

# Consensus Statement:

## Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland

We intend to advocate for practical changes and tangible solutions to improve access to good quality, timely dementia diagnosis across the three nations of England, Wales, and Northern Ireland. This statement sets the foundation for understanding what is needed now and in the future to improve access to a timely and accurate diagnosis for those living with dementia.

This consensus position was developed through research by Alzheimer's Society, in conjunction with three roundtable discussions with senior dementia stakeholders and people living with dementia across the three nations. Discussions identified the key barriers to accessing a timely and accurate diagnosis and proposed solutions. The solutions require commissioners, clinicians, patients, local systems, and Government bodies to work together to drive real change in increasing dementia diagnosis rates.

### Headline consensus statement

- As a collective, dementia stakeholders must come together to advocate for better funded and evidence-based dementia pathways. These pathways must deliver effective care, support, intervention and treatments for all those living with dementia. People living with dementia highlight the value of an early and accurate diagnosis in preparing for the future and this should be a fundamental right.
- Stakeholders should recognise the advent of new, disease-modifying treatments as a driver for immediate system change to increase diagnosis rates.
- National health systems must commit to returning diagnosis rates to pre-pandemic levels and build capacity for going beyond this in future.

### Consensus agreement on ways to improve diagnosis

#### 1. Workforce and new ways of working:

##### Barriers:

- Barriers included a lack of multi-disciplinary and innovative approaches to dementia diagnosis; poor pathway planning and development; and challenges with workforce capacity, training and development.

##### Recommendations:

- A multi-disciplinary approach to diagnosis is needed along with innovative ways of working to ease workforce pressure. These include; remote appointments, upskilling staff, and scaling up pilots like NHS England's DiAdeM project. All innovations must respect the right for patients to choose what works best for them and their families.
- Local and national health system leaders must recognise recruitment and retention in relevant roles such as in memory services as part of their overall workforce reviews.

#### 2. Health inequalities and public health messaging:

##### Barriers:

- Barriers included regional variation in diagnosis rates across the three nations, with those from rural and/or deprived communities and those whose first language is not English least likely to have timely access to a quality diagnosis. Further barriers were cultural differences and the stigmatisation of dementia as a condition.

##### Recommendations:

- Fair access to a dementia diagnosis for all regardless of ethnicity and other protected characteristics, as well as socio-economic status, language, or geographical location must be prioritised. Culturally relevant assessment tools and interpreters (including bilingual assessments for Welsh speakers and assessments for those who are deaf or British Sign Language users) should be introduced and made widely available, and co-production of local diagnosis pathways should reflect the local population.
- Better data collection on the impact of regional and cultural variations should be undertaken at a national and local level to allow for future-proofed commissioning of diagnosis pathways, including for bilingual Welsh-language speakers in Wales.
- An annual diagnosis public messaging campaign should be developed to overcome stigma.

#### 3. Financial and system pressures:

##### Barriers:

- Barriers included funding arrangements and commissioning processes; a lack of guidance on post diagnostic care and Mild Cognitive Impairment (MCI); balancing timely with accurate diagnosis; and lack of peri-diagnosis support.

##### Recommendations:

- Local systems should have a named dementia lead accountable for outcomes.
- In advance of new dementia treatments being made available to patients, the National Institute for Health and Care Excellence (NICE) should ensure that guidance on MCI is developed so that people living with dementia are diagnosed at the earliest opportunity and can take advantage of revolutionary new treatments as soon as they are available.
- Dementia pathways across the three nations are routinely underfunded, with commissioning arrangements often disincentivising an increase in diagnosis rates. Local systems should use Leeds Beckett University's ['Taking Memory Assessment Services \(MAS\) into the Future'](#) as a commissioning framework when designing memory services, and align funding for workforce capacity with future demand for services. National health systems should invest in dementia care to help prevent costly dementia crises.
- Dementia stakeholders should push for dementia to be given parity of esteem through equitable prioritisation and funding with other conditions, such as cancer and other mental health conditions.

