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Practice paper

Black, minority ethnic and refugee (BMER) communities and the National Dementia Strategy: the London experience

David Truswell BSc MSc (Econ) MBA
Dementia Implementation Lead, Commissioning Support for London, London, UK

What is known on this subject

- There is a rising proportion of people with dementia in the BMER populations residing in Greater London.
- There are concerns about effective engagement with BMER communities to develop appropriate services for people living with dementia and reduce health inequalities.
- BMER community groups provide an important source of advice and support to many people living with dementia and their carers.

What this paper adds

- It identifies how commissioners of dementia services can be provided with resources and tools for an evidence-based approach to engaging with BMER communities when commissioning services for people living with dementia.
- It illustrates working in partnership with BMER organisations in implementing the National Dementia Strategy in the London region.
- It identifies key concerns for some BMER community groups in working with commissioners of services for people living with dementia.

ABSTRACT

This article examines the role of black, minority ethnic and refugee (BMER) communities in the implementation of the National Dementia Strategy in London. Although recent government policy in health and social care has highlighted the need for local partnerships across sectors to deliver improved healthcare and reduce health inequalities, there has been limited research on dementia in minority ethnic groups. Despite the cosmopolitan mix of the capital's population, BMER communities have historically been marginalised from strategic health initiatives. This article highlights the work undertaken by the London Region Dementia Implementation Task Group to support commissioner engagement with BMER communities in planning dementia services, and to help these communities to have more influence on the implementation of the National Dementia Strategy in London. The potential health access and economic risks of failing to improve the involvement of BMER communities in planning dementia care are outlined.

Keywords: BME community, commissioning, community engagement, dementia, refugee community

Introduction

This article considers how the implementation of the National Dementia Strategy (Department of Health, 2009) will affect black, minority ethnic and refugee (BMER) communities in London (Social Policy Unit, Department of Health, 2010). Beginning with an examination of the policy context and demographic information, the article describes the approach taken by the London Region Dementia Implementation Task Group to ensure that implementing the strategy in London involves working in partnership with groups representing the capital's BMER communities. The Task Group has developed specific recommendations for commissioners and providers of dementia services from its partnership work, and the article contrasts the benefits of acting on these recommendations with the risks involved in failing to more actively and systematically engage with BMER communities in the delivery of improved dementia care.

The policy context

There were extensive consultations across London as part of taking forward the National Dementia Strategy. These consultations involved clinicians, voluntary organisations, people living with dementia and their carers, and led to the productions of the *Dementia Services Guide* (Healthcare for London, 2009), which was launched in October 2009 at Congress House. This guide addresses the 17 objectives of the National Dementia Strategy to improve the quality of life of people with dementia and their carers by prioritising three key themes:

- raising awareness and understanding
- early diagnosis and support
- living well with dementia.

A London Dementia Implementation Steering Group was set up in January 2010 to oversee the implementation of the recommendations of the *Dementia Services Guide*, ensuring consistency in application and the communication of best practice across the capital. The Steering Group oversees a multi-agency Task Group which collates information, provides advice, develops guidance tools and directly supports primary care trust (PCT) commissioners in improving dementia services. Organisations represented in the Task Group are the Department of Health London Region, Commissioning Support for London, the Alzheimer's Society, London Councils and London Carers. The Task Group continues to be supported by the Clinical Reference Group that developed the *Dementia Services Guide*. One of the priorities of the Task Group in its first year has been to raise public awareness about dementia and promote early access to diagnosis.

