



Ethnic minority communities

Increasing access to a dementia diagnosis



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For a full list of thanks see the Appendix.

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Executive summary

In 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 looked at four stages of NHS England's Dementia Well pathway:



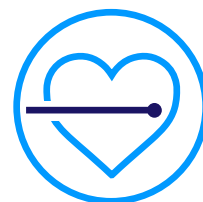
Diagnosing Well



Supporting Well



Living Well



Dying Well

It explored 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 laid the groundwork for deeper explorations into the dementia pathway. As part of a short series of reports into diagnosis, this report seeks to identify and address the barriers to diagnosis for ethnic minority communities.



Our research finds that there is inequality of diagnosis for people from ethnic minority communities.

We found that community-led issues deter people from accessing formal support for dementia symptoms. Some languages do not explicitly recognise the concept of dementia, or there is stigma or taboo around the condition. Cultural perceptions – particularly around health, caregiving or dementia itself – affect the willingness of individuals and families to seek support for symptoms of possible dementia. People’s life history and social factors are also challenges.

However, community-related issues are not the only reasons for inequality of diagnosis for ethnic minorities. Lack of cultural accessibility can deter people from reaching out to diagnostic services. There is a feeling that these services would not understand people as individuals, including their beliefs and values relating to dementia. Access to, and quality of, interpretation services for memory services can vary, which can affect the quality of a diagnosis. A lack of culturally appropriate tools means that people’s language and cultural needs are not met, or their life history acknowledged. Finally, a lack of ethnicity data makes it difficult for commissioners to plan services appropriately for their populations.

This report sets out recommendations for services and commissioners to consider in reducing inequality of diagnosis for ethnic minority communities. However, a diagnosis is not the sole responsibility of any one organisation. Integrated Care Systems are ideally placed to take responsibility and provide direction by bringing together all organisations – both formal NHS diagnostic services as well as voluntary organisations supporting ethnic minorities – and enable them to work together to improve approaches to dementia diagnosis.



Introduction

Dementia is a progressive neurological condition. It occurs when the brain is damaged by diseases (such as Alzheimer's disease) or by a series of strokes. The symptoms of dementia can include memory loss and difficulties with thinking, problem-solving, language and physical function. The symptoms that a person experiences will depend on the parts of their brain that are damaged and the underlying cause of their dementia.

The importance of a dementia diagnosis cannot be overstated. It facilitates access to vital care and support that enables people to live well with the condition. Its significance is outlined in the Dementia Statements, which are grounded in human rights law:

'We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live!'

However, dementia is a growing challenge, particularly for people from ethnic minority communities. There is an inequality of diagnosis, with many people receiving either a late diagnosis or not at all. Too often, people with dementia and their families are left to bear the burden of care themselves.

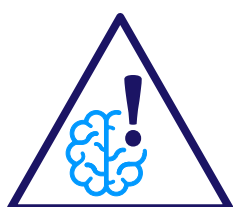
Everyone should have an equal right to a dementia diagnosis. England is a diverse country and dementia does not discriminate. It's time for services and commissioners to recognise the challenges that ethnic minority communities face, and to ensure they have equal and timely access to a diagnosis.

Prevalence

In 2013, the All-Party Parliamentary Group on Dementia reported there were an estimated 25,000 people living with dementia in the UK from an ethnic minority background.

This is expected to double to 50,000 by 2026, and rise to over 172,000 by 2051, nearly a 600% increase in just 40 years.² In comparison, it is projected there will be just a 100% increase in people with dementia across the whole UK population in the same time period.³

This is partly explained by the fact that some people from ethnic minority communities with dementia in the UK moved here during the 1950s and 1970s, and are now reaching an age at which they are more likely to develop dementia.⁴ Increased awareness of dementia, coupled with increased policy attention to boost timely diagnosis, may also play a part.⁵



However, the number of people with dementia from ethnic minority communities will also rise due to increased risk of developing dementia, in comparison to the White British population.⁶ Research suggests that these communities are at greater risk of developing vascular and early onset dementia.^{7,8}

This is particularly the case for those in Asian⁹ and African-Caribbean communities,^{10,11,12} where increased vascular risk factors for dementia – such as cardiovascular disease,¹³ hypertension^{14,15} and diabetes^{16,17} – may be more common. A recent study found that African-Caribbean people were more likely to be diagnosed with vascular or mixed dementia.¹⁸ Another study found that a diagnosis of vascular dementia was more common in both African-Caribbean and Irish patients.¹⁹

Young-onset dementia – dementia that affects people under the age of 65 – is more common in people from ethnic minorities. 6% of people from these communities have young-onset dementia in comparison to just 2% for the broader UK population.²⁰ One study reported that African-Caribbean patients in one memory service were diagnosed with dementia four and a half years younger on average than White British people.²¹

Diagnosis

Research suggests that people from an ethnic minority community are less likely to receive a diagnosis.²² One study found people from Asian ethnic groups had the lowest proportion of diagnoses, followed by Black ethnic groups, with White ethnic groups having the highest proportion of diagnoses.²³

However, our own analysis of Clinical Commissioning Group (CCG) diagnosis rates in January 2020 showed that, where an area's demographic could be identified, CCG areas with higher proportions of ethnic minorities (20% or more) correlated with a higher diagnosis rate. Additionally, areas with high proportions of White British people (95% or more) tended to have a lower diagnosis rate.

A possible explanation for this is that where there are traditionally larger ethnic minority populations, commissioners and services are more knowledgeable and better equipped to understand needs within their area, leading to more effective diagnosis.

Delayed diagnosis for ethnic minority communities

Evidence suggests that when people from ethnic minorities reach dementia services, they do so at a later stage of their condition than White British people, often after a health or behavioural crisis.²⁴

One study analysing memory clinic assessments found that African-Caribbean people had significantly lower cognitive scores compared to White British people, possibly because their dementia had progressed further by the time of assessment.²⁵ Another study found that Mini-Mental State Examination (MMSE) scores were lower for Asian and African-Caribbean

patients than for White patients.²⁶ Lastly, a study in Bristol found that people from ethnic minority communities were less likely to receive a cognitive assessment, and when they did, they scored lower, again suggesting that they accessed diagnostic services later in the progression of their dementia.²⁷

Memory services we spoke to reported providing diagnostic assessments for Indian, Bangladeshi, Caribbean, Somali, Polish, Romanian, Arab, Chinese, Greek, Irish and many other ethnic minority communities. **However, of the services who reported diagnostic differences between communities, 71% said ethnic minorities tended to reach assessment at a more advanced stage of their condition.** Commissioners and our own dementia support services also reported that people from ethnic minorities tended to access a diagnosis later in the progression of their condition.

