained that while clinical technology may achieve the best results, personal technology can make decisions from weaker signals when augmented through AI and existing clinical health data to give reliable decisions. She advocated deploying cheaper technology that, while not as effective diagnostically, is more cost-effective to be publicly available and collect the necessary data.

Lewis cited the National Institute for Health and Care Excellence (NICE) as a wealth of expertise and that they are in the process of assessing effective and cost-effective technology. He explained that their formula involved qualifying the cost per quality life adjusted year and if this meets the threshold, it should be paid for by the NHS.



Session Three: Improving Engagement and Tackling Stigma

- **Dr Hilda Hayo – Chief Admiral Nurse/CEO, Dementia UK**
- **Colin Capper – Associate Director of Evidence and Involvement, Alzheimer's Society**
- **David Truswell – Executive Director, Dementia Alliance for Culture & Ethnicity**
- **Sam Rodger – Assistant Director, Policy and Strategy, NHS Race and Health Observatory**

Professor Mike Bewick invited the participants to summarise their views on improving engagement and tackling the stigma of dementia. In her opening statement, Dr Hilda Hayo highlighted several key points related to patient engagement, person-centeredness, caregiver support, public awareness and education, inclusion, and partnership working in the context of dementia. She emphasised the need for broader and more representative engagement, involving individuals from different cultures, age ranges, and locations to share their stories and experiences. In terms of person-centred care, she stressed the importance of understanding individual strengths and areas that require support and development. Regarding caregiver support, Dr Hayo highlighted the lack of post-diagnostic assistance for families dealing with the complexities of dementia.

Dr Hayo explained that caregivers feel abandoned and struggle to access specialised advice and support. She suggested that public awareness and education efforts should also target the workplace as colleagues may notice early symptoms of dementia in individuals who are still employed. In terms of inclusion and social support, Dr Hayo emphasised the need for tailored care and support for people with rarer types of dementia or younger individuals with dementia. Dr Hayo noted that existing dementia services often cater to those over the age of 65, leaving younger individuals feeling excluded. Healthcare training should address the recognition of rarer dementias and atypical responses to dementia as memory disturbances may not be prominent in the early stages of these conditions. Lastly, Dr Hayo called for genuine partnership working, aiming to avoid fragmentation among different organisations involved in dementia care. She stressed that families should be able to easily navigate and access information and support from various sources without confusion.

Colin Capper focused on language and the importance of clarity in communication. He highlighted the various terms used in relation to engagement, such as participation, involvement, coproduction, and co-creation, and emphasised the need for a clear understanding of their meanings. Capper advocated for a shift towards more active and meaningful involvement of people with dementia in their care planning and the development of policies and services rather than passivity. He acknowledged that currently, the percentage of individuals affected by dementia who are actively involved is very small, possibly around one per cent, and expressed concern about the inverse involvement challenge. Capper explained challenge refers to the fact that the individuals who are most in need, vulnerable, and affected by health inequalities are often the least likely to be involved in decision-making processes. He stressed the importance of including these voices and addressing the gaps in involvement to ensure that discussions and actions are inclusive and representative.

Community engagement and dementia

Truswell emphasised that the belief that communities take care of their members with dementia, particularly within African, Caribbean, and South Asian communities, is a misconception. He explained that in reality, the rates of dementia in these communities are often higher than in the White majority population. Truswell discussed the higher likelihood of individuals in minority communities, especially those over 65, living alone or in households that are more at risk for dementia. He emphasised that the burden of caring for someone with dementia often falls on a single family member, who may face cultural expectations of fulfilling their filial duty stoically, without seeking help or support.

Truswell highlighted the lack of knowledge and understanding about dementia within minority communities. He explained that many caregivers are unfamiliar with the psychological impact of supporting someone with dementia and may not receive adequate information or resources. Truswell feels that media portrayals often reinforce the perception that dementia mainly affects White, middle-class individuals. He noted that the isolation experienced by caregivers and the lack of avenues for open communication can lead to abusive dynamics in caregiving relationships. Truswell added that both the person with dementia and the caregiver can feel coerced or manipulated, and there may be instances of financial abuse. He emphasised that cultural stigma further exacerbates the challenges, resulting in cultural exclusion within their own communities. Truswell advocated for efforts to be made to provide personalised information and support to carers and individuals from these communities, considering their specific needs and circumstances.

