




Better
Health
Briefing

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**Black, Asian
and Minority
Ethnic
Communities
and Dementia
– where are
we now?**

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Key messages

- 1 Dementia is recognised as a worldwide health priority but research on dementia in general is poorly funded. Little is known about its relative prevalence in black and minority ethnic populations, although there is a growing body of evidence that the Black African-Caribbean community in the UK has a higher prevalence of vascular dementia than other communities.
- 2 Although the National Dementia Strategy provides strong policy recommendations, there is a need to ensure that these are implemented appropriately, and take into account the information and support needs of black and minority ethnic communities.
- 3 Prevalence of dementia in some communities in the UK has been significantly underestimated.
- 4 Dementia is misunderstood and highly stigmatised in many UK black and minority ethnic communities. There are organisations that have developed good practice in working with black and minority ethnic communities, but there needs to be a more developed structure to share the learning from good practice. There should be a vision of a culturally appropriate approach to the dementia pathway that starts from raising awareness, leads to facilitating early diagnosis and lasts into appropriate end-of-life care
- 5 An economic case could be developed for financing improvements in 'living well' with dementia for people in black and minority ethnic communities, with targeted awareness raising and improvements in community based support.

Introduction

The importance of dementia as an international issue was reinforced in 2012 when the World Health Organisation produced a report declaring dementia a 'public health priority' (World Health Organization and Alzheimer's Disease International, 2012). The number of people living with dementia worldwide currently stands at 35.6 million, and is expected to double by 2030, and triple by 2050.

The Alzheimer's Society's *Dementia* 2012 (Lakey *et al*, 2012) reported that annual cost of dementia to the UK economy stood at £23 billion. A significant proportion (36%) of this cost is borne by informal carers (World Health Organization and Alzheimer's Disease International, 2012).

This briefing looks at developments in the UK since the launch of the National Dementia Strategy in 2009. It considers the extent to which the Strategy is addressing the information, support and care needs of those in black and minority ethnic communities and ensuring that they are supported in 'living well' with dementia. While issues have been raised with the connotations of the term 'black and minority ethnic' (for example, Jutla, 2013) this paper is focused on the term as used for self-description by those completing the 2011 Census.

1 What is dementia?

'Dementia' is a term used to describe a range of illnesses associated with irreversible chemical and neurological changes in the brain that result in progressive functional and behavioural deterioration. Dementia is a terminal illness, usually with an onset in later life. About 60% of people with dementia suffer from Alzheimer's disease. The life expectancy of those living with Alzheimer's disease can vary between 5 and 12 years. Vascular dementia makes up another 20% of cases, and most of the remainder are mixed dementias of various kinds (Banerjee & Lawrence, 2010).

Available treatments can produce some delay of onset of symptoms but the illness is incurable and there is limited understanding of its origins. However, there are lifestyle changes that can reduce the likelihood of developing some dementias. For example, vascular dementia can result as a sequel to stroke, and improved stroke care can reduce the risk of it developing. The risk of stroke itself can be reduced by a healthy diet and regular exercise which reduces the risk of hypertension (The Stroke Association, 2012).

2 The UK Dementia Policy Framework and its implementation

The UK's National Dementia Strategy (Department of Health, 2009a) is an ambitious programme with 17 key objectives to support people diagnosed with dementia and their carers in 'living well' with dementia. The Strategy anticipated that significant improvements would be achieved nationally within a 5 year time scale. An important emphasis for the Strategy was raising awareness of dementia in the general public and through this reducing stigma and facilitating early diagnosis. The supporting joint commissioning guidance document for the Strategy identified black and minority ethnic communities as a group that '*commissioners should particularly considerto ensure their specific needs are met*' (Department of Health, 2009b, p.11). This was taken forward in 2010 in the London region with consultation work with black and minority ethnic communities developed by Commissioning Support for London, DH London, the Alzheimer's Society and the Afiya Trust (Truswell, 2011)

The current Prime Minister, David Cameron gave new impetus to the Dementia Strategy in 2012 with the Prime Minister's challenge on dementia, which stated that '*We must ensure that every person gets the treatment and support which meets their needs and their life*' (Department of Health, 2012). The key focuses of the Prime Minister's challenge are:

- improved diagnosis;
- better support for carers;
- dementia friendly communities;
- improved research.