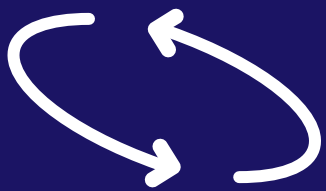
Ensuring equality of diagnosis

It's important to recognise that dementia does not discriminate – it affects everyone in society, regardless of ethnicity, gender or socioeconomic status.²⁸

National dementia guidance emphasises accessibility of diagnostic services. It states that 'service providers should design services to be accessible to as many people living with dementia, including... people who may be less likely to access health and social care services, such as people from black, Asian and minority ethnic groups'.²⁹ However, an inequality means that some people from these communities access a diagnosis later than other groups, or not at all.

A literature review found that inadequacies of services and cultural norms within communities are the main barriers to accessing dementia care for different communities. This suggests that targeted interventions in improving access to a diagnosis should be directed at both service and community level.³⁰ This report therefore sets out the challenges of diagnosing ethnic minorities in relation to community-level issues and service-level issues.

Interventions to improve diagnosis for ethnic minorities should ideally happen at community and service level at the same time. **As one memory service reported, 'there is a role for community outreach, but you need to be able to provide a service that is attuned to cultural aspects before stoking demand for it'.** Integrated Care Systems are ideally placed to provide oversight and direction for these interventions.



What needs to change?

This report outlines the barriers and challenges of accessing a diagnosis for ethnic minorities, both at service and community level. These have been identified through extensive engagement with commissioners, memory services, Voluntary and Community Sector Organisations (VCSOs), our own support services and people affected by dementia. The following recommendations provide a roadmap to improving access.

Integrated Care Systems should:

- identify cultural community interest groups and include them in the planning and delivery of dementia diagnostic pathways
- consider the provision of dedicated Community Link Workers to improve awareness and understanding of dementia and access to services in ethnic minority communities. This should be accompanied by baseline and referral data to test efficacy for further implementation
- ensure there are clear pathways to dementia assessment from health services supporting conditions that are risk factors for dementia among ethnic minority communities, including stroke, high blood pressure, diabetes and heart conditions. Service professionals within these services should have sufficient dementia awareness
- consider provision of a dedicated cultural worker at primary care level to support referral to memory assessment
- audit referral patterns to memory assessment for people from ethnic minority communities to ensure they are reflective of local demographics
- identify future projections of ethnic minority populations in each area and commission services that are culturally appropriate. This should be accompanied by separate minority ethnic community diagnosis rate targets
- consider, where appropriate and feasible, cultural and linguistic skill provision when commissioning memory services
- review access to interpretation services to ensure provision aligns to the language needs of the local population, and ensure these services have sufficient dementia training
- review the use of cognitive instruments and ensure that memory services can access validated tools for the assessment of ethnic minority communities
- ensure GP practices adhere to contractual requirements of ethnicity data collection and provide additional guidance and resource to support this.



Community-level issues

Language barriers

Of those who identified issues affecting diagnosis for ethnic minorities, 54% of memory services and 68% of those in our own support services told us that difficulties with language and communication were a significant barrier to diagnosis.

Language barriers and the inability to speak, read or write English can affect the use of services.³¹ **2011 Census data shows that in England and Wales, 1.3% of people (726,000) reported that they could not speak English well and 0.3% (138,000) said they could not speak English at all.**³²

Language barriers are a significant challenge for people living with dementia, particularly when the person cannot speak English fluently enough to interact with health professionals.³³ These barriers may hinder the diagnostic process as they may make it difficult for a person whose primary language is not English to access information about dementia, if it is not available in their primary language.³⁴

In a survey of German GPs, 70.9% reported uncertainties diagnosing dementia in patients with a migrant background, and 89.3% reported that language barriers affected or prevented diagnosis.³⁵ Another study reported language barriers as a major obstacle to dementia diagnosis in ethnic minority migrants in Norway.³⁶



In a recent survey of memory assessment services in England and Wales, 45% of respondents said that the most significant obstacle to diagnosing ethnic minority patients was a language barrier. Communicating via letters – such as appointment letters – in English was an obstacle to assessment.³⁷

Stigma and taboo

Of those who identified issues affecting the diagnosis of ethnic minorities, 72% of memory services and 84% of those in our own support services told us that stigma or taboo were barriers to diagnosis.

Stigma around dementia can contribute to low awareness in some communities.³⁸ It may be more common in Asian and Eastern European communities^{39,40,41} as well as African-Caribbean and Irish communities.⁴² As a result, some families may conceal or ignore early signs of dementia and delay seeking support,⁴³ resulting in difficulty accessing a diagnosis.⁴⁴

In some communities with a culture of arranged marriages, families may be deterred from joining with another family with a relative who has dementia. This is because of the perception that mental health conditions run in the family, reducing the chance of marriage or increasing the likelihood of a breakdown in the marriage.^{45,46,47} In close-knit communities, fear of embarrassment or gossip can also deter people from reaching out to services.⁴⁸



Versha Patel

Carer for mother, Sitaben, who lived with dementia

‘My Mum, Sitaben, was born in Kenya in 1943 and lived in India before getting married in her early twenties. She came to England with Dad, Mohanbhai, in 1964. They both owned a corner shop for around 20 years.’

In 2010, I began noticing symptoms with Mum – things like forgetting to turn off the gas or losing her way when she dropped my daughter off to school. I spoke with the GP who arranged an initial assessment and then she was referred onto a neurology consultant. The consultant was really nice and understanding – she came to see Mum twice and just understood her. There was also an Asian consultant nurse. I think that really helped as he knew exactly how to support Mum and deal with her when he came to assess her. He just appreciated those little nuances and intricacies of our culture. In 2011, she was diagnosed with vascular dementia.