Sam Rodger highlighted the ethnic inequality in dementia diagnosis, age of onset, and mortality rates. He explained that BAME communities tend to be diagnosed and die at a younger age, and they often present to specialist dementia services at a later stage. Rodger emphasised the need to consider various levels of engagement in dementia care. He included interpersonal engagement between healthcare professionals, patients, and their families, as well as national-level engagement through communication and guidance to destigmatise dementia conversations. Additionally, he advocated that community engagement and participation should inform service design, provision, and local communications. He stressed that healthcare needs to be culturally adaptive, particularly concerning dementia.

Rodger highlighted trust is a key element in all forms of engagement; trust cannot be easily established but needs to be earned, nurtured, and maintained. He stressed that trust is particularly crucial when engaging with ethnic minority communities, where there may be a significant trust deficit due to different barriers and



historical factors. Rodger acknowledged that engaging with ethnic minority communities can be more expensive due to the trust deficit and unique barriers. He discovered this while lobbying for the Adult Psychiatric Mobility survey to include ethnic minority participants, which almost did not happen due to the additional cost. He added that it may require additional resources and efforts to overcome these challenges. Rodger advocated for recognising the importance of the NHS serving all communities and working effectively for everyone.

Involving patients and carers in policy-making

Lord O'Shaughnessy asked the panel how policymakers can involve the broadest range of patients and carers in policy making process. In response, Capper highlighted the importance of valuing the expertise of people with lived experience equally alongside professional expertise in policymaking. He advocated for clarity around decision-making and democratising involvement in policy. He mentioned the example of Scotland's dementia strategy, which involved a Lived Experience panel working alongside an advisory group. He explained that they went directly to the communities that would not have been surveyed otherwise. Additionally, he emphasised redistribution of power, clarity in decision-making and accountability, clear goals and approaches, time and resources for trust-building and communication, and the evaluation and sharing of impact.

“ This idea of not offering people a seat at the table but taking the table to them, I think, is particularly important.”

– Colin Capper

Rodger emphasised the need for transparency, validation, and involvement of communities beyond initial consultations. He stressed the importance of resource allocation to ensure equitable engagement and mentioned the significance of addressing concerns and barriers through open and meaningful dialogue. He cautioned against dismissing cultural reservations and emphasised viewing system barriers rather than community issues. He further warned that the NHS should not deem issues as cultural when those issues occur because those cultures are underserved by the system. He advocated that policymakers need to consider the barriers that the system creates for minorities.

Fostering collaboration between organisations and policymakers to address stigma and improve care

The next question was proposed by Corinna Bull, who asked how collaboration can be fostered between healthcare providers, patient advocacy groups, community organisations, and policymakers to address stigma and improve dementia care. In response, Dr Hayo highlighted the engagement with integrated care systems (ICS) and integrated care partnership boards (ICPB) to address the complex issues faced by families affected by dementia. She focused on the cost-effectiveness and human cost of different care models, expanding access to diagnosis beyond specific age groups and societal sections, and promoting engagement with various healthcare providers and community services. Dr Hayo added that post-diagnostic support will save money in the long term due to reducing emergency admissions. She stressed the importance of reducing fear and increasing hope through accessible advice and support. Dr Hayo also emphasised that diagnosis should not focus on a specific age group but should be broadened to younger age groups who are also affected. She advocated that policymakers should work with community practitioners to enable the public to seek advice when facing difficulties. She explained that people are often reluctant to seek advice due to fear and a lack of hope post-diagnosis.

Truswell added that one size does not fit all and that there should be local solutions for local circumstances as different communities have different infrastructures. He advocated that the best way is grassroots-led coproduction that involves the experience of dementia patients and their carers. Truswell wants more focus on higher-risk communities but stressed that these efforts need to be bought into by those communities.

Capper recognised that more perspectives at the local level can create improved solutions that would develop shared accountability and responsibility for driving change. He explained that this would allow individuals and communities to take ownership of the change and that there is an appetite for this at the local level.

Tackling dementia stigma

Gillian Leng asked the panel how we can tackle the stigma of a dementia diagnosis. Dr Hayo initially responded that there is still significant confusion regarding the types of dementia and that patients who receive a diagnosis not termed dementia, such as Alzheimer's, express relief that it's "not dementia". She explained that the umbrella term of dementia is very misunderstood by the public and that there is a great deal of fear surrounding a diagnosis. However, she suggested that that fear could be utilised to encourage preventative measures. Dr Hayo advocated a balance between utilising fear to encourage prevention and maintaining the message that there are treatment options to encourage people to seek a diagnosis. She explained that patients often immediately think that they will be deemed incapable of supporting themselves post-diagnosis and there needs to be more effort to raise awareness of the gradual decline of dementia.

