June 2026

South Asian communities in Bolton

Improving access to dementia diagnosis and support

Executive summary

Dementia is a progressive, irreversible condition with a range of symptoms including memory loss, difficulties understanding and communicating, personality changes, and difficulties carrying out day-to-day activities. [1]

Due to the progressive nature of dementia and the lack of curative treatment, it remains the leading cause of death in the UK, accounting for 11.8% of deaths in 2024 (76,894 deaths). [2]

In 2013, 25,000 people from global majority communities were estimated to have a diagnosis of dementia, estimated to double to 50,000 by 2026. [3 4 5]

In Bolton, there are 2,528 (all age, Sept 2025) patients on the Dementia Register. [6] With age being the strongest risk factor for a dementia diagnosis [7], it is important to acknowledge that **9.78% of people in Bolton age 65 years or older are from global majority communities** (including 5% Indian and 2% Pakistani). **This is due to double over the next 10-20 years** with 21.7% of 45-64 year olds in Bolton being from global majority communities; including Indian (8.11%), Pakistani (5.57%), and Black African (2.06%) communities. [8]

A literature review highlighted that global majority communities experience systemic disparities in dementia diagnosis and care. [9 10 11]

To review the perceptions of dementia services within Bolton, **focus groups were conducted with participants from South Asian community groups to discuss support during the diagnostic and post-diagnostic journey for dementia**.

Adult social care services within Bolton were praised for working hard to meet the needs of global majority communities, including provision of culturally appropriate carers who can speak the appropriate languages. It was acknowledged that delivering such care has a significant positive impact on the quality of life of the person with dementia. In addition, **Bolton Public Health's Community Champions programme was commended.**

Nonetheless, some ongoing fear around health and social care was acknowledged within the community. Other key themes highlighted were:

- Persistent **stigma exists despite increased awareness within the community**.
- Due to the varied presentation of dementia, **families struggle to recognise the symptoms of dementia leading to delay in seeking advice and diagnosis**.
- There is an ongoing expectation for female family members to provide caring duties, however **there is a growing acknowledgement of the value of external carers due to female carers needing to balance work and family life**.
- **GPs are highly valued as the first point of contact** within health and social care; often community members will not seek alternative sources of information unless directed by the GP.
- There is a big emotional burden upon the family members caring for someone with dementia; due to the multi-generational nature of South Asian families, they generally provide support to each other, but **there was varied awareness of external agencies for support, such as respite options**.

Considerations for developing culturally appropriate support:

- **Deliver dementia prevention and awareness sessions within local community groups**, inviting wider organisations such as healthcare professionals, social care, and charity groups within Bolton.
- **Develop co-produced community sessions** to ensure that the event design and delivery fully address the specific needs.
- **Develop links with places of worship** to facilitate drop-in health awareness sessions.
- **Develop dementia prevention and awareness sessions within schools**, targeting the younger members of multi-generational families to facilitate awareness within the community.
- Acknowledge that males and females within the South Asian communities tend to meet in separate groups, and **therefore interventions may need to be targeted based on gender**.
- **Include GPs and clinicians in any intervention planning,** as they are generally highly respected within the South Asian community.

Bolton Council

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Introduction

Dementia is a progressive condition, made up of a group of symptoms that can affect a person's memory, problem-solving skills, language and functioning. [12]

There are several types of dementia. The three main types of dementia are Alzheimer's disease (50-75% of cases), vascular dementia (20%) and dementia with Lewy bodies (10-15%). [13] Due to the progressive nature of dementia, it can cause significant complications including:

- Disability, such as mobility issues, eating problems, incontinence, and social isolation
- Behavioural and psychological symptoms of dementia, such as agitation, depression, psychosis and sleeping difficulties
- Increased care needs and institutionalisation in care homes
- Carer stress and burnout
- Financial hardship; it is estimated that the majority of the costs associated with dementia are paid by people with dementia and their families/carers. [13]

Due to the lack of curative treatment for dementia, it remains the leading cause of death in the UK; accounting for 11.8% of deaths in 2024. It has been the leading cause of death in women since 2011, while in men it is the second leading cause of death after heart disease. [14] [2]

There are several established risk factors for dementia including:

- older age
- genetic inheritance
- long-term comorbidities (such as diabetes, high blood pressure, hearing impairment, Parkinson's disease and depression)
- lifestyle factors (reduced physical activity, smoking, alcohol consumption, and social isolation). [7] [15]