In my community, the concept of dementia doesn't really exist. When she was diagnosed, I thought 'Will they understand? Will they not?'. For my broader family, I had to print off information about what dementia was in their language. I didn't feel embarrassed, but I knew they weren't going to understand; I thought they were going to think I was making it up.



We know about cancer in our culture and people understand what it is, but when it comes to dementia there is just no understanding or awareness. It really does permeate every aspect of life – some people would not marry into families if there was a history of dementia, since mental health is such a stigmatised concept. This further entrenches the stigma surrounding the condition in my culture.

Raising awareness of dementia in our culture is so essential. I wanted to go into my local Hindu Temple to talk about dementia and was prepared to do it. But temples can be places of hearsay and gossip – people don't understand the concepts of caregiving in relation to dementia because looking after your parents is so ingrained in our culture that the role of a 'caregiver' doesn't really exist. Yet no person is really prepared to care for their loved one living with dementia, it's such a challenge and people really do need formal support. When I did a story for the Society, I left some magazines in the temple and afterward I had two people come up to me and say, 'I never realised what you went through, I want to speak to you about it more'.

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. People have their religions and faiths because it forms who they are as a person and helps them understand the world, particularly when things aren't going well in life. When a person is diagnosed with dementia, your life inevitably changes, so I think there is a role for local community figures to come and understand what dementia is about and teach people about it.

I am incredibly proud of how I supported Mum and I did absolutely everything possible for her so she could live as well as possible with dementia. I now want to use my experience of what I went through to help others.'

Cultural perceptions of dementia, health and caring



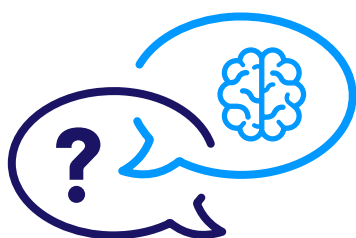
Of those who identified issues affecting diagnosis for ethnic minorities, 64% of memory services and 71% of those in our own support services told us that cultural perceptions, including those relating to dementia, health and caregiving, are a significant barrier to diagnosis.

Dementia

Cultural perceptions of dementia vary between communities. Dementia is often seen in the context of a culture's broader beliefs and values. This can sometimes impact awareness of it as a medical condition, limiting the extent to which some communities are able to identify symptoms and contact services.

For example, in communities with a belief in reincarnation, dementia can be seen as a punishment for behaviour in a past life.⁴⁹ Amongst Eastern European communities, understanding of dementia can sometimes relate to experiences of persecution.⁵⁰ In some Muslim communities, mental health and neurological conditions including dementia are often attributed to 'Jinns'⁵¹ – supernatural creatures that harm humans or drive them mad.⁵²

Some African-Caribbean communities see dementia as a result of possession by evil spirits.⁵³ Other communities may see dementia as a form of evil spirits, witchcraft, Black Magic or God's will.⁵⁴ Healthcare professionals' lack of understanding of these cultural beliefs may deter these communities from contacting services with concerns about symptoms.



Giving something a name means acknowledging its existence. However, in many communities there is no word for dementia, or it is neither easily translatable or commonly used, particularly in some South Asian and Chinese communities.⁵⁵ This is a barrier to accessing a diagnosis.

Words to describe dementia can also be derogatory in some communities, which entrenches stigma and limits recognition of dementia as a condition. In many Indian languages, 'pagal' describes behaviours similar to dementia but refers to madness caused by evil spirits or past misdeeds. In Chinese communities, while there are various words to describe dementia symptoms, the Mandarin word 'chai-dai' means idiocy or dull-wittedness.⁵⁶

Much evidence suggests that ethnic minority communities have lower levels of awareness of dementia as a condition, partly because there are no direct translations of the word. However, awareness-raising and policy efforts have drawn attention to dementia among these communities. A recent study of a small cohort of Bangladeshi carers found that most saw dementia as a medical condition and did not attribute stigma to it.⁵⁷



Health

It is a common misconception that dementia symptoms are a normal part of ageing. Though this misconception is found in all communities, it may be more common in ethnic minority communities.

Where dementia is seen as a normal part of ageing, it is thought that symptoms cannot be treated or managed. This deters people and their families from seeking support for their symptoms.⁵⁸

In a literature review, this issue was found to play a significant role in getting a later diagnosis.⁵⁹ It may also lead to people accepting and tolerating certain symptoms as normal behaviour, which can then deter people from accessing services. This may be particularly common in communities where family is of central importance and where cultural norms or traditions around respecting and caring for older relatives are common.⁶⁰

The concept of 'cognitive impairment' may be less recognised in ethnic minority communities. VSCOs we spoke to suggested that in some Asian communities, people feel they have received healthcare only when physical checks have been carried out, such as blood pressure tests. Where mental health assessments such as cognitive tests are carried out, they are less likely to see its purpose or clinical relevance.

Stigma around mental health services may play a part in a reluctance to seek help.⁶¹ For example, one study found that some people from Caribbean communities were reluctant to engage with statutory services, associating visiting mental health doctors with being 'locked up'.⁶²

It is also important to consider how officials are viewed in the experiences of people from ethnic minority communities. Formal NHS services may be seen as 'the authority'.⁶³ Our own dementia support services also reported fear of officials in those they supported, particularly in migrants or refugees whose home countries were rife with persecution, bribery or corruption. This deterred people from contacting services with concerns about symptoms.

Caring

Commissioners, memory services and our own support services identified the role of caring in different communities and its relationship to dementia as a factor preventing families from contacting services with concerns about symptoms.

Different cultures have different beliefs about the role of family in people's lives.⁶⁴ In some communities there may be a view that older people should be looked after by their families, and that a diagnosis serves no purpose.⁶⁵ This can mean that people tend to delay seeking help for dementia until they can no longer cope. There may be a perception that accepting 'outside' help could be interpreted by the wider community as a failure of family duty or responsibility.⁶⁶

In many South Asian communities, it is the norm to care of family members for longer than the general population does.⁶⁷ There is a similar culture of caring in African-Caribbean and Chinese communities, often due to a sense of duty.⁶⁸

Other research suggests that South Asian communities do not identify with the concept of 'carer', perhaps because caring is so much a part of their culture that explicit recognition of a caring role is unnecessary.⁶⁹ As a result, families caring for people with dementia is part of an existing responsibility.⁷⁰

'I decided to do a piece of work in my area to reach out to the Nepalese community as they were not represented in our client group. I worked with a local primary school and, with the help of an interpreter, I delivered a Dementia Friends session to elders and other members of the local Nepalese community. They listened and interacted and at the end they all thanked me for my time but assured me that they do not have dementia in their community.

