

# Improving awareness of and reducing the stigma associated with neurodegenerative conditions in British Black and South Asian communities

## Background

As the ethnic composition of the UK changes, health and social care systems face growing challenges in delivering equitable, effective care. People from Black British and South Asian communities living with neurodegenerative conditions experience inequities across the care pathway, contributing to poorer health outcomes and quality of life. Around 18% of the UK population are from a minority ethnic background (1). In the UK, about 50,000 people from minority ethnic communities live with dementia (2), 7,650 with Parkinson's disease (3), 1,440 with Huntington's disease (4) and 900 with motor neurone disease (5).

Culturally relevant and accessible awareness-raising and stigma-reducing initiatives are essential to address these inequities. Improving understanding of neurodegenerative conditions and reducing stigma can support earlier help-seeking, timely diagnosis, and proactive management of long-term conditions. These are core ambitions of the 10-Year Health Plan focus on prevention and early intervention. However, the ways in which initiatives can be effectively tailored for British Black and South Asian communities remain poorly understood. In this project we:

- Identified relevant campaigns aimed at raising awareness or reducing stigma associated with neurodegenerative conditions in British Black and South Asian communities.
- Consulted people from British Black and South Asian backgrounds with lived experience, practitioners, and other stakeholders about their views on effective campaigns.
- Identified implications and recommendations for policy and practice.

## Key messages

Lack of awareness and stigma of neurodegenerative conditions may deter people from seeking help. Community-focused campaigns to raise awareness and reduce stigma are crucial in addressing ethnic inequalities and other inequities in health and social care outcomes. We identified **five ways that inequalities can be addressed**:

1. **Culturally tailored campaigns:** Awareness campaigns should be designed with specific attention to culturally tailoring the format, content and delivery.
2. **A culturally aware workforce:** A diverse workforce confident in engaging with and respecting people from different ethnic backgrounds is essential to building relationships that raise awareness of neurodegenerative conditions.
3. **Strengthening collaboration:** Building and maintaining meaningful connections with minority communities requires expertise and resources. Enhanced efficiency can be achieved by pooling knowledge and resource through cross-sector collaboration across health and social care providers, charities, community groups, faith organisations, and academic institutions.

4. **Recording of ethnicity data:** Information about people's ethnicity is often not recorded, making it difficult to know where to direct campaigns and how much resource to give them. More accurate data would enable better planning of how to target campaigns.
5. **Sustainability:** Creating a dedicated long-term strategy, with involvement of people and organisations from relevant communities, and underpinned by adequate funding will help raise awareness of neurodegenerative conditions.

## Key findings

### The number of campaigns varied across conditions reflecting prevalence

- 21 campaigns were focused on dementia, nine on Parkinson's disease, two on Huntington's disease and one on motor neurone disease (MND).
- Most campaigns designed for South Asian communities occurred in the UK and those designed for Black communities occurred in the USA.
- Campaigns assumed a variety of formats, including short videos, podcasts, online guides, posters, webinars, and community-led initiatives.

### Audiences engaged with relatable stories

- Higher engagement was achieved in campaigns featuring personal stories of people from minority ethnic backgrounds, that included delivery by people with lived experience and/or professionals, delivered in community languages, and addressing culturally sensitive topics.

## Policy implications

Our research highlights that lack of awareness of, and stigma associated with, neurodegenerative conditions are still prevalent in minority ethnic communities. There is an urgent need for **diverse culturally-targeted, culturally-tailored campaigns, underpinned by collaboration between UK health and social care providers, and a need for sharing of accessible, culturally relevant resources. Improving access to and collection of ethnicity data** will allow professionals to identify and address inequities due to ethnicity more effectively.

## Policy recommendations

Consultations with lived experience experts and professionals identified key conditions for effective campaigns. The table below presents each feature with an accompanying policy recommendation.