It is unclear whether ethnicity has any direct impact on developing a dementia illness, however it has been consistently recognised that there are disparities in diagnosis and treatment of dementia for global majority communities due to a lack of culturally adapted services. [9] [16]

A report from Alzheimer's Society identified the following barriers to diagnosis of dementia in global majority communities:

- **Delayed diagnosis**
- **Language barriers**
- **Stigma and taboo**
- **Cultural perceptions of dementia**
- **Limited identification and referral**
- **Limited culturally appropriate service provision and diagnostic tools**
- **Limited interpretation services.** [11]

Alzheimer's Society recommends that integrated care systems should *identify future projections of ethnic minority populations in each area and commission services that are culturally appropriate*. [11]

In September 2025, the prevalence of diagnosed dementia in people aged 65 and above in England was 4.3% (of 11.6 million registered patients in this age group) [17]. In 2013, 3% or around 25,000 people with dementia were from global majority communities, expected to double by 2026 with the steepest increase in the South Asian population. [4]

Bolton population

Based on 2021 census data, 9.78% of people in Bolton age 65 years or older are from global majority communities (including 5% Indian and 2% Pakistani). This is due to rise over the next 10-20 years with 21.7% of 45-64 year olds in Bolton being from global majority communities. The two main global majority communities within the 45-64 year old population are Indian (8.11%) and Pakistani (5.57%). [8]

In Bolton, there are 2,528 (all age, Sept 2025) patients on the Dementia Register as collated by NHS England. 68.4% of patients on the Dementia Register are of White British ethnicity; with 8.3% Asian or Asian British. There are 21.5% on the register with a 'not defined', 'not stated' or 'inconclusive' ethnic group. [6]

Literature review

A qualitative study in 2023 in Leicester and London – cities known to have large South Asian populations – identified that South Asian people affected by dementia may experience a 'double disadvantage' of having fewer financial resources and fewer options of care and support services that meet their needs. [18] A similar study in East London reflected the cultural differences in family structures contributing to delayed diagnosis; the difficulties with using interpreters to describe the term 'dementia' into languages where the same word does not exist; as well as the complexities of accepting a diagnosis in a place that is different to a person's country of birth. [19]

A review in 2025 reflected many of the findings from the Alzheimer's Society report, and makes recommendations for provision of culturally appropriate activities for people with a diagnosis of dementia from ethnically diverse communities. [20] Such recommendations include: running focused activities celebrating cultural diversity; acknowledging key historical events and festivals; and considering activities which do not require a 'shared language' such as cooking, art and gardening. [21] Another recent literature review in 2025 highlighted that people from Black and South Asian ethnic groups in the UK are more likely to be diagnosed with dementia at a younger age and at a later stage of the disease. The review highlights the need for collaboration between healthcare professionals, policymakers, and people from global majority communities to tackle the disparities and promote inclusive dementia care. [22]

Aim and methodology

Focus groups were conducted with the aim of understanding the experiences of South Asian communities within Bolton with regards to diagnosis and support regarding dementia, with the overall aim of identifying good practice to be shared and highlighting areas of improvement to be addressed.

Participants were recruited via existing community groups who already have links with Bolton Public Health. Attempts were made to recruit participants from Black community groups, however this could not be completed within the available timeframe.

Ethical approval was obtained via a research approval panel, and data was stored securely. Consent forms were completed following review of a participant information sheet.

To encourage participation and active listening during the focus groups, participants would speak only when holding the 'talking object' – a friendly crocodile!

Two focus groups were conducted with semi-structured interview questions. The first focus group consisted of seven South Asian female participants who were members of the same community group and same faith (Muslim), from Indian and Pakistani backgrounds. The second focus group consisted of 10 South Asian female participants who were members of the same community group; this group consisted of Indian and Pakistani participants, as well as African Asian, Pathan, Ethiopian, and Middle Eastern individuals. Participants in the second group identified themselves as either Hindu or Muslim faith. Remuneration was provided.

Interpreters were offered to participants but were not required. The focus groups were conducted in English. The focus groups were recorded via a secure handheld device. The recording was uploaded to a secure computer within 24 hours and subsequently deleted from the handheld device. The focus group dialogue was transcribed.