The first progress report on the Prime Minister's Challenge highlights the inquiry of the All-Party Parliamentary Group on Dementia as a source of recommendations for work with dementia in black and minority ethnic communities (Department of Health, 2013). However, the progress report itself lacks any vision of these black and minority ethnic communities as integral partners in the implementation of the strategy when it outlines its

approach to funding allocations and stakeholder building. In practice, black and minority ethnic communities are likely to find themselves late arrivals to strategic discussions that are already dominated by clinical and academic institutional interests. Yet this is an opportunity to take forward previous work (for example, from Oomen *et al*, 2009; The Royal College of Psychiatrists, 2009; the Race Equality Foundation 2011; Salway *et al*, 2013) on relevant priorities for healthcare research in relation to black and minority ethnic mental health needs, including dementia, and developing a more active role for black and minority ethnic communities in the design of studies and as co-researchers (Jolley *et al*, 2009; Vickers *et al*, 2012).

The All-Party Parliamentary Group on Dementia's inquiry report (2013) is significant in placing issues for black and minority ethnic communities and dementia at a national policy and political level not previously seen in the implementation of the National Dementia Strategy. It puts the figure for the number of people in England and Wales from black and minority ethnic groups living with dementia at 25,000, substantially revised from the previous estimate of 15,000 in the 2009 National Dementia Strategy.

While UK minority ethnic populations are generally widely dispersed, these communities are generally concentrated in urban areas (Crosby, 2004), making shifts in prevalence estimates of this order challenging for commissioners and the new commissioning structures. Current Joint Strategic Needs Assessments (JSNAs), critical documents for understanding local commissioning priorities, are variable in the attention paid to dementia and few attempt to analyse their dementia information by ethnicity. New commissioning structures could make use of the extensive guidance readily available for working with and commissioning services for black and minority ethnic communities produced by the Race Equality Foundation (Salway *et al*, 2013) and other sources (Blood & Bamford, 2010; Turner *et al*, 2012).

3 Prevalence of dementia and black and minority ethnic communities

In the UK there has been very little work done on the impact of dementia in black and minority ethnic communities. However, there are increasing indications that the prevalence of dementia in Black African-Caribbean and South Asian UK populations is greater than the white UK population (Turner *et al*, 2012) and that the age of onset is lower for Black African-Caribbean groups than the white UK population. Since these groups are also more likely to experience high blood pressure, it is suggested that the increased risk of vascular dementia contributes to increased prevalence (Bhattacharyya, 2012).

This briefing estimates the prevalence of late onset dementia (over 65) in black and minority ethnic communities using rates identified by the Alzheimer Society (Alzheimer Society, undated) and population figures from the 2011 Census (Office of National Statistics, 2013).

Table 1: *Estimated prevalence for all dementias by age cohort (adapted from Alzheimer's Society)*

Age	% prevalence all dementias
65-69	1 in 100
70-79	1 in 25
80+	1 in 6

Fig.1 *Estimated dementia prevalence for England and Wales black and minority ethnic population (2011 Census) - by age cohort*