Key conditions for effective campaigns	We recommend that
<b>Culturally tailored:</b> Campaigns target specific ethnic groups using culturally tailored messaging aimed at all generations.	Integrated Care Systems (ICs) and public health bodies can strengthen engagement by designing awareness campaigns that reflect the cultural values, languages and communication preferences of minority ethnic communities in their localities. This aligns with ICS statutory duties to reduce inequalities

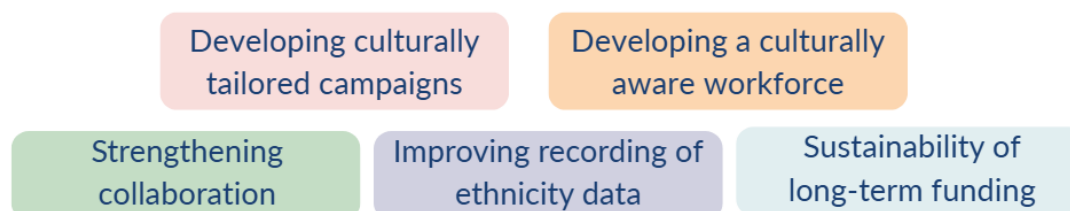
	in access, experience and outcomes, and can be embedded within Joint Forward Plans and Core20PLUS5 delivery for locally identified “PLUS” populations.
<b>Co-production:</b> Campaigns that incorporate lived experience from the target communities are more likely to reflect their voices in the messaging	Review how ICSs and local authorities embed co-production with patients, carers and community organisations in awareness campaigns to ensure lived experience informs every stage. Positioning co-production within Core20PLUS5 and community engagement strategies enables clearer accountability for reducing inequalities.
<b>Sustainable:</b> Establishing trusting, sustainable relationships between people of minority ethnic groups and those providing services is central to changing attitudes.	Campaign development can be integrated within wider place-based prevention and neighbourhood partnership structures, linking with established voluntary, faith and community sector organisations. This supports ICS responsibilities for population health improvement and community-led prevention.
<b>Data driven:</b> Improving recording of ethnicity data will help direct campaigns and appropriate resource.	Review how ethnicity data from local populations is shared between ICSs and partner organisations to enable targeted outreach. Strengthening data infrastructure aligns with ICS responsibilities to identify and address inequalities in access, experience and outcomes, including through Core20PLUS5 monitoring and reporting.
<b>Collaborative:</b> Campaigns may circumvent stigma through integration into broader health or community initiatives.	ICSs can explore mechanisms to support partner organisations in developing collaborative awareness-raising opportunities. This can be delivered through existing prevention, health inequalities or community development funding streams within ICS governance frameworks.
<b>Informative:</b> Effective campaigns emphasise conversation and personal stories, delivered by people from shared ethnic backgrounds or qualified professionals.	Campaign content can explicitly address culturally grounded barriers, including perceptions of dementia as a mental illness, concerns regarding confidentiality and autonomy, and values that prioritise family-led care. Addressing these barriers supports earlier help-seeking, timely diagnosis and proactive long-term condition management, contributing directly to prevention and early intervention ambitions within the 10-Year Health Plan.

**Culturally aware workforce:** A culturally knowledgeable workforce is crucial for effective community engagement.

Review existing cultural awareness training across systems and develop a scalable national model adaptable at ICS-level to reflect local ethnic diversity. Embedding culturally responsive practice within workforce development strategies supports statutory inequality duties and Core20PLUS5 ambitions. Modelling the cost-benefit of implementation at scale would strengthen the economic case by linking improved awareness, earlier diagnosis and reduced crisis presentations to system sustainability.

## Conclusions

Our research highlights the importance of raising awareness and reducing stigma of neurodegenerative conditions in British Black and South Asian. It also emphasises the need to broaden the focus of campaigns and research beyond dementia, to include other conditions such as Parkinson's disease, Huntington's disease, MND and rarer neurodegenerative conditions. To improve awareness and strengthen community engagement the following need to be considered:



## Contact details and where to find out more

Read the full policy report at: Parveen, S., Caulfield, M., Oyebode, J., Prina, M., Charlwood, C., Windle, K., Comas-Herrera, A., Quinn, C., Clare, L. (2025) *Improving awareness and reducing stigma of neurodegenerative conditions in minority ethnic communities*. NIHR Policy Research Unit in Dementia and Neurodegeneration, University of Exeter.

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## References

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- (3) MND Association (2023) What is MND
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- (5) Parkinson's UK (2022) Taking steps towards race equality in Parkinson's research.