



**Dementia in black and minority ethnic communities:
Meeting the challenge**

**Findings from a one day learning event from
Age UK and the Race Equality Foundation**

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**Compiled by
Kat Clayton, Jabeer Butt, Farah Islam-Barrett, Zoe Gardner,
Race Equality Foundation**

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Contents

Introduction	3
Background	3
Risk factors for dementia	4
The changing demographics of black and minority ethnic communities	4
Risk factors associated with black and minority ethnic communities	5
Better practice	8

Introduction

This one-day learning event, run jointly by the Race Equality Foundation and Age UK, brought together practitioners from across the voluntary, community and statutory sectors to explore ways to deliver better support to black and minority ethnic older people living with dementia. It was funded by the Department of Health as part of their Health and Voluntary Sector Strategic Partnership Programme, of which Age UK and the Race Equality Foundation are both partners.

Speakers and facilitators at the learning event included:

Jabeer Butt

Race Equality Foundation

Charlotte Curran

Irish in Britain

Beth Hill

Age UK

Alli Anthony

Alzheimer's Society

Akhlak Rauf

Meri Yaadin Project (Bradford)

Helen Jones

LeedsGate

Anne-Marie Hamilton

Public Health England

Jemma Mindham

CSV

David Truswell

Central and North West London Foundation NHS Trust

Lorraine Jackson

Department of Health

Lorna Easterbrook

Independent Consultant (Older People)

Lucy Hamer

Care Quality Commission (CQC)

Fiona Goodall

Care Quality Commission (CQC)

The learning event also saw the launch of a new briefing paper, [Black and minority ethnic communities and dementia: Where are we now?](#) The paper was produced by David Truswell for the Race Equality Foundation's Better Health briefing collection. It not only models the number of people living with dementia in the UK from different ethnic backgrounds, but also proposes potentially cost-saving strategies for the care and support of these individuals.

This report outlines the learning from the event and the issues that speakers and participants raised.

Background

In spite of the rising numbers of people with dementia in black and minority ethnic communities in the UK, research in this area is limited. Opening the conference, presenters outlined the particular challenges faced by people in black and minority ethnic communities with dementia, detailing:

- risk factors for dementia;
- the changing demographics of black and minority ethnic communities;
- risk factors associated with dementia in black and minority ethnic communities.

Risk factors for dementia

Jabeer Butt, Deputy Chief Executive of the Race Equality Foundation, highlighted that around 35.6m people are currently living with dementia worldwide; a figure that is expected to double by 2030 and triple by 2050. He noted that, in the UK, the annual cost of dementia is £23bn ([Truswell, 2013](#)).

Anne-Marie Hamilton from Public Health England said 48% people with dementia do not receive formal diagnosis and that in a survey of members of the public aged over 55, 39% said they feared developing dementia compared to 25% who said they feared getting cancer.

Although significantly more evidence on the causes and prevalence of dementia is needed, Jabeer Butt presented research suggesting that the following factors are relevant:

- *Age*: this is the most significant factor in the development of dementia and the likelihood of developing it steadily increases with age: 40-64 years: 1 in 1400; 65-69 years: 1 in 100; 70-79 years: 1 in 25; 80+ years: 1 in 6
- *Gender*: 2/3 people with dementia are women (this may be because women on average live longer than men)
- *Genetics*: individuals who have relatives with dementia appear to be at increased risk
- *Medical history*: in particular this relates to factors which have an impact on the heart, arteries or blood (this may be of particular relevance to black and minority ethnic communities)

Based on [Alzheimer's Society](#)

Jabeer Butt also noted that, in relation to medical factors, lifestyle factors, such as diet, exercise, smoking and alcohol, may also be risk factors in the development of dementia.

The changing demographics of black and minority ethnic communities

In his presentation, Jabeer Butt stressed that the black and minority ethnic population in the UK has traditionally had a younger demographic than the majority white population. However, he argued that the 2011 census has demonstrated that a growing proportion of the black and minority ethnic population in the UK is now aged over 65, with particular growth taking place in the 75+ age group ([NOMIS, 2011](#)). This presents challenges for providers of dementia services if they have not worked with these groups previously or if their commissioning processes do not take into account the major shifts in demographics currently taking place.

Jabeer also highlighted that many communities may not themselves be prepared for the changes which are occurring and that it may be difficult to reconcile the needs and expectations of older people with those of their families: for example, older people may expect to be looked after by their extended family, whilst families may struggle to juggle caring responsibilities.