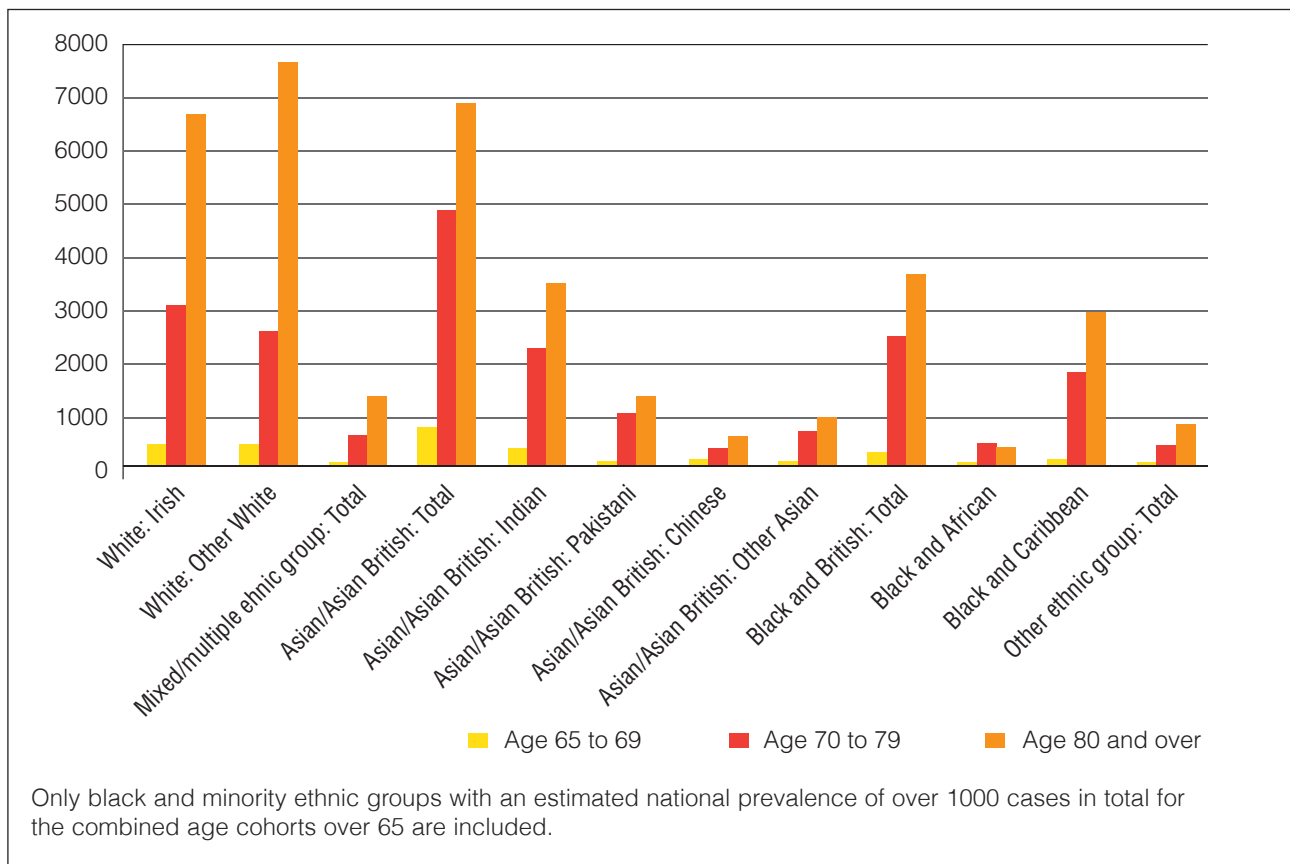
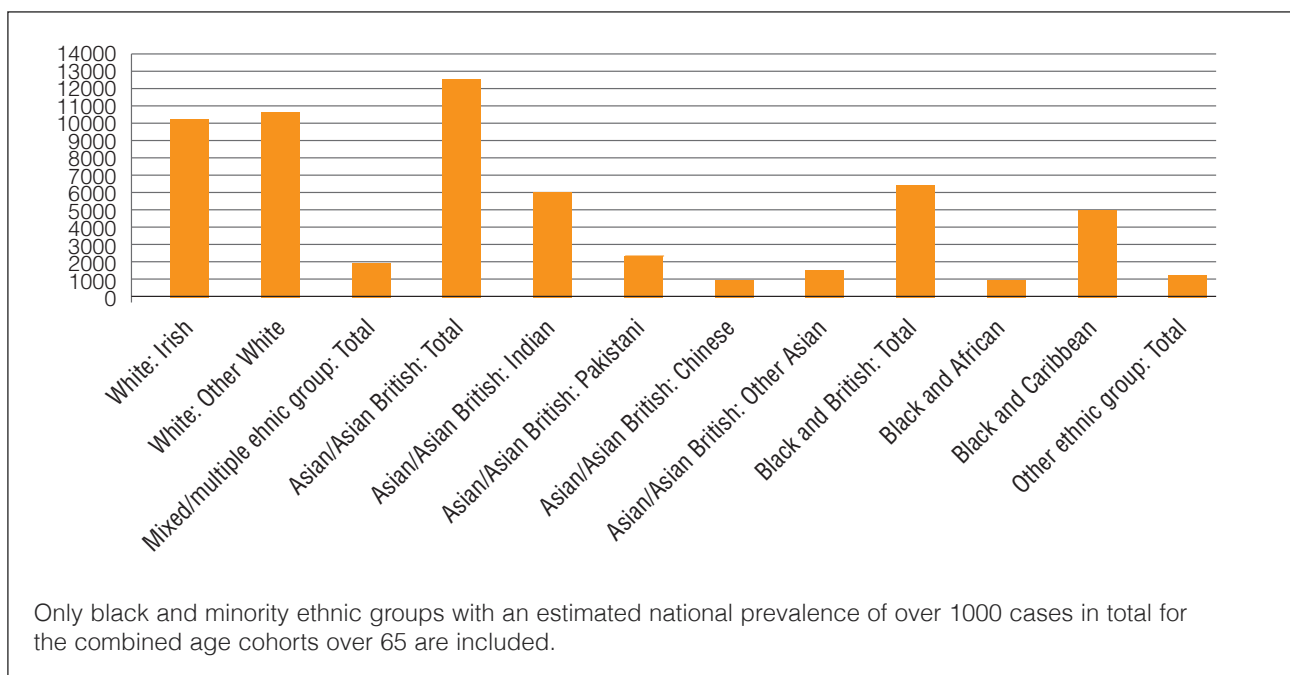