Rodger added that stigma and fear surrounding dementia can be linked with cultural perceptions regarding ageing. He advocated for culturally adaptive diagnostic and therapeutic tools as ethnic minorities do not perceive ageing and care in the same way as the NHS.



PATIENTS, CARERS AND SERVICE DESIGN



Co-chair of the NHS Innovation and Life Sciences Commission's Dementia Program, Lord James O'Shaughnessy, welcomed attendees to the inquiry session, highlighting issues including diagnosis and awareness, challenges in communication, the emotional impact of diagnosis, quality of life and independence, the caregiver burden, and much more besides.

The session focussed on key issues regarding patient experience, the impact on carers, service provision, and the design of a new service pathway. The format included introductions by speakers followed by a question-and-answer session. The below report outlines a summary of the key topics of discussion.

Session One: Key Issues Surrounding Patient Experience and the Impact on Carers

The panel for the first session of the inquiry were:

- **Fiona Carragher – Director of Research and Influencing, Alzheimer's Society**
- **Helen Walker – Chief Executive, Carers UK**

Contributions were made by:

- **Dr Hilda Hayo – Chief Admiral Nurse/CEO, Dementia UK**
- **Alison Rose – Real World Evidence Director, HCD Economics Ltd**

Fiona Carragher began her introduction by outlining diagnosis and the lack of post-diagnosis support. Carragher believes that a system-focused response is necessary, particularly to tackle the struggles of unpaid family carers. Carragher stressed that dementia is the most complex challenge facing the health and care system now and that it cuts across the health and care system. She cited that dementia is Britain's biggest killer and that it needs to be made a priority. She criticised the healthcare system for failing to deliver timely or accurate diagnoses and falling below the 67 per cent national diagnosis target, which has not been met since before COVID-19. Carragher emphasised the need to follow the National Institute for Health and Care Excellence (NICE) guidance around diagnosis, with PET-CT and CSF testing being clearly indicated. She lamented that it frequently takes up to two years to receive a diagnosis and that often, it is not specific which dementia it is. She cited that as many as 300,000 individuals who show symptoms have not been diagnosed.

Carragher was, however, hopeful regarding the disease modifying therapies currently going through regulatory processes. She did note that unfortunately, only 2–2.2 per cent of dementia patients have an accurate enough diagnosis to determine if they are eligible for those therapies, and that specialised testing is needed to facilitate this. Carragher stated that personalised support is needed for patients to live safely and independently and to manage their symptoms, which would lower hospitalisation rates. She emphasised the importance of carers and explained that suitable respite care is the key element in avoiding crisis. Carragher has found that many patients must be placed in a care home due to carer burnout, which is causing a crisis. In general, she feels that better carer training is needed, particularly given that over a million people will be living with dementia in the near future and will need support. She finished by calling for an integrated care system (ICS) with a dedicated lead supported by a steering group, and for each ICS to have an accountable dementia strategy.

Representing Carers UK, Helen Walker began by emphasising that each caring experience is different. She continued to say that declining mental and physical capabilities in dementia sufferers often leave the carer feeling frustrated and guilty. Walker advocated for regular check-ins to ensure carers are coping and make them aware that support is available. She explained that carers need regular information and support, with information being reiterated to them. Walker has found that solutions are often broadly the same and include more visibility of unpaid carers as part of the healthcare system and better health and well-being. She stressed the need for early identification, which leads to positive outcomes. Walker also suggested the risk stratification of carers, particularly those with their own conditions who would need support quicker than those in good health. Walker also highlighted the overall economic impact of dementia.

“ We know the estimated value of unpaid caring in the UK is a staggering £162 billion each year. So effectively, a second NHS. Therefore, I think there is a strong business case for supporting carers because quite frankly, if a carer themselves goes down, the system then has to look after two people.”