Jabeer noted that, in other cases, it may be that the experience of dementia itself is new. Most families from black and minority ethnic groups who migrated to the UK were of working age, meaning they did not grow up with older relatives around them. Additionally, they may have never intended to remain in the UK for their retirement. Jabeer also said that, for many communities, life expectancy in the UK may now significantly exceed life expectancy in their country of origin. He said this may mean a greater likelihood of them developing dementia than would be the case in the

Dementia in black and minority ethnic communities: Meeting the challenge

country they originate from. For example, the current life expectancy for Pakistani women living in Pakistan is 67.5 whereas for Pakistani women living in the UK it is 77.3 ([Civitas, 2011](#)).

Risk factors associated with dementia in black and minority ethnic communities

Presenters spoke about a number of risk factors related to dementia within black and minority ethnic communities. Although some of the risk factors described are also relevant to the white majority population, it was stressed that the limited attention given to black and minority ethnic people living with dementia could mean that the impact would be greater for these communities.

Genetics/medical factors

David Truswell's report for the event, highlighted that emerging research has suggested that the prevalence of dementia is higher in the Black African Caribbean and South Asian UK populations, and also that the age of onset is lower for Black African-Caribbean groups ([Truswell, 2013](#)).

Health issues

- *Smoking* is higher amongst Black Caribbean and Bangladeshi men, and use of chewing tobacco is particularly prevalent among South Asian and Asian communities ([Millward & Karlsen, 2011](#)).
- People from the South Asian population have the highest risk of developing Coronary Heart Disease (CHD) in the UK ([Astin & Atkin, 2010](#))
- South Asian people in Scotland have a 60-70% higher incidence of heart attacks than the general population.
- Prevalence of type 2 diabetes is 3-5 times higher in the black African-Caribbean population than the white European population in the UK.
- One in five people of South Asian origin in the UK develop type 2 diabetes, compared to one in 25 of the general population ([Ooldroyd, Banerjee, Heald & Cruickshank, 2004](#))
- Rates of hypertension are higher in black African and Caribbean populations than in the white population
- Gypsy-Travellers have a significantly lower life expectancy than the general population, and accordingly delegates stated that they had experience of seeing symptoms emerging at a younger age.

Support networks

During the event, there was discussion around the often commonly held perception that black and minority ethnic communities "look after their own", living in extended families and providing support to older family members. However, it was argued that research illustrates these trends are changing, with an increasing number of black and minority older people living alone, for example ([NOMIS](#)). In addition, evidence was presented showing that black and minority older people have, on average, lower incomes than the white majority population ([gov.uk](#)). There was therefore concern that many individuals in these groups may be socially and financially isolated.

Awareness of services

Increasing black and minority ethnic communities' awareness of available services is a challenge that presents itself in relation to a range of health issues, particularly for newer migrant communities in the UK, such as people from Yemeni or Somali backgrounds. However, a number of people at the event suggested that the need to raise awareness is particularly apparent in regard to dementia as this is a relatively new condition amongst these groups – and one with rapidly increasing prevalence.

In regard to this issue, Lucy Hamer of the CQC mentioned the difficulty of assessing the effectiveness of services for different communities if they are not actually being used by those groups already.

Stigma

Several participants suggested that the support received by black and minority ethnic people with dementia is limited due to the stigma that is attached to dementia in some communities.

Throughout the day there were a number of specific examples from individuals working with people with dementia and their families and carers, who had experienced isolation or were treated differently by their own communities due to a lack of understanding of dementia. They said that often it is misunderstood and categorised as a general “madness”, rather than as a specific condition. Other issues raised in this context included:

- *Close knit communities:* Some black and minority ethnic communities are very close knit and most people are related or know each other. This may lead to fear or embarrassment about being the subject of gossip or damaged pride at having to ask for help with caring for a family member with dementia. One attendee spoke of working with an Asian woman who was ostracised by her community for taking on external support to help her care for her mother-in-law who had dementia. A Caribbean delegate stated that pride was often a barrier to conversations about dementia in her community.
- *Individual burden:* Against the stereotype of communal responsibility/care, several examples were given of individuals (for example, in South Asian communities in Bradford) who took on the sole caring responsibility for relatives with dementia. A number of reasons were given for this, including a reluctance to seek help due to shame surrounding older relatives behaviour or perceived “madness”; community traditions or expectations about caring responsibilities, such as religious duties to care, the role of women in the family, only allowing close relatives to provide support; or because the family themselves are isolated in the community. This was said to often be the case for Chinese families, for example.

People said, in these situations, the carer was then left caring for often undiagnosed relatives with dementia, which took its toll on their own health. In these situations, it was only when the situation reached crisis point that individuals turned to statutory services. One delegate described this as the experience of the “forgotten family”, highlighting the need to support family members as “they are suffering from dementia too”.

