

Welcome to the Councillor Network Webinar Series

November 2023



Agenda

- Welcome
- Presentation on the All-Party Parliamentary Group on Dementia report:
 - “Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England”
- Questions and discussion
- Close

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.

“I had to fight for everything to do with my late husband’s dementia.”

“It’s a postcode lottery. I’ve been a carer for two family members [in different parts of the country] and had two very different experiences.”

“My mum was terrified of dementia, and she avoided the diagnosis until we made her go to the GP.”

“The GP thought [a diagnosis] was unnecessary and I had to ask several times to be referred...”

“The local consultants could not wait to pass me on to someone/anyone else. There needs to be far greater clarity about who is the key or central coordinator of care.”

The challenge

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

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

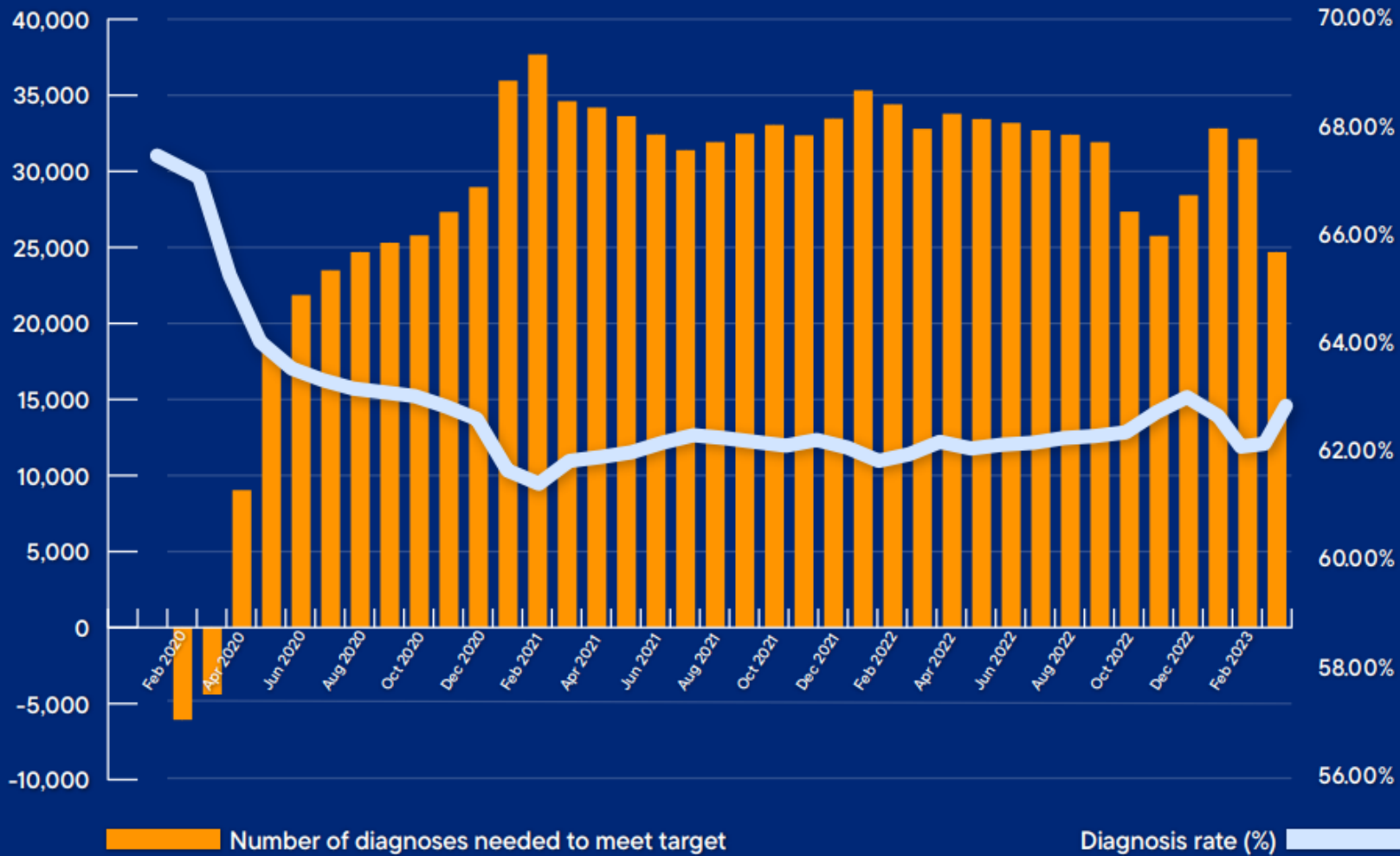
257,390 people with dementia living in England without an accurate diagnosis at the time of this report

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



National Diagnosis Rate



“Unwarranted regional variation in dementia diagnosis rates must be tackled by national and local systems.”

Regional barriers to diagnosis

- Reluctance to seek a diagnosis.
- Reluctance to provide a diagnosis.
- Difficulties travelling to appointments.
- Better communication needed between parts of the healthcare system.
- People not having knowledge of their diagnosis (or diagnosis of family member)- particularly in ethnic minority communities.
- System capacity and waiting times.

National recommendations

- NHS England must continue to develop its methods for calculating dementia prevalence and dementia diagnosis rates.
- A national Dementia Observatory should be created to facilitate robust data collection.
- Government should ensure the primary care workforce is adequately planned and resourced.

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">• To ensure all residents have access to dementia diagnosis services and ongoing support.• Ensure dementia is being considered at every level of the system.
All dementia diagnoses must include an accurate subtype.	<ul style="list-style-type: none">• Lack of access to advanced diagnostics can result in people receiving the wrong type of support.• Increased insight into subtype will help further research and understanding.
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">• This will help local systems target their resources more effectively according to need.• This will also enable systems to identify where improvements need to be made.• This will ultimately mean that people receive better care.

Local recommendations conti.

Recommendation	Why
<p>A broader range of regional and local channels for communication must be utilised to reach those who may be lost to the system.</p>	<ul style="list-style-type: none">• To tackle stigma and reach people who are living with dementia but unaware or unable to access a diagnostic services.• 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.
<p>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.</p>	<ul style="list-style-type: none">• People living with dementia to have equitable opportunity to access the help and support they need.

Main takeaway

While factors such as **rurality and deprivation** can **challenge** the diagnostic process, these **can be addressed** and should not lead to a postcode lottery.

How you can help

Raise the following with your local **Health and Wellbeing Board** and **Integrated Care Partnership Board**:

- What are their plans to increase the local dementia diagnosis rate?
- How do they plan to identify areas where diagnosis rates are low and take action to increase these?
- Could they create opportunities for sharing best practice across their locality?

Support from Alzheimer's Society

Your local officer can:

- Attend local Health and Wellbeing Board meetings to discuss dementia diagnosis in more detail.
- Provide support to develop Integrated Care Systems or place-based dementia strategies and action plans.
- Share best practice from other local authority areas/Integrated Care Systems.
- Share access to the latest policy reports and briefings.

Alzheimer's Society resources

- Dementia Strategy Toolkit
- Briefing for local Councillors
- Dementia information for councillors and elected representatives
- Local dementia statistics
- Dementia Experience toolkit
- Dementia Symptoms Checklist

Questions and discussion



Thank you for joining us.

For more information, please
contact us via:

Local@alzheimers.org.uk