Fig.2 *Combined estimated total figure for over 65s from black and minority ethnic backgrounds living with dementia. Only Census categories with an estimated total of over 1000 cases are included.*



4 Differential impact of dementia in black and minority ethnic communities

It should be noted that the number of estimated cases in the 'Other White' category is substantial. In the UK very few studies exist on stigma, information needs and support issues in relation to these communities. Those UK studies that have been done (Mukadam *et al*, 2011, Botsford *et al*, 2012) have been very small scale but indicate significant culturally specific values and expectations need to be taken into account. The dearth of research on the Irish population is a concern as it has the highest estimated prevalence of dementia of any ethnic group from the 2011 Census data, due to a demographically 'older' Irish population than the native white population. The lack of research on the needs of the Jewish population in relation to dementia is also an area of concern. The 2011 Census indicates that 21% of those identifying themselves as Jewish are over 65.

Lievesley, in updating his previous work on the UK black and minority ethnic ageing population, has pointed out that the 2011 Census shows that 58% of the black ethnic groups (Black African-Caribbean, Black African and Black Other) live in London and also that the Black African-Caribbean population is demographically the 'oldest' of the black ethnic groups (Lievesley, 2013). From the 2011 Census data this would mean over 2,700 of those who identified as Black African-Caribbean in the capital over 65 are likely to be living with dementia. It is probable that this figure is considerably underestimated as it assumes that the Black African-Caribbean population has the same prevalence of dementia as the indigenous white population, when there are studies to suggest that the prevalence rate is higher (Livingston *et al*, 2001; Adelman *et al*, 2009a; Banerjee & Lawrence, 2010); that early onset dementia is more prevalent (Healthcare for London, 2009); and that the Black African-Caribbean population has greater risk factors for vascular dementia, such as hypertension (Adelman *et al*, 2009b, 2011; Moriarty, 2011).