I spoke to staff from the Royal Gurkha Regiments and asked them if they knew why I was being told that dementia didn't exist. They believed in the family hierarchy in that the young care for the old. They do not ask questions; they just provide the best care they can for parents and grandparents so they would not see a family member's behaviour as something that needed a diagnosis. Instead, they just needed to alter their care to make sure they were safe, clean and fed.'

Dementia Connect Local Services Manager



Changing views of caring

This view (known as ‘familism’) has traditionally been accepted in many communities where extended families care for older relatives without external support.⁷¹

However, while evidence suggests this is still common, it is important to consider changing views within communities. While some communities still hold traditional views about caring, non-traditional views within some communities can mean that people are more open to receiving outside help and seek more from services.⁷²

Where services have traditional views about caring roles within ethnic minority communities, they can wrongly assume that people with possible dementia in these communities are well-supported at home. This leads to services not being tailored to the needs of different communities.⁷³ **It is important that services do not assume that ethnic minority communities do not need health services due to their cultural values.⁷⁴**

Kash Khunkhuna

Daughter of father who lived with dementia

‘My father in-law came to the UK in 1963. He was set a work permit for Qualcast where he worked for over 35 years. Dad was totally committed to work and his family, a very loving husband and father.

When he retired in 2000, he spent lots of his time gardening, socialising and building his retirement property in India. Dad was relatively fit and looked after himself; however, in 2014 he had a heart operation, and after this he began displaying some fundamental changes. He started to become less sociable, more insular, and not wanting to go places.

We began noticing changes in his behaviour – he was becoming very argumentative, particularly over small things or he would say something and there would be no filter. Simple tasks like going to the shops would give him anxiety. He wasn’t able to tell us these concerns because, as a family, we were not aware of the signs of Alzheimer’s. We would also often find him leaving taps or the stove on. He was driving instructor back in India, but car bumps and scratches became a regular occurrence. Whilst we were concerned these things were happening, he seemed complacent about it.

Dad had begun getting these strong headaches and there were a couple of incidents where a doctor had to be called home. We booked an appointment in with the GP and he was referred to a memory clinic. He had brain scans which showed signs of Alzheimer’s disease.

The diagnosis did take a long time, and I don’t think he was particularly supported in terms of language barriers – it was always me or my husband having to do this. Whilst he was integrated and spoke English, by this point Dad didn’t really understand the language or terms they were using to describe the condition, so we had to explain to him afterwards what the clinicians had said at the appointments. I don’t think the memory clinic had experience in supporting people from a different cultural background.

Dementia is taboo in our culture – there’s a lack of understanding and awareness of it as a condition. The Punjabi language can be quite harsh and direct and how it refers to dementia can be derogatory and offensive. It’s often described as someone ‘going mad’ or ‘losing their mind’. I found this particularly difficult to take. Everyone has the same basic needs – love, comfort, food – and it’s no different for a person with dementia. Yet Dad was just treated differently.

I remember when I used to take him to the temple after he was diagnosed. Friends and family couldn’t understand why he wasn’t speaking to them or able to keep up with the social situation. They thought he had hearing problems. People were not patient in waiting for him to talk at his pace so we would take on the conversation for him. Temples aren’t adapting quick enough to people’s needs.

Caring responsibilities in Punjabi culture tend to fall on the next generation. Sometimes people would talk about other families getting carers in to support older relatives and how they had done it or how we were not getting the right care. People were quick to judge but Dad’s care was of the highest, living in a warm loving family who wanted him to be at the heart of everything we did.

Dementia services aren’t really versed in culturally appropriate care, in my experience. But cultures themselves really lack awareness and understanding of dementia as a condition. I think if organisations can come into places of worship and provide the right information then this can filter down to members and improve understanding.’



Life history

Services' lack of understanding of life history can deter people from seeking help for dementia symptoms. To provide person-centred care, services need to respond to each person's life history, valuing their unique needs and preferences.⁷⁵

This approach enables services to avoid making assumptions about the needs of certain communities based on stereotypes and generalisations about different cultural groups.⁷⁶

A person's life experience will influence their view of dementia. There must be greater attention to the complexity and diversity of the life stories of people from ethnic minority communities.^{77,78}

Identities of people from ethnic minorities can be shaped by socio-political factors, including country of origin or birth and experiences such as migration. To be accessible, services must recognise this by developing cultural awareness, sensitivity and competence.⁷⁹

When services fail to provide cultural accessibility, this results in individuals not being valued. People from Caribbean, Chinese and South Asian communities reported a dilemma of being affected by their or their loved one's cognitive decline but also fearing not being valued by services that do not meet their needs.⁸⁰



Social stressors

For some communities, disadvantages or ‘social stressors’ can also be a barrier to seeking help. Higher rates of poverty, poorer health and unemployment can mean that possible dementia symptoms are not prioritised,⁸¹ as can hostility and racism.⁸²

A study of Vietnamese migrants found that social problems such as unemployment, language difficulties and overcrowded living conditions took precedence over seeking help from mental health services for symptoms of possible dementia.⁸³ Additional social stressors, such as transport issues, living in high-rise estates or access to transportation may prevent older people from leaving their home and accessing services.⁸⁴

What is best practice?

BAME Dementia Adviser, Oldham

Oldham has a higher proportion of minority ethnic community residents (22.5%) than Greater Manchester (16.3%), the North West (9.8%) and England overall (14.6%). While the largest ethnic population is White (77.5%), it has large Pakistani (10.1%) and Bangladeshi (7.3%) populations.⁸⁵

Oldham CCG commissioned a Black, Asian and Minority Ethnic (BAME) Dementia Adviser, provided by Tameside and Glossop Mind, to engage with local communities to increase awareness of dementia. The role focuses on building trust and recognising the nuances of different communities, such as language and religious belief systems.