Limitations

It is acknowledged that recruitment methods were via existing groups with established contacts with Bolton Public Health; this introduces sample bias, as participants may have a higher awareness of health compared to people not previously acquainted with Bolton Public Health. However, due to the time constraints, this was the most feasible recruitment method. It is also noted that all participants were female and did not identify themselves as having a diagnosis of dementia. Thus, the male caring role and the perceptions of people with dementia are not represented, though the carers who participated were keen to reflect on their personal experiences of the issues faced by people with dementia. Participants identified themselves as Muslim or Hindu, thus views from other faith groups are not represented. While the focus group was offered to people who may require an interpreter, the participants of the groups did not require an interpreter. Therefore, the views represented are those of English-speaking participants; it is likely that the themes are amplified in non-English-speaking communities and communities without links to Bolton Public Health.

Key findings: focus group perspectives

Persistent stigma within South Asian communities despite increased awareness

Participants commented that while there is a growing awareness of dementia compared to previous generations, stigma remains within South Asian communities.

> *"They still judge you. And we haven't moved on from 25 years ago. There's just more awareness now."*

Participants expressed that they would feel more comfortable discussing health concerns with an external person or agency due to concerns around stigma and lack of confidentiality within the community.

> *"It's a touchy subject and very emotional subject."*
>
> *"It's like, oh, I don't want that person to know I've got memory issues."*
>
> *"I would go to another group, that random person, a stranger, and tell them my whole life story."*

Understanding of dementia

Delays to diagnosis

Families often struggled to recognise early symptoms of dementia, due to the variable nature of such symptoms. Symptoms were often attributed to stress or the normal ageing process. This resulted in delayed diagnoses and missed opportunities for early intervention. Several participants highlighted that – in hindsight – personality changes had been the first sign of dementia, but these were more difficult to spot than the classic memory impairment symptoms.

> *"With mum's dementia, we didn't think it was dementia to begin with."*
>
> *"Maybe he did have dementia sooner, but we didn't pick up on it because he was always saying 'don't talk to me'."*

"And I just hope that it doesn't take other families as long as it took us to recognise and get the help that their family member needs."

Participants discussed that it is often the family members who recognise the memory impairment prior to the person with the impairment. This can lead to difficulties in encouraging the family member to seek medical assessment. Participants reflected that the person with a memory impairment may be fearful of accepting a dementia diagnosis due to the stigma attached.

"She just won't go to that appointment. And I can't drag her."

Progression of disease

There appeared to be a lack of awareness of the progressive nature of dementia, including its impact on physical health in the later stages of the disease, and the later psychiatric symptoms of the disease such as hallucinations.

"We knew a little bit... we knew that it's an illness, we knew it's a disease, and we knew it was a very sad disease because that's what the doctor said, that it's one of the saddest diseases."

"We never thought it would get so severe."

"The hallucinations were the hardest to deal with."

Impact on family

Participants commented that the caring responsibility primarily falls on family members. There is a general expectation that female family members will take on the caring role, however due to work responsibilities it is becoming increasingly difficult for females within the family to provide round-the-clock care. This leads to increased need for external carers.

"And it was the daughter-in-law 's duty to look after the mother-in-law and father-in-law. Now everyone's at work. Nobody's available all the time for you. So you have to have a carer."

The caring role can be particularly difficult for elderly spouses who are trying to support their loved one with dementia despite their own health issues. Elderly family members looking after their spouses may be reluctant to accept support from external agencies.

She said, "No, I don't want someone else looking after my husband, it's my duty".

Several participants highlighted the difficulties that family members experience as carers. They highlighted that it can be difficult for family members to accept support, and difficult for them to find support if needed.

"My dad doesn't even sleep peacefully because obviously he's thinking he's got to keep look over her all the time."

Carers experienced varied support from social care; one family member of a person with advanced dementia was completely unaware of the provision of respite care options despite describing significant carer burnout, while another family member declined such support due to their perceived duty of care.

"But it was very hard to understand what our care needs were, where to get help from, because we just didn't know where to turn at all."

"Support wise, they were trying to tell my mum that she needs help as well with carers, but my mother didn't want any support because she felt that was her duty as a wife to look after him."

Access to health and social care

It was highlighted that people with dementia respond well to routine, familiar faces, and communication via their native language. This can be difficult when involving external care agencies, however one participant highlighted the positive support that they had received from adult social care services when seeking carers for their family member. The participant praised the ability of social care to provide carers in an appropriate language.

> *"So if they can speak in her language... she's getting a bit of quality of life if you know what I mean."*

Some participants highlighted that there is an ongoing fear of social services amongst some community members due to fear of institutionalisation.