From the 2011 Census data there is estimated to be over 12,400 people in England and Wales of a South Asian ethnic background over the age of 65 living with dementia, over 5,200 of these living in London. The small amount of research in the UK on dementia in South Asian communities (Seabrooke & Milne, 2004, 2008; Jutilla *et al*, 2009) has illustrated the importance of understanding how expectations and obligations regarding care are likely be negotiated within South Asian communities and the challenge of developing effective awareness raising.

Resources

Good practice examples from a variety of black and minority ethnic communities

Meri Yaadain

www.meriyadain.co.uk

An information and advice service for the South Asian communities in Bradford, established in 2006 by the Council's Adult Services Department. Its website is a good example of accessibility to black and minority ethnic communities and they have developed a short DVD to explain dementia to South Asian communities. Their Caring for Dementia guide is also a useful example of an information leaflet setting out both the cultural issues as well as the care issues for South Asian communities.

Culture Dementia UK

www.culturedementiauk.org

An energetic third sector organisation that has been working in Brent for the past 15 years with the African-Caribbean community, providing information, a crisis line, a monthly support group and respite. The organisation exemplifies the rich network of informal contacts that are a common feature of voluntary organisations in Black African-Caribbean communities, particularly within faith communities.

Dementia UK

www.dementiauk.org

A national charity which promotes and develops Admiral Nursing - a specialist nursing intervention focussed on meeting the needs of families and people with dementia. It is committed to the delivery of person-centred, culturally competent care. There are a number of examples of positive practice by Admiral Nurses in working with black and minority ethnic carers. For example, one Admiral Nurse has recently led the development of awareness raising about dementia in the Tamil-speaking community in the Royal Borough of Kingston upon Thames with South West London and St. George's NHS Trust (Jackson et al, 2008). Central and North West London NHS Trust (CNWL) is currently working with an Admiral Nurse covering Brent and Harrow in developing dementia service information for black and minority ethnic communities. In Haringey, North London, Admiral Nurses have led on the establishment of a culturally inclusive social and therapeutic club ('Tom's Club', Orr et al, 2013). Dementia UK Admiral Nurses in London have extensive experience and knowledge in support black and minority ethnic carers.

An initiative started in Wolverhampton informed by Dementia UK's work is the development of the post of Asian link worker, where a community nurse fluent in Punjabi and English provides an outreach role to local South Asian communities, raising awareness of dementia as well as advising across the professional spectrum on cultural issues. As well as facilitating greater direct engagement and understanding between the local community and health services, the role ranges flexibly across the primary care and acute hospital interfaces of the dementia pathway (Kaur, 2010).

Jewish Care

www.jewishcare.org/home

Jewish Care have a dementia care and support service based at their Maurice and Vivienne Wohl Campus in North London which supports those living with dementia and their carers across the whole dementia pathway, from awareness raising activities to residential care. An important feature is their commitment to the family throughout the pathway from diagnosis onwards. Their challenges in reaching the Orthodox Jewish community illustrate the limitations inherent in assuming ethnic or religious communities are homogenous

The Alzheimer's Society

www.alzheimers.org.uk

The Connecting Communities initiative provides dementia community development workers for black and minority ethnic communities in the London Boroughs of Hillingdon, Lambeth, Merton, Enfield, Newham, Redbridge, Hounslow and Croydon. This initiative is committed to working closely with local community groups to develop raising awareness events. The Alzheimer Society also has a nationwide project underway focusing on developing awareness raising materials for South Asian communities. The Alzheimer Society's Dementia Knowledge Centre online is a very good information resource for research and reports on dementia in black and minority ethnic communities.