– Helen Walker

Walker noted that dementia sufferers frequently become anxious if there is a change in care and that well-being needs to be at the heart of care strategies. She would like increased awareness of unpaid carers in the workplace. Whilst some carers find respite from caring whilst at work, Walker advocated for paid carers leave to support them financially. She suggested that digital technology can be used to support carers, particularly in the initial stages, such as location trackers to ensure peace of mind. Walker also explained that carers can share caring responsibilities via Carers UK's "Jointly" App. However, she felt that more could be done to support carers digitally and suggested proxy access to the NHS app for carers and for them to be able to register on the NHS app as a carer. Walker stressed the need for it to be clearly marked on patient's records who their carer is. She concluded that families will only trust services if they are well run, considerate, compassionate, reliable, and use the same staff to ensure continuity of care.

Improving diagnosis and public awareness of dementia

Richard Stubbs began the question section of the inquiry by asking the panel, “How can the healthcare system improve early diagnosis and raise awareness about symptoms among healthcare professionals and the public?” Carragher responded first and referred to the national diagnosis target of 66.7 per cent, suggesting that the UK needs a more ambitious target for diagnosis. She did, however, stress that this would need to be backed up by funding. Carragher cited that currently, diagnosis is predominantly conducted in memory clinics in mental health trusts by psychiatrists that specialise in old age. To improve diagnosis rates, she suggests that investment is needed in diagnostic techniques outside of memory clinics, such as the blood tests used in clinical trials. Carragher emphasises the need to develop real-world evidence to implement in the NHS. She noted that the Alzheimer’s Society in partnership with Alzheimer’s Research UK has a five-year plan, with £5 million of funding and the use of care system leads as part of the project. Carragher would prefer a multidisciplinary approach to improve the quality of diagnosis, particularly given the four-year wait those with younger onset or rarer dementias often endure. To improve public awareness, she suggested a messaging campaign to change the belief that dementia is a natural part of ageing.

“ **There needs to be a real change in the kind of understanding by society that this is not getting old, it’s getting ill.**”

– Fiona Carragher

Dr Hilda Hayo then explained that younger people often have three or four incorrect diagnoses before dementia is finally diagnosed. She noted that this diagnosis journey is very crippling to mental health. Dr Hayo concurred with Carragher that a higher ambition for diagnosis is preferable. She added that there is a lack of specialist post-diagnostic support, especially with more complex dementias. Private clinics, particularly, do not offer post-diagnosis support at all as patients are referred back to their GP. This lack of joined-up services, Dr Hayo noted, makes it difficult to navigate the healthcare system and makes communication difficult. She found that frequently, a failure in communication is the fault of healthcare professionals rather than the carers of patients.

Alison Rose added that patients at the mild cognitive impairment stages of dementia are difficult to diagnose if just looking at their electronic records. When she discussed this with healthcare administrators, they cited that the electronic records only suggested there were ten patients at that branch, but they could name fifty more. Rose concluded by stating that data points are not being recorded, particularly those that speak to outcomes that caregivers desire, which means the true story is not apparent from electronic records.

Improving communication

Next, Stubbs asked the panel, “What are strategies we can use to support better communication between patients, carers, and professionals?” Walker feels that, in terms of carers being recognised, there is more to be done as they often have to repeat their story to different professionals to convince them they are a carer. She suggested that there should be a single place where carers can be recognised as such, where information is kept, stored, and shared. Walker believes this validation would make a massive difference to unpaid carers.

Carragher added that, with progressive diseases, the family carer relationship is pivotal as they advocate and understand the patient’s needs best. She found that less than half of people living with dementia rated professional carer staff’s understanding of dementia positively. Carragher recommended that all staff caring for dementia patients be trained in the Dementia Training Standards Framework to at least tier two. She stressed that consistency of care is important but that unfortunately, there is significant turnover in the carer workforce, which leads to a lack of consistent relationships.

Carer wellbeing

Corinna Bull invited the panel to address the emotional well-being of carers and answer the question, “How can we mitigate the emotional burden they deal with to prevent caregiver breakdown?” Walker began by stressing that breaks are key but only effective if there is a provision of people to ensure consistent care. She lamented that many respite centres closed during COVID-19 and most have not reopened. She cited that the situation became so bad that as many as 36 per cent of carers considered suicide due to burnout. Walker stressed that carers need to prioritise their own health as a third of carers are waiting for their own treatment. She suggests that the NHS should prioritise carers’ support and treatment. Regarding emotional well-being, Walker believes that peer-to-peer support groups are immensely powerful. She stressed that as unpaid carers often take two years to self-recognise they are a carer, diagnosticians need to stress that at the point of diagnosis, family supporters have become unpaid carers.