> *"People are so scared of going to social services."*
>
> *"They're going to get into trouble, or they're going to take them away."*

While there were some comments made regarding the decline in trust for healthcare services considering recent difficulties accessing appointments, overall the participants praised GPs as providing positive experiences for diagnosis and support for dementia. Participants frequently expressed that they would seek the advice of the GP if they were concerned that a family member had dementia. Participants stated that they would be unlikely to seek information online or elsewhere until they had spoken to a doctor.

> *"And there was no help out there apart from our GP who really helped us go through the right channels."*

Gender differences in accessing care

All participants were female. They perceived that men were less likely to seek support from medical professionals due to an unwillingness to accept a diagnosis and/or help. Female participants commented that the burden to make medical appointments for the family falls upon the female family members. Participants speculated that male family members struggle to seek medical advice as men feel that they need to be the strongest within the family. It was also highlighted that male members of the community may be less likely to follow medical advice.

"He doesn't want to accept the problem and he doesn't want to go to the doctor."

"Men think nothing is wrong unless somebody else... like a wife, a mum, a daughter... makes an appointment for them."

Raising awareness and education

Community based solutions

The groups highlighted that education and support is best provided in community settings, as healthcare settings can be seen as too "clinical" with a perceived lack of emotion from healthcare practitioners. Participants expressed that they preferred community-based education sessions and conversations as this allowed meaningful connections and conversations amongst people with lived experience.

"Community is a lot better because they've gone through it and they've seen it."

Participants spoke positively about organised events in which multiple healthcare providers and charity organisations attended their community group sites to provide education. It was highlighted that the education sessions delivered to 'Community Champions' by Bolton Public Health were well received and praised as "brilliant". Distance was perceived as a big barrier to accessing community-based activities.

"It's a lovely atmosphere, but it's such a shame we don't have anything like that around here."

One participant highlighted that South Asian people attend a variety of groups; they commented that their local Sea Cadets group was a useful group to disseminate health related information.

Both groups highlighted that their mosques are a central part of their community and would therefore be a good place to deliver education sessions as a large proportion of the community would be present.

"Firstly, you need to get the mosques involved."

"Once you've got a whole load of middle-aged men in that room, say, 'Right, we're going to have a little talk on dementia.'"

Suggestions included running education sessions following prayers or lunch meetings, or having a drop-in or pop-up health clinic at the mosque.

Educational materials

Participants highlighted that educational materials – such as leaflets or videos – should be delivered in the appropriate languages. Some commented that translated leaflets are often difficult to understand as the message "gets lost in translation".

"Finding something in their language is a barrier for most people."

It was recognised that people may not pick up a leaflet. Posters on the back of toilet doors were highlighted as a useful intervention to grab people's attention.

"I feel a poster on a public toilet door is the best place. We're sitting down and we need something to read."

It was discussed that the older population often find it difficult to access online materials, so other ways of disseminating information should be sought.

Culturally appropriate services

It was discussed that dementia friendly activities within Bolton are generally catered towards the White British population (for example dementia discos and music cafes with a Western cultural focus). Participants recommended the following activities as appropriate to their community:

- Attendance at existing community groups to build upon existing relationships, have conversations and build connections
- Art activities such as painting and colouring
- Brain training activities (such as "simple maths")

- Community meals.

Opinions regarding the Muslim population's desire for music-based activities were varied, however participants expressed that Nasheed music sessions may be well attended.

> *"Sometimes the music can make them remember."*
>
> *"Just have a cup of chai and share a packet of biscuits."*

The groups recognised that there are already some South Asian community groups that provide culturally appropriate activities, such as listening to Bollywood music and calligraphy sessions.

Educating younger generations

Both focus groups suggested that education sessions for the younger generations – from primary school onwards – would be helpful to facilitate discussions within multi-generational families.

> *"Teach them, educate them... so they'll go home, they'll talk to their dads, they will be able to pick things up."*

Understanding risk factors

While a handful of participants recognised some of the risk factors for dementia – these include genetics, physical inactivity, smoking, substance use, high blood pressure and high cholesterol[23] – most participants were unaware of the preventative measures they could take to reduce their risk of dementia.

Discussion

Similar to the national picture [24], despite increasing awareness of dementia within South Asian communities, stigma remains a significant barrier. Individuals often fear judgement within their local community, which can discourage open conversations about symptoms or diagnosis. As a result, some people may feel more comfortable discussing concerns with external services.