The Adviser is proficient in seven different South Asian languages but also well-versed in religious texts. They also recognise the importance of raising awareness of dementia through neutral language. Where awareness of dementia may be low, or where there is stigma around the condition, discussion and engagement based on physical health topics, such as diabetes and high blood pressure, is a way to introduce conversations around dementia. Understanding of religious and cultural views of dementia are considered essential to engaging with these communities.

The service recognises the importance of identifying places to engage with communities, such as mosques, temples and churches, as well as places such as money transfer agencies and cash and carries.

The Adviser also works with local GP surgeries and memory services to ensure that the local diagnostic pathway is as culturally appropriate as possible, such as through the use of cognitive tests. The Adviser role seems to have had a positive impact on referral to the local memory service.

Meri Yaadain CIC, Bradford

In an area with a high South Asian population, Meri Yaadain CiC (Community Interest Company) is a not-for-profit organisation assisting people affected by dementia from ethnic minority communities to access information and support. It does this by raising awareness of dementia (in partnership with statutory organisations where possible), supporting families by providing information and signposting to services, and working with dementia services to offer support, advice, guidance and training so they are better able to meet the needs of ethnic minority communities.

The service recognises that the primary method of communication for some communities is word of mouth. To raise awareness, Meri Yaadain delivers community roadshows and workshops to discuss, train and educate people about the different aspects of dementia. To combat illiteracy or language barriers in some communities, it also provides information on dementia through visual and audio media.

The service also recognises the importance of language for communities where dementia may not be explicitly recognised or is stigmatised. The service engages with communities by talking ‘around’ dementia and not directly about it. It recognises the need to understand the nuances of cultural values, including generational changes.

The organisation also engages with different services and professionals, such as GPs and memory services, to improve their understanding of cultural views of dementia and care. This is to ensure that accessing NHS services becomes less stigmatising for people from different communities. It does this by encouraging services to take a holistic approach to care, considering people’s worldviews and faith-based perspectives in relation to dementia symptoms. As a result of its activities, Meri Yaadain supported the local area to improve its diagnosis rate for ethnic minority communities.

BME Dementia Worker – Touchstone BME Dementia Service, Leeds

In an area with a high South Asian population, the Touchstone BME Dementia Service in Leeds, commissioned by the local CCG, has provided specialist support to people from ethnic minorities living with dementia or memory problems and their carers since 2012.

A BME Dementia Worker role was commissioned to support the engagement of ethnically diverse communities around dementia. It achieves this by signposting to professional health services and raising awareness of dementia amongst different communities, such as working with faith leaders. The role also supports the development of local services through involvement in local dementia boards and steering groups.

The service recognises the importance of awareness-raising in communities where knowledge of dementia may be low. It achieves this by providing culturally appropriate dementia awareness talks within community settings such as day centres, local community groups and religious centres. The talks are tailored to the needs of the group and can be delivered in English, Punjabi, Hindi or Urdu. The service also runs weekly dementia café and music sessions for people with dementia and their carers from a South Asian background.

The role supports people to engage with statutory services, enabling them to access a pathway to diagnosis. When engaging with communities, the service recognises the importance of merging conversations about dementia with risk factors associated with the condition, such as diabetes and high blood pressure. This is an opportunity to start conversations about a condition that may be stigmatised or where there is little awareness.

Recommendations

Integrated Care Systems should identify cultural community interest groups and include them in the planning and delivery of dementia diagnostic services.

Research suggests that ethnic minority communities underuse dementia-related NHS services.⁸⁶ However, they may be more likely to access community-led organisations that better understand their religious, cultural and language needs.^{87,88} Though more culturally aware, these organisations may not primarily be set up to address health or dementia-related needs.⁸⁹

Research suggests that awareness-raising activities led by memory services aimed at ethnic minority communities can have a positive impact on referral rates into those services.⁹⁰

A recent survey of memory assessment services found that some had run outreach activities,

21.9%

of which to community centres and

15.6%

to places of worship

30%

of services reported that these activities had no impact on referrals.⁹¹

During our own engagement, some memory services reported carrying out dementia awareness-raising sessions for different communities, but said they were only able to do so when demand for their diagnostic service was low. Many reported operating at capacity.

Community organisations are well-placed to deliver awareness-raising sessions. However, there are concerns around the longevity of these organisations, which are often reliant on unstable funding.⁹² VCISOs we spoke to reported similar struggles.

Commissioners, memory services and our own dementia support services reported the need for all services and organisations involved in dementia diagnosis and organisations that support people from ethnic minority communities to work together.

Proactive methods of inclusion and engagement with cultural community interest groups, enabled by more flexible partnership working, would help address some of the issues impacting ethnic minorities and their access to diagnosis. Commissioners need to recognise these groups' importance, both in their access to communities and their ability to enable people to engage with formal diagnostic services. Including these organisations to be part of the planning and delivery of dementia diagnostic services will empower local areas to address the underlying reasons for underdiagnosis of different communities.



Integrated Care Systems should consider the provision of dedicated Community Link Workers to improve awareness and understanding of dementia and access to services in ethnic minority communities. This should be accompanied by baseline and referral data to test efficacy for further implementation.

Dedicated Community Link Workers provide outreach to, and engage with, different communities to increase awareness and understanding of dementia. Ideally, they should be at least bilingual. While they do not need to be from the same ethnic group as those they are engaging with, they must be highly skilled and knowledgeable in different cultural aspects.

These roles have been found to be effective in engaging with different groups and improving understanding.^{93,94,95,96} Professionals in these roles told us that trust and recognition of the nuances of different communities, such as language and belief systems, are crucial to engagement. For many communities, and particularly for older people, the main form of communication is word of mouth. So as one Community Link Worker told us, engagement with communities should be focused on ‘getting out there and getting your face recognised’.

Conversations around risk factors associated with dementia, such as diabetes or high blood pressure, may be an opportunity to introduce conversations around dementia, particularly where dementia is not explicitly recognised as a medical condition.

Commissioners should recognise that engaging and building trust with communities and increasing awareness of a condition that is often not recognised will take time. Increasing referral rates to diagnostic services for different communities will not be quick and easy. But the potential to increase awareness and understanding of dementia for underserved communities is highly valuable.