Dr Hayo added that there has been an increase of 40 per cent in safeguarding incidents coming through helplines year-on-year due to a lack of support for carers and patients and the limited respite available. She also stated that the lack of consistency in care means that families decide not to have professional carers coming into the family home as it is usually at a time suitable to the carer and not the family.

Carragher would prefer for newly diagnosed patients to have access to dementia support workers at the point of diagnosis, particularly someone who understands the local area. She believes that services need to be part of an integrated stepped model so that, as disease progression increases, access to specialist care increases. She also shared that community liaison workers help with supporting ethnic minority communities and dementia sufferers.

Rose emphasised the importance of societal-level recognition that caregivers are a much-needed aspect of society in general and feels that the substantial evidence gap regarding the economic burden on carers needs to be addressed. Carragher concurred with Rose and added that there is no integrated data on dementia pathways. She would like a government dementia observatory to integrate this data and has commissioned the Office for Health Economics to do a big analysis of the health inequality and drivers of poor dementia outcomes. Carragher explained that there are massive gaps in data and that more research is required as there are massive hidden costs that need to be identified.



Dignity and respect, carer training and end-of-life care

Bull asked the panel, "How can we make sure patients are treated with dignity and respect and do you have any best practice examples?" Carragher suggested that the patchy annual care reviews need to be better, and she would prefer a care plan and holistic conversation with the needs of the carer tied into it. She felt that a primary care level GP should collaborate with a specific primary caregiver and conduct annual reviews.

Dr Hayo found that care plans are often hit and miss; if they even exist, GP consistency is exceedingly difficult to ensure. She stressed that care plans should focus on the patient's strengths so that they can still do meaningful activities, as long as they have peer support. Walker suggested that technology can be used to support carers so that they do not have to leave a patient alone as they can get support in the home.

Professor Mike Bewick also asked the panel, "What training packages can be coordinated and how can the trainers be trained?" Additionally, Professor Bewick asked the panel to discuss current approaches to dementia end-of-life care and advanced care plans. Walker answered that diagnosticians need to be empowered to say to the family support that they are a carer now and that it is a journey, emphasising that the family is a package from the beginning. Walker suggested that the healthcare system needs to normalise conversations about end-of-life care and have those conversations early. She stressed that carers need to get power of attorney sooner rather than later so that they have it in advance of health issues, and in general, have conversations before the patient's condition deteriorates and they are unable to be involved in the discussions.

Dr Hayo added that carers are given an overwhelming amount of information at diagnosis, which is not suitable at that point in time and which carers will discard almost immediately. She suggests that there should be focused information on the challenges facing carers at that point in time, with more pertinent information provided as the disease progresses. Dr Hayo also stated that dementia navigators would be useful at the first stage but too much information at diagnosis is less than useful to carers. Dr Hayo stressed that when discussing advance care plans, the earlier the better as often by the time of diagnosis, patients cannot engage in those plans. She stressed that healthcare professionals should not shy away from end-of-life care plans.

Carragher explained that diagnosis is a gateway to potential research and treatments. She suggested that diagnosticians should have supported conversations on advance care plans but added that there are significant variations across the UK for diagnosis rates, ranging from 48–84 per cent. Carragher suggested coproduction and bringing communities together to design pathways appropriately.

Lord O'Shaughnessy summarised session one and stated that systems need to be designed in partnership with patients and carers, but that infrastructure is not in place to support good outcomes. He stressed that the economic value of unpaid carers is tremendous. He stated that diagnostic infrastructure needs to be improved and that medical pathway kinks need a sociocultural pathway that is supported by improved data and continuity of care.