#### 4. Future-proofing the diagnostic system

##### Recommendations:

- We need access to subtype diagnoses, an enhanced workforce and an equitable offer to people with all types of dementia.
- National and local systems must increase the profile of dementia and recognise the ever-increasing prevalence of the condition, as a driver for change. People must be diagnosed in the early stages of their dementia, as new treatments will likely only benefit this group.
- People diagnosed with dementia must also be offered the opportunity to participate in research trials.
- Health systems must ensure equitable access to scans for memory assessment services. All diagnoses of dementia should be delivered with information on the person's specific dementia subtype.
- National health systems should plan for the introduction of blood-based biomarkers to ensure people developing dementia benefit from new treatments.
- Health systems must commit to ensuring that the advent of new treatments for Alzheimer's disease specifically does not divert resources away from diagnosing and supporting those with other subtypes of dementia. Diagnosis remains important in accessing timely care and support.

We, the undersigned, support the consensus statement and are committed to advocating for the real change needed to improve the lives of those living with dementia.

##### **Dr Afifa Qazi**

Executive Medical Director and Consultant Psychiatrist at Kent and Medway NHS & Social Care Partnership Trust

##### **Andy Woodhead**

Three Nations Working Group on Dementia

##### **Dr Anthony Bayer**

Emeritus Professor of Geriatric Medicine, Cardiff University

##### **Dr Catrin Hedd Jones**

Bangor University Centre for Ageing and Dementia Research (CADR)

##### **Dr Charles Marshall**

Clinical Senior Lecturer and Consultant Neurologist, Barts Health NHS Trust

##### **Clare Watson**

CEO, Dementia NI

##### **Dr Conor Barton**

Consultant Old Age Psychiatrist, Royal College of Psychiatrists in Northern Ireland

##### **Deirdre Lewis**

Consultant Nurse, MHSOP, South Eastern Health and Social Care Trust

##### **Efa Gruffudd Jones**

Comisiynydd y Gymraeg (Welsh Language Commissioner)

##### **Dr Farooq Khan**

Clinical Lead for Dementia West Midlands, NHS England and Consultant Psychiatrist, Birmingham and Solihull NHS Trust

##### **Fiona Carragher**

Director of Research & Influencing, Alzheimer's Society

##### **Dr Gillian Mullan**

Consultant Lead Clinical Psychologist for Older People, Western Health and Social Care Trust

##### **Professor Hugh McKenna**

Emeritus Professor, Ulster University and Alzheimer's Society Trustee

##### **Dr Ian Davies Abbott**

Lecturer in Healthcare Sciences (Mental Health Nursing), Dementia Studies Course Lead

##### **Dr Jen Roberts**

Bangor University Centre for Ageing and Dementia Research (CADR)

##### **Dr Joseph Kane**

Clinical Lecturer in Psychiatry of Old Age, Centre for Public Health, Queen's University Belfast

##### **Karyn Davies**

Senior Lecturer, Mental Health Nursing, University of South Wales

##### **Professor Dame Louise Robinson**

Professor of Primary Care and Ageing, Regus Professor of Ageing, Newcastle University

##### **Luciano Croskery**

Supported Housing Manager, Belfast Health and Social Care Trust

##### **Natasha Wynne**

Senior Policy Manager, Marie Curie Cymru

##### **Nigel Hullah**

Chair, Three Nations Working Group on Dementia

##### **Professor Paresh Malhotra**

Head of Division of Neurology, Imperial College London

##### **Dr Patrick Chance**

Clinical Director for Older Adult Mental Health & Consultant in Old Age Liaison Psychiatry and Consultant Psychiatrist

##### **Sue Strachan**

Alzheimer's Research UK Champion

##### **Dr Susan Mitchell**

Head of Policy - Prevention, Early Detection and Diagnostics, Alzheimer's Research UK

##### **Dr Tomas Welsh**

Research and Medical Director, The Research Institute for the Care of Older People; Co-Chair British Geriatric Society Dementia and Related Disorders SIG

##### **Versha Sood**

Programme Manager, Dementia, Cardiff & Vale RPB & Vice-Chair of National Dementia Steering Group