Focus group participants highlighted that GPs are a generally trusted source within the South Asian community and thus are the initial point of contact when there are concerns around memory. However, recognition of dementia is frequently delayed, as early symptoms are often attributed to normal ageing or stress. Behavioural and personality changes tend to be overlooked, with memory loss being seen as the key symptom within dementia. Similar to findings 20 years ago [25], stigma can lead to individuals resisting medical assessment, placing responsibility on family members to identify issues and encourage help-seeking.

Reflecting previous research [26], lack of culturally appropriate educational materials presented as a key finding with regards to limited awareness of symptoms and prognosis, including the later symptoms of dementia such as impact on communication, physical deterioration, and psychiatric symptoms such as hallucinations. This gap in knowledge can leave families unprepared for the trajectory of the illness and its increasing care needs.

The impact on families and carers is substantial. Reflecting 'traditional' South Asian cultural ideologies around caregiving [27], care is typically provided within the family, often by women, but increasing work commitments make full-time caregiving more difficult and lead to greater reliance on external support. Older spouses may experience stress while feeling a strong sense of duty to manage care themselves, sometimes resisting outside help. Overall, carer burden is high, and awareness or use of respite services varies considerably. Language, cultural familiarity, and continuity of care are important for effective support. In line with previous literature [27], fear of institutionalisation remains a barrier for some when accessing external support.

Community-based approaches to awareness and education were strongly preferred over more formal clinical settings. Reflecting the recommendations of the World Health Organization's global action plan on the public health response to dementia [28], mosques, schools and local community groups were seen as key venues for engagement, although distance and accessibility can limit participation. There was limited awareness of modifiable risk factors and preventative

strategies for dementia, highlighting the need for clearer and more accessible public health messaging in this area. Within Bolton, dementia-friendly activities are often perceived as culturally misaligned with South Asian communities. Again, this illustrates the need to encompass the WHO's recommendations regarding development of culturally appropriate dementia awareness programmes to *improve the quality of life for people with dementia, their carers and the broader community*.[28] Social gatherings, culturally relevant music, art, and simple cognitive exercises were highlighted as potential activities for engaging South Asian communities in Bolton.

Recommendations

1. Continue conversations and build trust

- Develop culturally sensitive awareness campaigns led by trusted community figures (e.g. faith leaders).
- Continue to use peer advocates or "community champions" to normalise discussions.

2. Improve early recognition and diagnosis

- Create targeted education on early symptoms.
- Provide simple, culturally appropriate guidance for families on when to seek help.
- Involve GPs in community outreach events to continue to encourage health-seeking behaviours.

3. Strengthen culturally competent services

- Increase availability of bilingual staff and carers.
- Co-design services with South Asian communities to ensure relevance.
- Following diagnosis, services should engage people with dementia and their carers in culturally adapted advanced care planning to prepare them for the journey ahead.

4. Enhance carer support

- Proactively identify carers and offer support early (not only at crisis point).
- Improve visibility and accessibility of respite care.
- Provide culturally sensitive messaging that reframes external support as complementary, not a failure of duty.
- Offer flexible support for working carers.

5. Expand community-based education

- Deliver education and clinics in mosques, community centres, and local groups.
- Use mobile/drop-in clinics to overcome travel barriers.
- Partner with existing social groups (e.g., cultural, youth, or hobby groups).
- Introduce dementia awareness in schools and youth programmes.
- Create intergenerational learning opportunities to encourage family dialogue.

6. Improve communication materials

- Develop clear, culturally adapted resources, not just direct translations.
- Use multiple formats: videos, storytelling, audio, and visual posters.
- Place information in high-visibility, everyday locations (e.g. community venues, public spaces).
- Reduce reliance on digital-only information for older populations.

7. Provide culturally appropriate activities

- Expand dementia-friendly services to include:
    - Culturally relevant music (e.g., Bollywood, Nasheed where appropriate)
    - Social gatherings and communal meals
    - Art, calligraphy, and simple cognitive exercises
- Embed activities within existing community groups to increase uptake.

8. Address gender barriers

- Develop targeted engagement strategies for men and women.
- Encourage male role models to promote help-seeking.

9. Raise awareness of prevention and risk factors

- Provide culturally tailored education on modifiable risks (e.g., cardiovascular health, lifestyle).
- Integrate dementia prevention into broader public health messaging.

Overall, services should shift toward community-based and culturally adapted services which are co-produced with South Asian communities.

Further research

It is recommended that the views of other global majority groups are explored to build a comprehensive overview of how to further develop dementia services within Bolton. Other groups of interest may include: South Asian males, Black community groups, and groups of different faiths.

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