Session Two: Service Provision and Design of a New Service Pathway

The speakers for the second session of the inquiry were:

- **Dr Wendy Burn** – Consultant in Old Age Psychiatry, Leeds, and York Partnership NHS Foundation Trust
- **Dr Hilda Hayo** – Chief Admiral Nurse/CEO, Dementia UK
- **Alison Rose** – Real World Evidence Director, HCD Economics Ltd
- **Anthony Woodhead** – Development Director, Health Science Implementation Ltd., and Associate at HCD Economics

Dr Wendy Burn began her opening statement by explaining that the NHS is wildly underfunded and that nothing can be changed without an increase in funding. Currently, mental health (where dementia sits in the NHS), Dr Burn noted, is the most underfunded area of the NHS. She suggested that funding should be used for a care records system that interfaces with social care services. She brought up Leeds Care Records as an example, which mental health practitioners can use to see GP records in a limited capacity, including medication, GP encounters, and letters from consultants. Dr Burn has herself used these records and found that they help support patients, she believes such systems should be widespread. Generally, Dr Burn emphasised that patients and carers need to be involved in care, pulling the care services together with somebody who can coordinate care across services and agencies. She noted that diagnosis targets have unintended consequences and come at the cost of long-term care. She found that an emphasis on diagnostic rates led to a culture of 'diagnose and discharge'.

Dr Burn would prefer improved training for all health service staff and for the NHS to provide opportunities for people to learn, as most staff want to develop their skills and knowledge. However, she cautioned that such learning should not be compulsory as staff do not engage with compulsory training. Outside the NHS, Dr Burn found that organisations to support carers are very underfunded. She advocated for a patient-centred approach in dementia care to foster a patient-centred culture. She was concerned that management systems often discourage care being patient centred as the priority is often statistics or targets. Dr Burn would encourage systems not to forget frontline clinicians' roles in dementia care. She explained that upcoming drug treatments will change services as they cannot be administered by mental health trusts, which currently manage dementia diagnosis and treatment. She suggested that as a result, dementia treatment could move to neurology departments as it is not the best use of mental health workers' skills to support dementia care. Dr Burn concluded that increased funding towards mental health services would be best directed to additional staffing as, while buildings and infrastructure are important, staffing is more essential.

Dr Hilda Hayo noted that there are some examples of integrated care pathways spread across the UK, but they are not implemented elsewhere. She explained that to implement them elsewhere, funding and staffing are needed. She presented Northamptonshire's integrated approach as the best example of an integrated care pathway, which involves memory hubs set up for those living with a dementia diagnosis, either carers or patients. Dr Hayo cited there is roughly one hub per 5000 individuals in Northamptonshire. She felt that integrated care systems should be the linchpin of the dementia strategy as they improve support, but this does not happen consistently. Dr Hayo found that frequently, integrated care systems do not mention dementia and so it is still a postcode lottery for dementia patients. She stressed that patient care plans should focus on what they can do rather than focusing on the negatives, which can destroy the patient's self-worth. Dr Hayo questioned whether primary care is the right place for annual reviews to sit. She concurred with Dr Burn that any training on dementia needs to be voluntary if staff are to engage fully. She cited that a 25 per cent minimum of hospital beds are occupied by dementia patients and encourages hospitals to learn more to better care for them.

Dementia data gaps

Alison Rose stressed the need to better inform society that dementia is getting sicker not older, and to improve awareness of the societal impact of dementia. She explained that varying data points are needed to understand the true impact of living with dementia and that there is a large data gap. Rose feels it would be ideal if there was an integrated system to acquire this data from, however, the silos where the data resides means there are significant hurdles. She would like to be better able to measure not just the direct impact of dementia but also the loss of productivity and the humanistic burden, which can dwarf direct costs. Rose gave examples including the caregiver not working, the cost of informal care, and how much a paid caregiver costs for that time. She stressed that these costs dwarf those of hospitals. She stated that a better overall picture of the burdens of dementia is needed. Rose noted that usually, this data sits outside of electronic records and is difficult to acquire. Rose explained that the outcomes that matter to patients and carers differ from clinical outcomes and that these can change over time, depending on disease progression.



Anthony Woodhead added that caregivers do want to give this information and that systems need to make it easier for them to do so. He suggested this could be accomplished by giving patients access to their own records to provide information themselves and curate the records. Rose then explained that caregivers rate their quality of life as lower than the average individual and that caregivers often adapt to a reduced quality of life. She stressed that the whole industry needs to work together to create data and evidence-generation methods run by patient advocacy groups that create standardised measures and parameters.

The causes of fragmented and inconsistent care

Professor Bewick asked the panel, "Is fragmented and inconsistent care due to a lack of specialised services, weaknesses in diagnosing, or a lack of appropriate care pathways?" Dr Burn responded that just a lack of staffing leads to a culture of 'diagnose and then discharge.' She felt that ideally, services would stay in contact after the patient is discharged, with a specific point of contact to ask questions. Dr Burn explained that this would nip in the bud several issues because they could be addressed early, and it would prevent carers from struggling, particularly with small issues that grow into larger problems.