- *Causes of dementia:* A representative from the Alzheimer's Society spoke of working with communities who believed that dementia was caused by spirit possession or jinn, or was a

Dementia in black and minority ethnic communities: Meeting the challenge

punishment for previous actions. She said that while outreach work did not challenge cultural ideology explicitly, it sought to make it clear that dementia was the result of physical changes, and not something that was a punishment or “just in the mind”.

In spite of these issues, others suggested that not all communities experience stigma related to dementia. A representative from a Gypsy-Traveller community gave an example of the shared caring responsibility taken on for an older man living with dementia. Everyone in the community knew “Old Daddy”, and they knew to look out for him if he wandered off or appeared confused.

Language and language barriers

The issue of language barriers was raised repeatedly throughout the day as a significant issue for care and support of people in black and minority ethnic communities. It was argued that, due to the nature of dementia, however, it may be more significant here than in regard to other diseases and conditions. This was due to the fact that not only are older people less likely to speak English in some communities, but also that, when people develop dementia, their ability to speak a second language can also decrease or become confused.

The lack of terminology relating to dementia was also discussed as a cause of some of the misunderstandings and stigma in some black and minority ethnic communities. Indeed, Akhlak Rauf stated that there is no word for dementia in any of the main five South Asian languages, so a project in Bradford was named Meri Yaadain (“My Memories”) to ensure people recognised the type of work it was doing. A project with Irish Gypsy-Travellers talked about “elders with memory-loss” rather than older people with dementia, as it was felt this would promote a more positive attitude towards older people and intergenerational respect and acknowledge the importance of life experience.

Limited knowledge of dementia/cultural issues amongst health practitioners

The limited knowledge amongst health professionals in relation to dementia was a recurrent theme throughout the day. Individuals recounted a number of experiences in relation to this including:

- *Late diagnosis* by medical professionals who did not recognise symptoms.
- *Misdiagnosis*, for example, by medical professionals who confused patients experiencing sight or hearing loss with those experiencing the symptoms of dementia. A representative from Sense highlighted that 1 in 6 people will experience hearing loss during their lifetime. There was also a question over whether the standardised diagnostic tools for dementia are appropriate for all communities.
- *Poor treatment* of older people by health practitioners who are over-stretched. There was also a suggestion that some may lack the empathy required to support people with dementia and their families.

Dementia in black and minority ethnic communities: Meeting the challenge

- *A lack of cultural understanding or sensitivity amongst health and care professionals* leading to a lack of flexibility in their responses to people with dementia. An example was offered of an individual who was fasting for Ramadan becoming very upset after staff told her that she would die if she didn't take medication orally. After negotiation with a community representative it was agreed that she could take her medicine intravenously. Likewise, a delegate from a Traveller community spoke of the difficulties of obtaining care for her father without being able to give a fixed address.
- *Expectations about families based on their ethnicity*, for example, the belief that black and minority ethnic families do not use residential care, which it was argued is, in fact, increasing.
- *The importance of sharing good practice* when working with black and minority ethnic people with dementia – one participant complained that useful information tended to end up in research journals, rather than with health practitioners, whilst another said that although volunteers were very good at expressing the needs of communities on the frontline, that they needed to influence the development of services at a strategic level since the individual volunteers would themselves come and go.

Better practice

The purpose of the learning event was to speak not only about the problems and issues surrounding dementia in black and minority ethnic communities, but also to share and encourage good practice.

Need for accurate data/information sharing

David Truswell's briefing models the number of black and minority ethnic older people living with dementia, using population data from the 2011 Census and statistics on the prevalence of dementia from the Alzheimer's Society. It predicts the number of people living with dementia from different ethnic groups. Ethnic groups are only shown where the number of individuals with dementia is calculated as equalling over 1000 people.

While this research is important, participants noted that it must not negate the need for further analysis. For example, the paper does not include Gypsy-Travellers, as the comparatively small size of this ethnic group means that calculations showed less than 1000 people with dementia in this community. However, a delegate suggested that the figures may be much higher due to low Census response rates and an earlier age of onset amongst Gypsy-Traveller communities. It was argued that the following should be considered:

- Mainstream research into dementia does not always include ethnic data, for example, the [State of the Nation](#) report has geographical breakdowns but no breakdown by different ethnic groups.
- Even in research specifically focussing on black and minority ethnic groups, there is the risk of small groups being "disappeared" from the data.