Service-level issues

Identification and referral

There are several stages in the pathway to diagnosis:⁹⁷



1. the recognition of a problem by the patient or family



2. consultation with the GP



3. recognition of the illness by the GP



4. referral to secondary care



5. recognition of the illness in secondary care

People and their families therefore need to navigate a series of gatekeepers before getting a diagnosis. This may especially disadvantage people from ethnic minorities.⁹⁸

Memory services, commissioners and our own dementia support services told us that a lack of contact with GPs was as a barrier to diagnosis across communities. However, research suggests people from ethnic minorities do access primary care at a similar rate to White British people.⁹⁹

However, how dementia is identified within primary care, as well as how it is assessed and judged as clinically appropriate for referral to secondary care, affects the extent to which communities access a diagnosis. **In a study of referrals to one memory service, it was found that only 44% of South Asian patients were likely to access dementia diagnostic services in a timely way, in contrast to White British patients (62%).¹⁰⁰**

GPs often use a 'watch and wait' strategy for patients suspected with dementia, to ensure that enough information is collected to support a referral to secondary care.¹⁰¹ Difficulties in cognitive screening or issues relating to language or culture may be more common when assessing people from different communities. This can result in people from these communities accessing a diagnosis later.¹⁰²



In comparison, other research suggests that GPs have a lower threshold for referral for possible dementia in some ethnic minority groups.¹⁰³ Another study found that Black and South Asian communities have a lower threshold for accessing diagnostic services than other groups do.¹⁰⁴

However, these studies included memory services in areas with high ethnic minority populations, so clinicians involved in diagnosis are likely to be well-versed in identifying, referring and diagnosing dementia in those groups.

The provision of a dedicated cultural worker, such as a nurse, at primary care level may help address reluctance of people from ethnic minorities and may increase referral rates to specialist assessment, by supporting both patients and referring clinicians. Auditing referral rates for dementia assessment with local demographics may also identify where improvements in referral pathways can be made.

Primary care may not be the only opportunity to recognise possible dementia in some communities. Given that dementia risk factors such as cardiovascular disease, hypertension and diabetes may be more common in ethnic minority communities. **Clear referral pathways to dementia assessment from services supporting people with these conditions may be appropriate.¹⁰⁵**

Additional screening for dementia within these services, along with education and awareness of dementia for clinicians, could help people from ethnic minorities access a diagnosis in a more timely and efficient way.

Lack of culturally appropriate service provision

A review of studies into barriers and facilitators to accessing dementia care in ethnic minorities found that cultural ‘inadequacy’ of services was an obstacle.¹⁰⁶ Generally, it is felt there is a lack of culturally sensitive and appropriate dementia services, and that needs relating to faith or culture are not addressed.¹⁰⁷

When cultural beliefs around dementia or caregiving prevent seeking outside support, the low level of take-up for diagnostic services may lead service providers to make inaccurate assumptions. For example, they may believe that communities are well-supported at home. These assumptions can impact their ability to make the service more culturally appropriate.^{108,109}

When services fail to be culturally accessible, communities may believe that they will not understand the values, beliefs and language preferences that are important to them. One study found that low representation of staff from a community’s own background in professional health services made participants use local community services, even when these did not appropriately cater for their health needs.¹¹¹

‘When people do approach the health service, does the service reflect the community they serve? Speaking from my own observation, it is dominated by White British people. So, the people I support feel, ‘Do I see health professionals that reflect me, how are you going to understand who I am, my cultural or health needs, if you don’t look like me? Can I trust you to understand or hear me?’

Some of the communities I have supported have experienced a lack of cultural awareness and sensitivity amongst health professionals, therefore making them reluctant to reach or continue with a service.’

Dementia Support Worker

Services and commissioners should recognise that professional health services may be alienating spaces for certain communities. While ethnic minority representation within diagnostic services can help them become more culturally accessible by communicating inclusivity,¹¹² there may be recruitment challenges if there is a lack of available workforces from different cultures. At the very least, it would be beneficial for staff to be trained on the cultural and religious differences of different communities.

Provision of literature in different languages is also important. However, a survey of memory assessment services found that just 20% of respondents did not provide any translated resources. One of these services reported that up to 30% of their patients do not speak English fluently.¹¹³

‘Our cultures change, but services don’t change with them.’

VCSO professional

We heard it is good practice for diagnostic services to use neutral language when engaging with communities in which dementia may not be well recognised, such as ‘memory problems’ and ‘looking after’ and avoiding the use of ‘carer’. Provision of materials, including leaflets, videos and other forms of communication, can also help communities in understanding dementia.

Even before communities reach diagnostic services, commissioners and services should understand their demographics and how accessible services are for these communities. Provision of explicit diagnostic rate targets may help provide a direction for this.

Interpretation services

Where people cannot speak English, or cannot do so fluently enough to engage in an assessment, the provision of interpreters is crucial to gaining vital information for a diagnosis of dementia. However, memory services and commissioners told us that access to, and quality and appropriateness of, interpretation services were barriers to this.

Accessing interpretation services

Memory services reported difficulty sourcing interpreters to carry out necessary diagnostic investigations.

A recent survey of memory services also found interpreters cancelling at short notice or not attending the appointment at all.¹¹⁴ Other memory services reported logistical issues with organising interpretation services, including costs, which can delay the diagnostic process.

This is especially relevant to areas with large ethnic minority populations. In one survey, a service reported that they used interpretation services 300 times in one year. Another service reported that the percentage of referrals requiring an interpreter was as high as 15%.¹¹⁵

Quality of interpretation services

Memory services reported the quality of interpreters as a barrier, particularly if they do not have sufficient knowledge of dementia.

Good interpretation service is about more than the literal translation of words, it is about engaging with the user’s view of their situation.¹¹⁶

Where interpretation services lack knowledge of dementia, this affects the quality of information relayed back to diagnostic services. Memory services told us that interpreters do not usually have training on dementia. They are more likely to repeat what the patient is saying, and less likely to ‘read between the lines’ of their language, an ability that is important in assessing possible dementia.



Challenges using interpretation services

People from ethnic minorities may want interpreters who share their background. However, this can be another challenge for diagnosis, particularly where there is stigma around dementia.

For example, in some cultures there are strict social hierarchies and caste systems. If the interpreter and patient are from the same community, there may be patient concerns around confidentiality.