The Policy Institute for Research on Ageing and Ethnicity (PRIAE)

www.priae.org

The PRIAE was established in 1998 and has produced a number of significant documents aimed at the national policy level. They have produced work on people from black and minority ethnic elders in long-term care and extra care housing (Patel, 1999; Patel & Traynor, 2006) and their website has an extensive collection of reports on dementia care needs across Europe.

The Pepper Pot

www.facebook.com/thepepperpotcentre

The Pepper Pot day centre in London is a third sector day service established in 1981 working with the Black African–Caribbean community, providing a variety activities of including aromatherapy, yoga and respite. It has recently taken to using social media to enhance its reach.

The London Dementia Strategy Implementation Team

www.facebook.com/pages/Resources-for-Dementia-and-Black-Minority-Ethnic-and-Refugee-Communities

The team explored the use of social media as a peer-led information source, but this approach remains underdeveloped. The team's legacy document on information for commissioners on working with black and minority ethnic communities (Healthcare for London, 2011) continues to be a useful source for online resources.

The Big White Wall

www.bigwhitewall.com

An example of a successful online initiative in the wider mental health field which could provide the template for similar developments in the dementia field. There are many third sector organisations that do invaluable work locally supporting people from black and minority ethnic communities that simply lack the time and resources to promote themselves beyond their locality and the growth of on-line resources modelled on the information sharing and informal support of social networking has considerable potential for such organisations.

Yecco

www.yecco.com

An example of emerging carers peer support sites that have the potential to be of significant value to black and minority ethnic carers.

5 The economic case

The economic case for investment in developing information dissemination and support services from the black and minority ethnic third sector has been largely unexplored. There is poor understanding of demand and JSNAs often fail to provide detailed differentiation of black and minority ethnic communities at higher risk of dementia, such as the Irish and Black African-Caribbean. The number of older people from these communities in nursing homes is unknown.

Health information about dementia could be more effectively disseminated into black and minority ethnic communities by investing in these communities as a resource for conveying health messages.

The arguments on cost savings from early diagnosis of dementia used by Banerjee and Wittenberg (2009) for the general population can be applied to the economic case for targeting information and resources to support early diagnosis and intervention in dementia for black and minority ethnic communities. Table 2 uses the Personal Social Services Research Unit (PSSRU) costs for 2012 for health and social care (Curtis, 2012) to illustrate an invest-to-save case. It is assumed that delaying transfers still incurs some costs for ongoing care provision, and uses PSSRU costs for critical care for social care as an estimate for these costs. It compares the cost per week of different kinds of residential care with the cost saving per week if 100 cases were delayed in transferring to residential care by one week. If there are 2,700 Black African Caribbean people over 65 living with dementia in London, then for every 100 who spend one week longer in the community as a result of targeted early information, the cost saving could be as illustrated.

Table 2: An ‘invest to save’ illustration for using cost saving benefits of delayed transfer to residential home to fund community support services

PSSRU Provider category	Cost per resident per week	Cost per resident per day	Cost saving per week for 100 cases by 1 week delay in transfer	Less cost of 1 week of Social Care Package Critical care package costs £363 per person per week
Private sector nursing homes for older people	£736	£105.14	£73,600	Less cost of critical care - saves £37,300 per 100 cases per week
Private sector residential care for older people	£522	£74.57	£52,200	Less cost of Critical care - saves £15,900 per 100 cases per week
Local authority residential care for older people	£1,007	£143.86	£100,700	Less cost of Critical care - saves £64,400 per 100 cases per week
Extra care housing for older people	£428	£61.14	£42,800	Less cost of Critical care - saves £6,500 per 100 cases per week
Costing for early interventions				
Voluntary adult befriending	£87 for 12 hrs per week		This could support development of 'black and minority ethnic dementia navigator'	
Targeted black and minority ethnic health promotion campaign	Unknown as depends on the scale of health promotion campaign		This could be partly directly invested in black and minority ethnic community groups. It is anticipated that economic benefits would be comparable with those found by Knapp <i>et al</i> , 2011. in reviewing the benefits of mental health promotion	