In the White Paper *Equity and Excellence: liberating the NHS* (Department of Health, 2010a) the incoming coalition government pledged that its vision for the future of the NHS is one that 'eliminates discrimination and reduces inequalities in care' (Department of Health, 2010a, p. 8) and 'is less insular and fragmented, and works much better across boundaries' (Department of Health, 2010a, p. 9). The Task Group's work supports this vision. The current government's commitment to addressing health inequalities through local partnership work involving local communities and joined up commissioning is set out in another recent public health White Paper, *Healthy Lives, Healthy People: our strategy for public health in England* (Department of Health, 2010b). This identifies vascular dementia as a specific public health issue. *Our Health and Well-Being Today* (Department of Health, 2010c), the supporting evidence summary for this White Paper, highlights the importance of early diagnosis in dementia. Finally, for people from BMER communities living with dementia in London, delivering on the 'Big Society' social care policy ambitions outlined in *Capable Communities and Active Citizens* (Social Policy Unit of the Department of Health, 2010) of 'helping people to stay independent as long as possible' (Social Policy Unit of the Department of Health, 2010, p. 27) and 'reducing spending on long-term residential care' (Social Policy Unit of the Department of Health, 2010, p. 29) will only be possible with substantial partnership involvement with BMER community groups. Thus working with BMER communities to provide good-quality dementia care information and dementia services in the capital has a significant part to play in implementing the National Dementia Strategy in London. However, the lack of any significant role given to BMER communities in shaping the development of care services has been extensively documented (e.g. Audit Commission, 2004; Butt, 2006; Patel *et al*, 2010). In addition, Oommen *et al* (2009) argue that there is a longstanding lack of research attention paid to services for people from BMER communities who are suffering from dementia.

The Task Group was determined to reach out directly to BMER organisations working with people living with dementia from the earliest stages to ensure that their needs and those of their carers were addressed in the implementation process. By developing links to BMER representative bodies, such as the Afiya Trust, the Task Group hopes to ensure continuity between its initial work and the service development and commissioning environment of the future, with its challenges of severe funding constraints and the emerging focus on localism as outlined, for example, in the consultation paper *Local Democratic Legitimacy in Health* (Department of Health and Communities and Local Government, 2010).

The demographic background

By 2051, there will be an estimated 2.8 million people aged 70 years or over from BMER communities in England and Wales (Lievesley, 2010). London has been estimated to be home to 45% of the national BMER population (Crosby, 2004). Engaging with these communities to communicate mental health messages to combat stigma and improve access to appropriate information and services presents many well-documented challenges (Wilson, 2009; Fountain and Hicks, 2010; Truswell and Bryant-Jefferies, 2010). For commissioners in London boroughs, public health awareness of dementia and involving the BMER communities in improving dementia awareness and improving access to services are key concerns. This is particularly the case in those areas with large settled BMER communities, such as the African-Caribbean and South Asian communities, which will see a significant rise in the number of older people and an associated rise in the incidence of dementia in the future (Katbamna and Matthews, 2007) (see also Table 1). While there is limited reliable evidence about dementia service access and BMER groups (Oommen *et al*, 2009), the current public health and social policy emphasis on reducing health inequalities and the requirements of the Single Equalities Act (Government Equalities Office, 2010) present a clear case for ensuring equal access to services and helping disadvantaged groups to navigate the dementia care pathway.

Demographic issues, health risks and health service access issues for BMER communities in London will have an impact on dementia care provision in the capital. Social and cultural factors militate against help-seeking behaviours in BMER populations, especially for mental health problems (La Fontaine *et al*, 2007). There is a perceived expectation among BMER populations of discrimination and/or lack of cultural competence in mental health services (Department of Health, 2005). Some groups have an increased risk of dementia. For example, South Asian and African Caribbean groups are more likely to develop vascular dementia (the second most common form of dementia), due to the higher levels of diabetes and hypertension in these groups (McKeigue and Chaturvedi, 1996; Nicholls, 2006). Professionals' assumptions about lifestyle and the caregiving cultural norms of BMER communities affect their expectations of carer and family support (Social Services Inspectorate, 1998; Daker-White *et al*, 2002; Katbamna *et al*, 2004), and suggest a need for standardised diagnostic tools in assessments (Lane and Hearsum, 2007).

The London Dementia Strategy Implementation Task Group and dementia in BMER communities

The Task Group recognised at an early stage that BMER communities were a significant group on which to focus when implementing the strategy. Without careful attention to the problems of stigma, improving engagement, challenging discrimination and the provision of culturally sensitive information and appropriate services, members of BMER groups are unlikely to fully benefit from the early intervention and awareness-raising work promoted in the national strategy.