Dementia in black and minority ethnic communities: Meeting the challenge

- Researchers should not ignore the experience of dementia for people aged under 55; this is particularly important for communities who have lower life expectancy (for example, Irish and Gypsy-Traveller communities).
- Service providers should have data on who is using their services, and also reasons why they are being used or not used. This should be used to increase uptake, whether in mainstream or specifically targeted services.
- Commissioners aren't always sure what they should be investing in, and a strong evidence base on the issues, and on what works to tackle these issues, is crucial.
- Small changes or an understanding of the health system can make big differences. It is important that "soft" evidence is valued and that voluntary sector organisations are confident to find ways to challenge the "tick box culture" and demonstrate the worth of the work that is being carried out (qualitative vs. quantitative).

Engaging with communities

A number of participants argued that in some communities it might be difficult to provide public health information or talk about the issues and challenges surrounding dementia, due to the stigma associated with the disease. However, there were ideas and suggestions about what could or should be done to help. Some of these are outlined below:

- *Know your communities:* Service providers should not just expect all communities to come forward and use services equally. Engaging with some communities may require more outreach work or support, but this does not mean that they are "hard to reach", just that different strategies might be needed. For example, at one time it was felt that black and minority ethnic communities would not use residential care. However, using different approaches, such as taster sessions on a day basis, can change perceptions.
- *Personalise care:* Different religious, cultural or ethnic groups are not homogenous – there is a need to speak to service users as well as representatives or "community leaders" and recognise that there are "communities within communities". One project recognising the need for personalised care for different groups is Age UK Lewisham and Southwark's Access BAME Elders project which supports older black and minority ethnic people to access mainstream and culturally specific services.
- *Be proactive and creative:* It is important that awareness campaigns are accessible to all and do not just target people who are already using services. The use of magazines, roadshows, guides, partnership working between the voluntary and statutory sector, word of mouth, prominent figures in community, and media were suggested. The Alzheimer's Society, for example, have created bespoke films on dementia for different communities and ethnic groups, tailoring language and examples appropriately.
- *Address dementia outside of a mental health setting:* Community events or engagement does not necessarily need to be explicitly about dementia. For example, an event for the Turkish

Dementia in black and minority ethnic communities: Meeting the challenge

community was publicised as a forum for speaking about “worries about getting older”.

Likewise, there is less stigma attached to some of the conditions associated with dementia, for example, hypertension/CVD, so it was suggested that practitioners could use discussions around these issues to broach dementia or to talk to individuals about dementia before symptoms presented, rather than just as a response to onset.

- *Learn from other successful VCS organisations:* this may not just be replicating a model, but being open to thinking creatively, putting an original spin on ideas, or developing ideas from other projects. Therefore, although organisations may be working with individuals from different cultural or ethnic backgrounds, some of the strategies may be the same. Cuiminhe was inspired by the ethos and ideas around movement of kinship and support employed by a charity in Nottingham (but did not explicitly copy their working model).
- *Opportunities for engagement with older people:* in Bradford, Meri Yaadain use activities such as cooking or craft which can cut across cultures as there is no need for language. There is also a need to speak to older people about the activities that they are interested in. For example, a group of Irish elders said they were “fed up of being packed off to bingo” and wanted reminiscence projects focused around talking; listening projects; befriending, with particular focus on getting out into the community by going to a café or library, for example; or singing activities.
- *Acknowledge that statutory services may not be well looked upon:* the relationship between statutory services and some black and minority ethnic groups might not always be good. For example, the experience of the Caribbean community with mental health services has been poor. Service users may find the voluntary and community sector less threatening than social services, so partnership working is recommended.
- *Work across the community and generations:* for example, work in schools can help children to educate their parents about the issue of dementia.
- *Providing funding for successful projects:* this was raised several times, particularly by organisations working with single identity groups. They said that it was increasingly difficult to gain funding for their work, despite clear successes in their frontline activities.

Working with volunteers and community representatives

The use of volunteers and community navigators appeared to be widespread as a method of supporting black and minority ethnic people living with dementia and their carers. David Truswell’s briefing paper sets out a strong economic case for the use of different care models. Several different approaches were highlighted:

- *Community dementia navigators:* befrienders who help people living with dementia and their carers to navigate health and social care systems.

Dementia in black and minority ethnic communities: Meeting the challenge

- *Health community champions*: figures who are trusted within a community, yet also engaged with health services. For example, CVS works with community champions to ensure that the messages that they deliver are both specific and appropriate, for example by using body painting with a group of Asian women. Health champions will often discuss taboo health issues such as mental health and sexual health – including for older people.
- *Dementia champions*: individuals with dementia who are asked to share their experiences with a view to raising awareness. The Alzheimer’s Society provide clear guidelines for volunteers in this capacity, outlining boundaries and expectations – for example, that the response of community to dementia may be complex or even hostile. Volunteers are asked to help for an initial period of 6 months – this takes into account the possibility of their dementia developing further and any difficulties they face after diagnosis.
- *Dementia friend champions*: individuals who deliver sessions in the community to raise awareness of dementia, including to small black and minority ethnic voluntary sector groups. In this approach, the group are also trained to deliver information to others, enabling them to pass it on to their own contacts.