Patients may be less willing to use an interpreter with the same background especially in close-knit communities where people know each other.¹¹⁷ Memory services reported that many people from ethnic minorities feel uncomfortable having another person in the room if they are from the same background, especially if they are ashamed or embarrassed about their symptoms.

Family members as interpreters

A survey of memory services found that services used interpreters in more than 70% of cases where indicated. 65% reported using family members as interpreters in less than 10% of cases where a patient did not speak English fluently.

The most common reason for a family member providing interpretation was a lack of availability of professional services in the required language.¹¹⁸

We found much variation in services' willingness to use family members rather than professionals as interpreters. For example, there were concerns around family members answering for the patient affecting the quality of assessment.

We heard it is good practice to use professional interpreters, since using family members as interpreters may compromise confidentiality or influence an assessment, causing further distress.¹¹⁹

Provision of explicit bilingual or multilingual workforces may overcome language barriers within services, but this may not be achievable for all areas. This is important because some validated assessments for dementia in different languages require either a bilingual or a skilled interpreter to administer them.¹²⁰

It's important that commissioners recognise the language needs of their populations, and ensure that interpretation service provision or linguistic skills within services reflect these demographics.

Lack of culturally appropriate diagnostic tools

Access to, and provision and use of, cognitive tools to support assessment of people from ethnic minorities was a barrier identified by professionals involved in dementia diagnosis.

According to reports, cognitive scores are sometimes significantly lower for some communities.^{121,122,123} This may be because they access services later and therefore at a more advanced stage of their condition.

However, another possible reason is unfamiliarity with the language and culture of test settings.¹²⁴ GPs have doubted the applicability of screening tools to some communities.¹²⁵ Our own dementia support services reported supporting people with dementia who were tested using questions that were Eurocentric or were reliant on knowledge of British history. This is inappropriate for some communities, particularly if they were born outside the UK.

The most-used test is the MMSE, due to availability and professional habit. However, scores may be difficult to interpret due to age, cultural and education bias.¹²⁶ Other cognitive tests such as the General Practitioner Assessment of Cognitive (GPCOG) and Mini-Cognitive Assessment Instrument (Mini-Cog) and less biased. The Memory Impairment Screen (MIS) is considered especially appropriate for use with people from ethnic minority communities, as it is less likely to show education or language bias.¹²⁷

The Rowland Universal Dementia Assessment Scale (RUDAS) is a quick cognitive screening tool designed to minimise cultural and language bias.¹²⁸ Research suggests this test is effective across many population groups who are linguistically and culturally diverse.¹²⁹ A recent survey of memory services found that 70% of respondents used alternative validated cognitive assessment tools for ethnic minority service users, most commonly the RUDAS.¹³⁰

However, in our survey services reported limitations, particularly the difficulty of translating certain cognitive tests. Given these difficulties, services have been required to use other aspects of diagnostic assessments such as patient functioning as well as collateral information.¹³¹ Research suggests there is a need to improve the development and validation of culturally appropriate diagnostic tools for different communities.

Local areas should consider the provision and use of cognitive tests in the assessment and diagnosis of people from different communities.¹³²



Diana Smith-Harris

Wife to Eugene, who lived with dementia

‘My husband, Eugene, was born and raised on the Caribbean island of Saint Kitts until the age of four. He was a skilled, self-employed upholsterer and built up himself a successful business through word-of-mouth recommendations. He was infectious and kind, but very much a perfectionist in his work. He was also a classically trained pianist and played the keyboard and steel pan. I met Eugene around 20 years ago; he played in a steel band and at one gig the singer couldn’t make it, so I stepped in. I ended up staying in the band and the rest is history – the music was what really pulled us together.

I began noticing those little subtle changes in his behaviour such as leaving the van down the road or not recalling which of his products belonged to which customer. Overall, I felt Eugene’s diagnostic experience was good. It took about 18 months to get a diagnosis, but I think he and I knew something wasn’t quite right a couple of years prior to that. We went to Eugene’s GP who did some tests and then referred us onto the local memory service.



Our GP was fantastic – he was a specialist in dementia which really helped, but overall, the diagnosis did take a while given Eugene’s age which meant ruling out other factors that the symptoms could be a result of.

At the memory clinic, they asked Eugene to do the clock test – asking him to draw a clock and write where the numbers would fit. 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 anyway because that wasn’t his experience growing up. I did ask the consultant whether these tests were sensitive to these kinds of things and people from different communities, but they assured me they had lots of experience with Caribbean people. Eventually, following a brain scan, he was diagnosed with early-onset Alzheimer’s disease in September 2016.

The Younger Dementia Team also managed to get us a Caribbean case worker after Eugene’s diagnosis which helped him feel like he was being provided with that person-centred care and someone he could just relate to. Having someone from a similar culture and background meant Eugene was much more receptive to care and support. I think in lots of faith groups and different communities, people tend not to be so trusting and can sometimes be suspicious of services, so having someone that Eugene could relate to really helped break down some barriers.’

Data

It's important for commissioners to be aware of the increase in the number of people from ethnic minority communities who are likely to need dementia services.¹³³

However, commissioners reported to us the lack of ethnicity data was a persistent barrier to commissioning and providing culturally appropriate services.

The collection and publication of ethnicity data nationally is generally poor. Our analysis of a random selection of 30 CCGs' ethnicity data in March 2021 showed that, on average, 71% of ethnicity data was recorded as 'not defined' (ranging between 58% and 87% across CCGs).

This has significant implications for commissioners, as it inhibits access to information with which to appropriately plan and commission services relative to local demographics.



Of those who responded to the question, a lack of access to data was considered the biggest factor in this response. 60% of memory services and 67% of commissioners told us that they did not know whether they were diagnosing people with dementia relative to their local demographics.

While some commissioners and memory services reported using population projection data, we found this is not standard practice across the country. The lack of compatibility between IT systems also prevented the collection and publication of real-time ethnicity data, particularly in cases where secondary care collected this data and it was not reported via primary care systems.

In some cases, commissioners told us that the 2011 Census was their most frequently used source of ethnicity data when planning services. Using 10-year-old population data is unlikely to be accurate or helpful for current healthcare commissioning.