Dr Hayo agreed that resources and staffing are the primary causes of fragmented and inconsistent care. She emphasised that after being discharged from memory services, patients need to constantly be referred back through GPs to contact memory services. She pointed to this delay as the cause of patients entering crisis and going into long-term care sooner than necessary. Carragher feels that dementia is usually seen as a social care issue, but it has many connections within the system, such as mental health, primary, and community care. She emphasised that seamless post-diagnostic support is essential for dementia sufferers.

Technology and national policy

Lord O'Shaughnessy invited the panel to discuss the interplay between national policy and technology to determine what the most appropriate balance of national direction and local initiatives is. Dr Hayo responded first and said that patients and carers should be allowed responsibility for their care plans. She suggested that healthcare systems should use the individual's data to design bespoke support as currently, care plans are non-existent.

"If we're doing annual reviews of care plans, why don't we ask the person that's living with dementia and their family member to have responsibility for the care plans? Because it's painfully not working at the moment, there's no reason why they shouldn't be able to." – Dr Hilda Hayo

Carragher felt that technology to enable independent living alongside caregivers is essential. However, she explained that what technologists think is important to patients is not necessarily what is needed, but the innovators are unaware of this due to their lack of lived experience. As a result, Carragher would encourage innovators to involve dementia lived experience in their design of technology. Dr Burn reminded the panel that as much as 70 per cent of dementia patients and their unpaid carers do not use the Internet or advanced technology.

Rose noted that some organisations insist on evidence and data, however, there are problems accessing the required data. She stressed that there needs to be quality of life measures. She found that caregivers do like to provide relevant data, so a registry would be helpful but needs to be clinical, humanistic, and economic.

Bull asked the panel to provide examples of technology that has been well-utilised in service areas. Dr Hayo explained that due to a lack of technology usage by dementia patients and carers, when most forms and processes moved online many became unable to engage with the process. She stressed that newer technology is more likely to be used by younger patients and future generations. Dr Burn added that unpaid carers do use some technology to track patients' locations for their own peace of mind.

Furthermore, Carragher explained that, while novel technology is challenging, the biggest step is diagnostic technology, such as home sensors to detect gait changes, falls, changes in sleep, and other indicators of disease progression. Woodhead concurred that sensor and camera technology will be particularly effective at monitoring comorbidities. Stubbs cautioned that the ethics and morals of surveillance and monitoring need to be considered to weigh against the potential benefits.

Ethnic communities and dementia

Stubbs then asked the panel, "How can we build care models that cater to ethnically and socioeconomically challenged communities?" Dr Hayo suggested a specific community healthcare outreach post, particularly with appropriate language skills. She noted that charities are frequently not utilised by ethnic communities as they are seen as not representative of their needs or views. Dr Burn concurred that staff need to represent the communities they are serving as best as possible, ensuring a continuity of care with appropriate translation services.

Professor Bewick summarised that session two had identified that technology is rapidly expanding but that pharmacology does not have a joined-up system in data or service design. He added that not many patients or carers are digitally savvy and diagnosis technology and early interventions are essential. Finally, he stated that the system needs to consider the personal costs and wide breadth of implicit costs with dementia, that there is a lot of work to be done before systems are comprehensive enough, and that training is very much needed for staff to assist with this.

Conclusion

As a follow up to the 2022 *NHS Innovation and Life Sciences Commission* report the Dementia Commission has aimed to apply the learnings from last year's report to a specific condition area. Given the exciting innovations and treatments on the horizon, this report sets out recommendations and a draft implementation plan for future service delivery models for patients with dementia and for those yet to be diagnosed.

Through the thought leadership of experts across the NHS and life sciences ecosystem, the commission has been granted insights into the areas of future technologies, population health and engagement, patients, carers, and service design. The aim to implement these recommendations will continue through utilising real-world data and examples of best practice to scale nationally.

In the New Year, the commission will work with stakeholders to model new care pathways to ensure patients are at the heart of the care pathway through a roundtable sprint meeting facilitated by the commissioners.

The commission looks forward to working with colleagues and relevant bodies to implement the recommendations set out in the four areas of inquiry.

In 2024, the commission will appraise the progress of the recommendations and continue to evaluate the real-world context of population health and gain further case studies to highlight good practice.

