

APPG on Dementia report

# Raising the Barriers:

## An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England

Alison Clowes  
Local Systems Influencing Manager  
[alison.clowes@alzheimers.org.uk](mailto:alison.clowes@alzheimers.org.uk)



# All-Party Parliamentary Group

- The All-Party Parliamentary Group on Dementia (APPG) is a **cross-party group** made up of MPs and Peers with an interest in dementia.
- The APPG is run in **partnership** with Alzheimer's Society, which provides administrative support and expert advice to the group.
- The aim of the APPG is to **influence legislation and policy making** to improve the lives of people with dementia and their carers.
- The latest report looks to **address variations in diagnosis rates** and experience of diagnosis across the country.

# Overview of report

- Published October 2023.
- Includes the views of over 2,300 people living with dementia.
- Addresses variations in dementia diagnosis rates and experience of diagnosis across the country.
- Ambitious recommendations.

# The national challenge

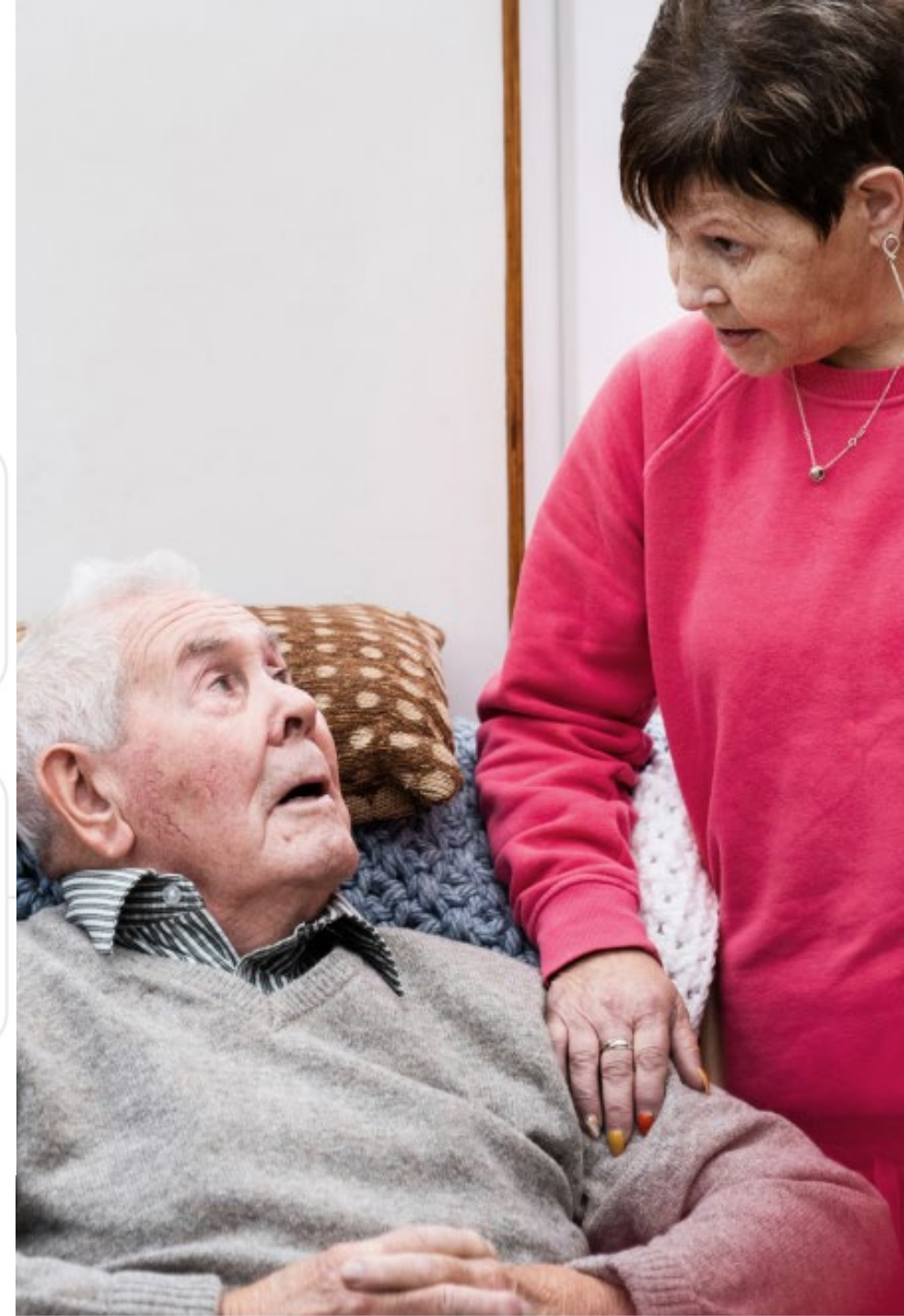
**91%** of people affected by dementia see clear benefits of getting a diagnosis