From 1 January 2021, it became a contractual requirement for GPs to record patients' ethnicity information if a patient, or someone who is authorised on their behalf, provides it. It is optional for patients to provide the information and does not affect registration to a GP practice.¹³⁴ The Office for National Statistics have produced guidance on ways to collect ethnicity data that may help primary care improve ethnicity data recording.¹³⁵

It's important that Integrated Care Systems ensure GP practices adhere to this new contractual requirement, and provide any additional guidance and resource necessary to help collection of ethnicity data.

What is best practice?

Slough Memory Service

Slough Memory Service is a nurse-led service that provides dementia assessments and diagnoses for people experiencing cognitive or memory impairments. It also has a broad service offer of post-diagnostic support.

It is in an area with large ethnic minority populations, with the largest being Asian/Asian British (39.7%), followed by Black/African/Caribbean/Black British (8.6%). Just 72.9% of the Slough population speak English as their main language, with 42% of the population born outside of the UK.¹³⁶

The service is situated in a broader Older People's Mental Health Team and referrals are triaged by a duty worker. This provides an opportunity to identify cultural and language needs ahead of an assessment. It takes a flexible approach to dementia assessment, addressing service users' needs and any cultural barriers, discussing concerns at every stage of the diagnostic process. This might include changing and adapting language and vocabulary relating to dementia when speaking to people whose primary language does not have an explicit term for dementia, such as using 'memory difficulties' instead of 'dementia'. The service also refers people with dementia and their carers to Alzheimer's Society leaflets and video clips, as well as having physical copies of key booklets in different languages. The service has their own medicine information leaflets that are printed in various languages.

Previously, the service had been active in raising awareness of dementia engaging with different communities to reduce cultural barriers, including faith groups and community centres. The cultural diversity of the team enhances their ability to reach out to places of worship such as mosques and faith centres such as Gurdwaras to raise awareness of dementia. The service also raised awareness by featuring on the local Asian radio network and engaging with local charity organisations representing ethnic minority groups.

The service highly values its cultural awareness and responsiveness to the needs of the populations it serves. Some of its professionals speak some South Asian languages, and there is a protected full-time role for a Punjabi-speaking Assistant Psychologist, created in response to feedback from service users and carers and a review of the needs of the local

population. The service will generally not use carers or family members as interpreters. Where an interpreter is needed, the service will work closely with them to ensure they are given the most appropriate information about the person's symptoms.

The service is integrated, and some professional roles within the team are jointly funded by the local authority. This means it has access to local authority population data to plan service provision, as well as POPPI (Projecting Older People Population Information) data.

Wandsworth Memory Assessment Service

Wandsworth Memory Assessment service, situated in an area of London with large South Asian, Black African and Black Caribbean populations compared to the rest of England, is a specialist diagnostic service for people experiencing memory loss and cognitive impairment.

The service provides expertise for dementia investigations and diagnosis, as well as preliminary advice and support for people post-diagnosis.

The service is well versed in providing a culturally accessible dementia assessment for people from ethnic minority communities. As a guideline, the service provides an interpreter in the initial assessment and ongoing meetings, if needed, unless the person wants a family member present. This is based on the principle that a carer or loved one should not be a tool in the clinical process, as well as the fact that the person with dementia may feel inhibited about disclosing issues with a relative translating.

The service bases a diagnosis on a range of information and tests, with a particular focus on the person's life story and symptom history. Staff use different cognitive testing instruments depending on the individual, such as MMSE, Montreal Cognitive Assessment (MoCA), Addenbrookes Cognitive Assessment III (ACE III), RUDAS and GP-COG, as well as translated versions of some of these. Memory nurses and some Occupational Therapists within the service are familiar with carrying these out.

When triaging patients who are referred into the service, a patient's needs, including their cultural and language needs, are assessed. After multidisciplinary discussion, a decision is then made on what cognitive testing should be applied.

Recommendations

Integrated Care Systems should:

- ensure there are clear pathways to dementia assessment from health services supporting conditions that are risk factors for dementia among ethnic minority communities, including stroke, high blood pressure, diabetes and heart conditions. Service professionals within these services should have sufficient dementia awareness
- consider provision of a dedicated cultural worker at primary care level to support referral to memory assessment
- audit referral patterns to memory assessment for people from ethnic minority communities to ensure they are reflective of local demographics
- identify future projections of ethnic minority populations in each area and commission services that are culturally appropriate. This should be accompanied by separate minority ethnic community diagnosis rate targets
- consider, where appropriate and feasible, cultural and linguistic skill provision when commissioning memory services
- review access to interpretation services to ensure provision aligns to the language needs of the local population, and ensure these services have sufficient dementia training
- review the use of cognitive instruments and ensure that memory services can access validated tools for the assessment of ethnic minority communities
- ensure GP practices adhere to contractual requirements of ethnicity data collection and provide additional guidance and resource to support this.





Conclusion



Understanding of dementia varies considerably. Each community will have its own set of values and beliefs, and each person experiences dementia differently. While the quality and effectiveness of the diagnostic process should be consistent for everyone, how services approach and talk about dementia should be tailored to the individual.

However, we found that for commissioners, memory services and our own support services, diagnosis in ethnic minority communities is affected by two issues. First, many communities do not recognise dementia, or management of the condition varies according to how it is viewed culturally. This can impact the extent to which people and their families reach out to support services. Second, where they do reach out, services struggle to understand how to be accessible to a range of cultures, religions and languages.

Integrated Care Systems are ideally placed to bring together all health, social care and voluntary sector organisations and provide direction to improve the uptake of dementia diagnosis in different communities. This report has set out the challenges both for communities and services, and provided a series of recommendations with which to address this urgent challenge.



Appendix: Methodology

Literature review

We carried out a literature review of local diagnostic pathways, datasets and documents relating to dementia diagnosis and ethnic minority communities.

Engagement with health, care and voluntary sector organisations and professionals

To supplement our understanding of dementia diagnosis and ethnic minority communities, we conducted semi-structured interviews with a range of health, care and voluntary sector professionals.

These included commissioners, General Practitioners, psychiatrists, psychologists, geriatricians, nurse consultants, memory service managers, Voluntary Sector and Community Organisation staff, and researchers working in dementia care, as well as our own support services such as Dementia Advisers/Dementia Support Workers and Dementia Connect Local Service Managers.

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