Further inquiries will be held on specific therapeutic areas including a neurodegenerative diseases commission and inquiries including oncology, rare diseases, and women's health. The commission seeks to utilise the inquiry areas this year to find pragmatic, implementable solutions to specific patient populations, improving health outcomes and reducing inequalities.

We would like to sincerely thank all those that have contributed to the discussions and provided their insight.

To access the full library of videos from Dementia Commission inquiry sessions:



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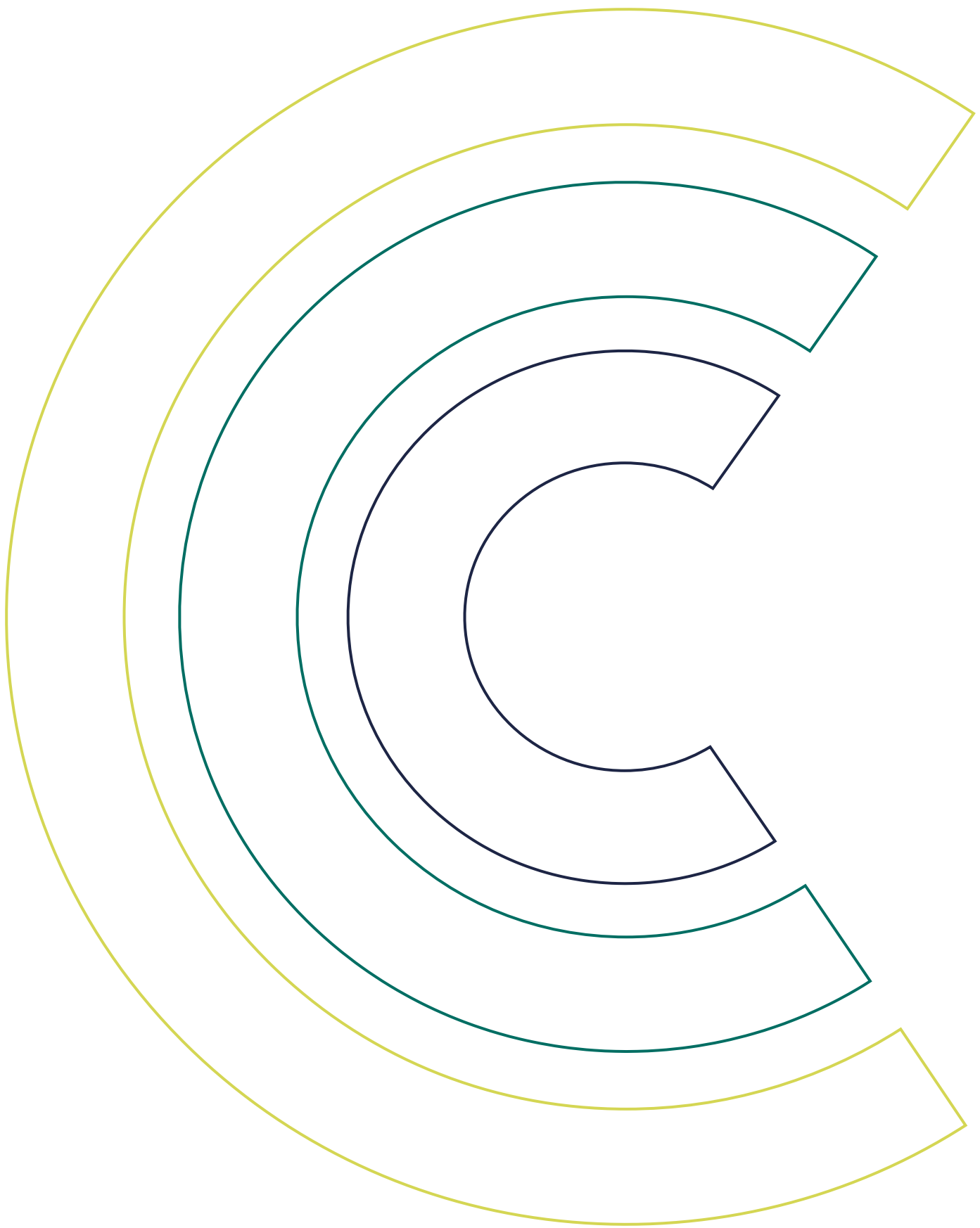
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