

Increasing access to a diagnosis: ethnic minority communities

This briefing outlines the challenges of diagnosing people from ethnic minority communities and provides a summary of recommendations from the full report

Background

In October 2020, Alzheimer's Society published a report on the dementia pathway, [From diagnosis to end of life: The lived experiences of dementia care and support](#). Grounded in the voices of people affected by dementia, it looks at four stages of NHS England's Dementia Well pathway – Diagnosing Well, Supporting Well, Living Well and Dying Well.

It explores in detail what national guidance and government say people in England should be receiving at each stage, and therefore the care and support they say will enable people to live well with the condition. We benchmarked this against the experiences of people affected by dementia. A key finding of the report was a sense of disjointed, fragmented care.

The report lays the groundwork for deeper explorations into the dementia pathway. The following reports aim to understand and address the barriers behind accessing a diagnosis:

- [Reducing regional variation](#)
- [Care homes & hospitals](#)
- [Ethnic minority communities](#)

Dementia is a complex condition crossing over primary, secondary, acute and social care. The care for people with the condition therefore requires it to be provided in an integrated way. Integrated Care Systems will provide a footprint in which to establish better planning and delivery of dementia care.

The reports make a series of recommendations aimed at Integrated Care Systems. The new healthcare landscape will enable us to understand how healthcare is being delivered on a local level. Most importantly, it will allow local areas to tackle the challenges that exist for dementia and ensure those with the condition can access a diagnosis in a timely and equitable way.

Key findings and recommendations

“Everyone has the same basic needs – love, comfort, food – and it’s no different for a person with dementia” – carer of person with dementia.

- **Reduce community barriers to dementia diagnosis.** Language barriers, stigma, cultural perceptions of dementia and caregiving as well as social stressors can all contribute to an inequality of diagnosis for some communities. Provision of cultural link workers to improve awareness and understanding as well as inclusion of organisations representing ethnic minority communities in the planning of services will help reduce these barriers.

“It definitely is a challenge in our culture. Dementia is scarcely recognised and when it isn’t recognised, there is little understanding in how to reach out to formal support. It’s about getting that message out there in different communities – dementia exists, and a diagnosis unlocks a wealth of care and support to help people and their families live with the condition.” – carer of person with dementia.

- **Improve identification and referral processes.** Some communities are less likely to access a dementia diagnosis in a timely and equitable way. Ensuring there are sufficient referral processes in place from services supporting conditions commonly affecting these communities will enable more people to access a diagnosis. A dedicated cultural worker at primary care level as well as auditing referral patterns to memory assessment will also enable areas to address underdiagnosis.
- **Make services more culturally appropriate.** Some communities may deter help seeking for dementia symptoms due to believing formal NHS services will fail to understand their culture and beliefs. Identifying future projections of ethnic minority populations as well as provision of separate diagnosis rate targets for these communities will help areas understand where improvements can be made.

“Our cultures change, but services don’t change with them” – VCSO professional.

- **Improve access to, and quality of, interpretation services.** Family members should not be used as interpreters, yet services struggle to source quality interpreters for dementia assessments. Where appropriate, memory assessment service staff should have sufficient cultural and linguistic skills. Reviewing access to interpretation services to ensure provision aligns to the language needs of local populations will also enable will help address language barriers during assessment.
- **Improve access to appropriate diagnostic tools.** Many cognitive tests used for assessment can be too Eurocentric or over reliant on knowledge of British history and this can impact some people from ethnic minorities, particularly if they were born outside of the UK. Ensuring services can access validated cognitive tests that are less likely to show cultural, language or education bias is essential for assessment.

“The psychologist also did some other tests – asking about notable events or periods in British history or questions that a typically British person would be able to answer. One question asked about types of gates, but Eugene was born and raised in the Caribbean, and I don’t think, even memory and cognitive symptoms aside, he would’ve been able to answer them” – carer of person with dementia.

- **Encourage better demographic data collection.** Without a cure or disease-modifying therapy, data is crucial to delivering services that enable people to live well with the condition. Yet collection and reporting of demographic data nationally is poor, with many commissioners using datasets that are a decade old. Ensuring services are encouraged to collect ethnicity data will enable areas to better understand their local populations and deliver services appropriate for them.

Contact details for further information

To discuss any of the information raised in this briefing paper or for further information about Alzheimer's Society and its work, please contact the Regional Public Affairs and Campaigns team via local@alzheimers.org.uk