Religious figures: working with religious groups or figures and asking them to pass on the information to their communities. For example, the Alzheimer’s Society “Faith in Health” project provided training for 120 imams to raise awareness of dementia. The imams then gave sermons on dementia. They have also established a bespoke Dementia café for Muslim people within a mosque. Alli Anthony of the Alzheimer’s Society said that such work has helped to challenge the view of the Alzheimer’s Society as “a big white organisation that carries out tick box exercises with black communities”.

Actions for black and minority ethnic communities: taking control and getting involved in opportunities to influence healthcare

Dementia has been highlighted as a strategic priority for several health bodies in the UK. During the event speakers talked about:

- Public Health England rolling out the three year “Dementia Movement” campaign during 2013-14;
- The Department of Health recently releasing [Dementia: A state of the nation report on dementia care and support in England](#);
- Half of health and wellbeing boards prioritising dementia this year;
- The Care Quality Commission starting a review of dementia care (Dec 2013-Feb 2014) in 20 Local Authorities across UK focusing on pathways when using services post-diagnosis;
- The Prime Minister’s challenge which places dementia at the top of the political agenda.

At a time when health services are undergoing major changes, it was argued that it is essential for black and minority ethnic communities to be involved in these processes, and that they do not “find themselves late arrivals to strategic discussions that are already dominated by clinical and academic institutional interests” ([Truswell, 2013](#)).

Dementia in black and minority ethnic communities: Meeting the challenge

In addition to this, people argued:

- *Black and minority ethnic communities need to take ownership of the issues that affect them:* communities need to be more vocal, organised and aware of changes taking place at the policy level. They should partake in consultations and follow up to ensure that their opinions and needs have been included and considered in Joint Strategic Needs Assessments, Health and Wellbeing Board strategies and other local plans. If they haven't, then this needs to be followed up with the relevant organisations. One project facilitating this kind of engagement is Age UK Hillingdon's BME Access Project. As part of this project, Age UK Hillingdon recently held a conference focussed on enabling conversation and collaboration between black and minority ethnic groups and health and care professionals with a view to improving services and support for people with dementia and their carers.
- *Challenge the "hard to reach" label and get involved:* some communities have been in the UK for 60+ years; they should not accept that they are ignored. Instead, these groups should take control and participate in the opportunities available, whether as a health practitioner, volunteer, charitable employee, or as a member of the National BME Dementia Forum.
- *Need for communities to find better ways of speaking and listening:* for example, releasing some of the burden of care by shifting the expectation that only the family can care for older family members; being better at asking for help; and researching the services which are available to them.

Diagnosis and training for professionals

Late diagnosis was felt to be a key problem and there was criticism of the failure to diagnose dementia early. Several representatives spoke of being "fobbed off" by GPs, who merely put symptoms down to "old age". Issues raised included:

- *Recommendation for all GPs to undergo dementia training:* this was proposed in the Dilnot review. Although health checks at age 65 may help, doctors may not always recognise the symptoms of dementia, or for some individuals, onset may be earlier. The Alzheimer's Society are currently in the process of training 12,000 staff to spot the signs of dementia, but a delegate stressed the need for this to spread to all GPs as they are often "gatekeepers", connecting patients with specialist health care and support services. It was argued that by providing GPs with training they could make "every contact count", whether in health checks for older people, or when patients go to the doctors for other medical reasons.
- *Empowering carers to "train" health staff:* It was suggested that carers could be given two leaflets, one in English and one in the carer's language, and asked to give the English language leaflet to their GP to "prove" symptoms were present.
- *Change social norms around dementia and support:* Public Health England are seeking to create "dementia friendly communities" by training professionals in a number of fields beyond healthcare to understand how to support people living with dementia in different aspects of their life, for example, in housing services, on public transport and in shops. This echoes the

Dementia in black and minority ethnic communities: Meeting the challenge

sentiment voiced by some attendees that only when it is very advanced is dementia strictly a “mental health issue”- until that point it is about living well.

- *Acknowledge needs of carers:* the burden on carers can have an impact on their own health, particularly for older carers. Equally, carers should be involved in decisions about ongoing care, as most will not want to feel that decision-making is being taken out of their hands.