In January 2010, the Task Group agreed on the basis of an internal scoping report to develop an electronic resource handbook (available online at: www.londonhp.nhs.uk/publications/dementia) for health and social care commissioners that provides an Internet-based accessible resource for current research, guidance and materials on dementia and engagement with BMER communities. The materials referenced in the handbook are freely accessible electronically or available in hard copy at very low cost. They include toolkits for developing community engagement and tools for service audit of cultural sensitivity. The electronic handbook also provides hyperlinks to dementia awareness information in a variety of languages, in both written and audio-visual form, and links to organisations where such materials can be ordered, again either free or at very low cost. All of the handbook information is derived from UK-based work.

The Task Group also worked with the Afiya Trust to develop a seminar held in June 2010 for third-sector groups (also known as voluntary-sector groups or non-government organisations) working with BMER communities and dementia to explore current issues for these communities with regard to dementia information and services in the capital. The Afiya Trust is a London-based national organisation with substantial experience and policy development influence in highlighting mental health-related issues for BMER communities.

This seminar, entitled *Dementia: Connecting with Black, Minority Ethnic and Refugee Communities*, was limited to 30 places to provide an opportunity for participants to engage in detailed small-group discussions and to provide an environment that would support networking. The event was free of charge to participants, and was publicised through BMER voluntary-sector information networks known to the organisers, including mailing lists, email groups, online newsletters and webzines to encourage take-up by a wider range of organisations than the usual large third-sector providers. The event, which was co-facilitated by the Task Group and the Afiya Trust, was heavily oversubscribed. Participants included a wide range of third-sector organisations and also a number of NHS and local authority representatives with community engagement roles.

Within the six London National Dementia Strategy Demonstrator Sites, there is a Peer Support Project developing dementia peer support groups for BMER communities in Hackney. The author provides

Table 1 Percentage increases in the number of people from black, minority ethnic and refugee groups with dementia by primary care trust, 2001 to 2021

PCT	Number of people from BMER groups with late-onset dementia in 2001	Estimated number of people from BMER groups with late-onset dementia in 2021	Percentage change
Barking and Dagenham	42	302	619
Barnet	348	798	129
Bexley	70	164	134
Brent	777	1317	69
Bromley	84	227	170
Camden	143	268	87
City and Hackney	330	562	70
Croydon	375	910	143
Ealing	562	1095	95
Enfield	231	642	178
Greenwich	119	368	209
Hammersmith and Fulham	160	278	74
Haringey	271	429	58
Harrow	377	972	158
Havering	40	106	165
Hillingdon	157	491	213
Hounslow	297	653	120
Islington	149	252	69
Kensington and Chelsea	145	215	48
Kingston	72	226	214
Lambeth	392	631	61
Lewisham	235	582	148
Newham	337	849	152
Redbridge	276	833	202
Richmond and Twickenham	56	140	150
Southwark	242	557	130
Sutton and Merton	261	674	158
Tower Hamlets	266	498	87
Waltham Forest	226	545	141
Wandsworth	266	448	68
Westminster	196	345	76
London total	7566	16 846	123

Adapted from Healthcare for London (2009) *Dementia Services Guide*. Appendix 1: Needs Assessment.

mentoring to the Project Co-ordinator, and the seminar provided an opportunity to share some of the early findings of this project with the seminar participants, and compare experiences.

Outcomes of the Dementia: Connecting with Black, Minority Ethnic and Refugee Communities seminar

A substantial part of the seminar day was taken up with small-group facilitated discussions that focused on three key themes, namely sharing experience of the barriers that BMER organisations encounter at local level, designing services, and involvement and partnership. It resulted in the production of a series of recommendations and proposals for the Task Group (see Box 1).

All of the seminar participants recognised and welcomed the notion of developing much more effective partnerships both across the third sector and also with statutory providers and commissioners, but as equal partners with a valuable contribution to make in the partnerships. However, finding an effective way to create a dialogue with people from BMER groups about dementia was sometimes quite difficult. The participants reported that existing community support structures, such as lunch clubs for older African-Caribbean people, provided the most effective way of making contact.

