

# Race Against Dementia – A Call to Action

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### Introduction

The Race Against Dementia Campaign is an alliance of groups currently providing information and support to people from black, Asian and minority ethnic communities in the UK. Although currently mainly London based we want to invite the support of any and all of those who feel the time has come for the UK to 'step up its game' in meeting the challenge of dementia in black, Asian and minority ethnic communities.

Organisations and groups in the UK have known about the issues facing the diverse communities living with dementia for some time and there is a growing body of research emphasising the challenges. It is time to take a different approach. We need an investment and funding strategy that builds up further the competencies of grass roots organisations and develops their ability to work effectively with mainstream organisations to support more dementia friendly communities. This would include integrating not merely with health and social care services but also transport, emergency services and schools and faith-based organisations.

### Our Aims

We want to see increased investment in capacity building in grass roots organisations to provide competent support and information to those in black, Asian and minority ethnic communities living with dementia and their relatives and carers.

The outcomes that would result from this capacity building would be:

- Improvements in practice
- Improvements in knowledge and awareness of dementia
- Improvements in inclusive policy making
- Improvements in research

### Our Experience

While there has been some improvement in the recognition of the impact of dementia on black, Asian and minority ethnic communities by policymakers in the past few years there remains a lack of urgency regarding the scale and scope of this issue for some of the largest and most longstanding communities in the UK.

Little attempt is made to encourage under-represented communities into research programmes.

The All Party Parliamentary Group report *Dementia does not discriminate* in July 2013 indicated that the numbers of people from black, Asian and minority

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communities in the UK living with dementia will increase sevenfold by 2051 to reach 172,000<sup>1</sup>. This will mainly impact on those settled migrant communities with the oldest age demographic; those arriving in the UK during the 1960s and 1970s. Chief amongst these are the Irish, Indian and African-Caribbean populations, but other smaller more dispersed long-standing communities such as the Chinese will be significantly affected.

Previously we have seen a piecemeal approach with short term funded research that has often led to 'reinventing the wheel'. A more sustainable approach is needed that uses research findings and good practice more effectively in the commissioning and design of information and support services. There should also be better capture and use of community intelligence and communities' capacity for cohesion and resilience to support those living with dementia and their relatives and carers.

The historical lack of understanding of dementia in many black, Asian and minority ethnic communities contributes to a lack of support and can encourage stigma. With increasing longevity there will be a substantial increase in the number of people living with dementia or caring for people living with dementia. Black, Asian and minority ethnic communities are ill prepared for this and commissioners of dementia services have often only grasped this in a patchy local way across the UK. Although there is some excellent local work in different parts of the UK this is often barely known of outside the local area.

### **What we want to see**

Community and faith groups across London and throughout the UK have a potentially powerful role to play in both educating communities, working with commissioners and delivering support and guidance but this role is currently barely tapped into. Modest investment in their potential to deliver these life changing improvements could produce relatively rapid changes by mobilising community resources and creating the diverse dementia friendly neighbourhoods that anyone from the black, Asian and minority ethnic communities growing older in the UK would want to see. We believe these improvements and changes need to focus on:

1. Services need to be culturally acceptable to improve the support and understanding given to people from black, Asian and minority ethnic communities living with dementia and their relatives and carers
2. Dementia information and ageing well strategies need to be made relevant to black, Asian and minority ethnic communities including the newer migrant communities that will face the same issues in the future (e.g. East European)

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<sup>1</sup> House of Commons All-Party Parliamentary Group on Dementia

***Dementia does not discriminate*** *The experiences of black, Asian and minority ethnic communities* July 2013

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3. Appropriate cultural competency training for staff that encourages them to recognise their own stereotypes will affect how they engage with people living with dementia and their relatives and carers. They must recognise how the fear of discrimination may prevent people from engaging with services
4. There should be some readily available targeted resources: for example, advice and expertise on good practice involving housing, dementia, and black, Asian and minority ethnic communities.
5. Local authority housing strategies should be more inclusive of black, Asian and minority ethnic people older people including those living with dementia, supporting their participation in planning and evaluation of services.
6. Staff training and educating communities need to challenge the use of stigmatising and negative language and terminology
7. People from BAME communities with dementia need encouragement to seek help earlier and be supported to do this through advocacy where necessary
8. Engaging with people from black, Asian and minority ethnic communities needs to more directly involve community groups, this means direct investment in these groups with the learning gained disseminated nationally.
9. It is important to collect evidence of needs and what works for people from BAME communities affected by dementia, including recognising the importance of people's lived experience.
10. There needs to be a dementia investment strategy for this work that uses and builds on the knowledge of community groups, offers sustainable funding for the community groups involved and makes more use of co-production in designing services
11. Work funded through this should deliver strategic objectives rather than isolated 'stand-alone' initiatives. Funding allocation should prioritise partnership initiatives involving community groups in sustainable delivery.
12. Steps must be taken to ensure that under-represented groups are included in national research programmes e.g. UK Brain Banks Network, Dementias Platform UK
13. For London, a London-wide 'Race Against Dementia Campaign' needs to be developed to support this strategy that can directly engage with local Black, Asian and Minority Ethnic communities.
14. It is important to work across **all** communities.

The Call for Action was developed by Race Against Dementia Campaign group, consisting of:

The Alzheimer's Society

Nubian Life

Dementia UK

Chinese National Healthy Living Centre

Community Action on Dementia, Brent

PLIAS Resettlement

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Culture Dementia UK

Asian People's Disability Alliance

Race Equality Foundation

Irish in Britain

Mental Health Foundation

For Further Information contact

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