The cost saving could be invested in the early interventions outlined and this investment could also provide a useful stimulus for the black and minority ethnic third sector. Commissioners could review existing system dynamic models for modelling dementia costs by inputting the new Census data and factoring in the emerging information on higher prevalence rates for dementia in some black and minority ethnic communities. There should also be attempts to tackle the rising rates of costly unscheduled hospital admissions or transfers to residential care funded as urgent spot purchases of care packages for complex, late presenting black and minority ethnic patients who have been living in the community with undiagnosed dementia needs.

6

A new role – a black and minority ethnic community dementia navigator?

Use of dementia navigators, befrienders who provide support to people living with dementia and help them to find their way around the health and social care system, has been identified as good practice in Barnsley (Department of Health, 2011). Models for community health service navigators for minority ethnic communities are well developed in the US for navigating health systems (Rush, 2012), and may have a casework focus, as in the case of bilingual patient navigators at the Seattle Children's Hospital (Jackson, 2013). Navigators are usually fluent in the community language of the person they are supporting and have lived knowledge of their cultural background.

Is it time for a new role focusing on dementia navigators focusing specifically on the information and support issues for black and minority ethnic communities? Such navigators need not be clinical experts but would ideally stay with the person until the end of their life, supporting other professionals, such as the Admiral Nurses. Community dementia navigators could be of particular value in supporting those living alone in black and minority ethnic communities or who have very limited sources of informal help. However, such provision of a culturally informed service needs to move beyond the limitations of simple 'ethnic matching' which risks importing negative stereotyping of dementia from the culture of origin into the care relationship. Further work needs to be done on defining cultural competency that achieves a nuanced understanding of the complexity of lives lived out geographically displaced from the culture of origin and involving mixed generational experience of migration and discrimination. This complexity has been highlighted by Jutlla (2013) and others (Bhattacharyya & Benbow, 2012). Experience across the NHS even following from specifically focused national policy initiatives in mental health, such as Delivering Race Equality, is that cultural competency in service delivery remains a sharp challenge (Sewell & Waterhouse, 2012).

Although the role would be very challenging, the appointment of black and minority specific dementia navigators could align with the culturally congruent narratives of resilience and spiritual succour which are finding increasingly prominence in end of life care, but remain neglected in the dementia field (Regan *et al*, 2013, Selman *et al* 2010).

As suggested above there is scope for considering this as an 'invest to save' opportunity when considered on a local authority or regional scale and could be an economic stimulus to hard-pressed minority ethnic community organisations.

Conclusion

There is a worldwide recognition that dementia is one of the key public health issues for the 21st century, yet there is very little research on the illness despite the fact that it absorbs a significant and rapidly growing amount of expenditure on health and social care. For carers, it presents a profound psychological as well as financial burden. Very little is known about the prevalence of dementia in the UK black and minority populations despite some of these communities being at higher levels of risk than the indigenous white population. Policy guidance on understanding the issues for black and minority ethnic communities has not yet found its way into practice when implementing the UK National Dementia Strategy. Information from the 2011 Census indicates that there are substantial increases in the number of people from black and minority communities likely to be living with dementia, but the understanding of dementia in such communities is limited and the illness highly stigmatised. A more targeted approach to information and support for people in black and minority ethnic communities living with dementia and their carers must be taken, and could be financed by reducing the rate of transfers to residential care. A whole pathway approach to 'living well' with dementia should be developed using a community dementia navigator or some similar role, and improved training in cultural competency amongst professionals throughout the pathway would help them to support people with dementia from black and minority ethnic communities.

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We welcome feedback on this paper and on all aspects of our work. Please email briefings@racefound.org.uk

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