The diagnosis rate in England is just **63%**

**257,390** people with dementia living in England without an accurate diagnosis at the time of this report

**20%+** difference between highest and lowest diagnosis rates in ICSs in England

**2,300+** people took part in this inquiry via surveys, and oral and written evidence



# Local context

- Sandwell has a dementia diagnosis rate of **71%** (Dec 2023) which is above the national average and the national 66.7% target.
- Between 2019 and 2030 the number of people with dementia in Sandwell is predicted to **rise by 25%**
- The diagnosis rate for the Black Country ICB is 64.1%
- Almost a **quarter (24%)** of recorded dementia cases in the Black Country are vascular dementia cases.
- Sandwell has a dementia strategy in place that is due to be refreshed in **2025**. The Black Country ICB is also in the process of developing a dementia strategy setting strategic direction across the place-based systems.

# Key findings

- 90% of people asked said they **benefited from receiving a diagnosis** rather than not knowing.
- Dementia diagnosis varies vastly across the country, including wait times for diagnosis.
- Over **258,000** people with dementia lack an accurate diagnosis and support in England.
- Good practice needs to be scaled up across the country; we need to find out what works and **share knowledge**.
- NHSE should refine method for calculating Dementia Diagnosis Rates (DDR) to include more variables.

# Local recommendations

Recommendation	Why
Each ICS must develop a comprehensive dementia strategy which includes plans to meet and go beyond the national 66.7% dementia diagnosis rate.	<ul style="list-style-type: none"><li>• To ensure all residents have access to dementia diagnosis services and ongoing support.</li><li>• Ensure dementia is being considered at every level of the system.</li></ul>
All dementia diagnoses must include an accurate subtype.	<ul style="list-style-type: none"><li>• Lack of access to advanced diagnostics can result in people receiving the wrong type of support.</li><li>• Increased insight into subtype will help further research and understanding.</li></ul>
Key stakeholders like OHID, NHS England, and ICS leaders must commit to increasing the detail and quality of dementia data collection and publication and translate learnings into action.	<ul style="list-style-type: none"><li>• This will help local systems target their resources more effectively according to need.</li><li>• This will also enable systems to identify where improvements need to be made.</li><li>• This will ultimately mean that people receive better care.</li></ul>

# Local recommendations conti.

Recommendation	Why
A broader range of regional and local channels for communication must be utilised to reach those who may be lost to the system.	<ul style="list-style-type: none"><li>• To tackle stigma and reach people who are living with dementia but unaware or unable to access a diagnostic services.</li><li>• Improving relationships between dementia services, primary care network. The VCSE and community sectors will improve health inclusion for people living with dementia in rural and deprived communities.</li></ul>
Post-diagnostic dementia support services must be available more equitably across England and supported by a named professional to coordinate each individual's dementia journey.	<ul style="list-style-type: none"><li>• People living with dementia to have equitable opportunity to access the help and support they need.</li></ul>



# What does this mean for Sandwell?

- Continue to make sure that **Sandwell's local needs** are represented within the Black Country ICB dementia strategy.
- Work with the ICB to implement the dementia strategy and continue to improve the experience of diagnosis and ensure that the **right level** of post-diagnostic support is ready at **the right time**.
- Continue **developing capacity** to make sure that everyone with a diagnosis of dementia has access to an accurate sub-type diagnosis
- Work with the ICB to continue **improving data collection** on dementia, particularly those with young onset dementia.