A key issue was the concept of fourth-sector organisations. These were defined as very small and highly specialised voluntary organisations, usually consisting of three people or fewer, with substantial highly specialised skills and information. These organisations required the support of the larger third sector to gain funding, but risked losing their specialised skills and unique contributions if they were permanently absorbed into larger organisations.

In response to the wishes of the participants to have access to a sustainable network of organisations across London working with dementia and BMER communities, the Task Group set up a Facebook Community Page in August 2010 to facilitate such networks, contacts and information sharing in the capital (www.facebook.com/pages/manage/#!/pages/Dementia-and-Black-Minority-Ethnic-and-Refugee-Communities-in-London/122493921131184).

The participants were also keen to establish a virtual Expert Reference Group for London to provide an information source for commissioners, which would include helping to identify good practice and helping providers to develop cultural competence. The Task Group is currently exploring potential hosts for such a reference group.

Box 1 Key objectives emerging from the tabletop discussions held during the seminar

- Produce a report (this article) from the event that will advise and inform relevant regional and national bodies.
- Develop an expert reference group for BMER issues and dementia services for London.
- Ensure that the expertise of BMER communities is recognised and valued.
- Improve the clarity of the accountability structures for commissioners.
- Improve the role and financial stability of fourth-sector organisations (i.e. small BMER grassroots groups that struggle to secure funding).
- Larger third-sector organisations need to work more closely with the fourth sector.
- Improve promotion of the work of providers who demonstrate good practice.
- There needs to be more effective publicising of information on dementia to BMER communities.
- Help third-sector organisations to develop influencing strategies and business skills.

Next steps

Whatever final form the new GP commissioning arrangements take, moving the National Dementia Strategy forward across London requires effective engagement with BMER communities, in order to ensure that people from the capital's diverse communities access diagnosis at the earliest possible stage and benefit from early diagnosis. In addition, commissioners must take a proactive approach to targeting early-access messages at BMER communities. Otherwise, late presentation due to cultural stigma and fear of discrimination will remain the norm for BMER patients with dementia. This leads to an increased risk of the problems associated with comorbidities, severe carer burden and unmet cultural needs that characterise such late presentations.

A small but significant body of work already exists, collated by the Task Group in its *Resources Handbook*, which provides background information, materials and guidance for commissioners to begin to work on engaging with BMER communities to improve early access to diagnosis for dementia. There are also a number of BMER community groups, a small proportion of whom attended the June 2010 seminar, who are keen to work with commissioners to improve early access and to have a role in providing support services to people living with dementia and their carers. The *Dementia Services Guide* provides a road map to help commissioners to align the role of community organisations with an integrated dementia pathway. Emerging findings from the Hackney Peer Support Project (see Box 2) illustrate some novel but replicable approaches to reaching out to BMER communities and stimulating increased dementia awareness and community peer support. Many other BMER community groups working with people living with dementia could be more supported in delivering such approaches.

Box 2 Hackney Peer Support Project

- Hackney is one of the most culturally diverse boroughs in London. More than 100 languages are spoken in the borough.
- The project is one of 40 pilot sites (known as demonstrator sites) that were set up following recommendations in the National Dementia Strategy for England.
- The project targets groups from BMER populations that are under-represented in terms of access to dementia support by engaging with representatives from four identified groups to develop support networks that reflect the specific requirements of those communities.

To do nothing risks adding to the economic challenges for commissioners in London in the future, as the population of settled elderly people from BMER communities who are living with dementia increases. Individual and carer costs per case will be high if diagnosis is late. Modest initiatives begun now could support a developing partnership with BMER third-sector organisations for dementia service development. These initiatives include working to improve dementia awareness, to improve access to early diagnosis, and to develop effective and appropriate support services linked to the integrated dementia care pathway set out in the *Dementia Services Guide*. This is an opportunity to initiate a more thoughtful and co-operatively managed approach to this long-term healthcare issue that will increasingly challenge London's commissioners over the next 10 years and beyond.

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CONFLICTS OF INTEREST

None.

ADDRESS FOR CORRESPONDENCE

David Truswell, Dementia Implementation Lead, Commissioning Support for London, Stevenson House, 75 Hampstead Road, London NW1 2PL, UK. Email: David.Truswell@nhs.net

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