

## Inclusion of people from Black, Asian and other minority ethnic communities in research on dementia.

### How getting a haircut and playing Mahjong enhanced a qualitative research study in Bristol in 2016/17.

The aim of this case study is to share some flexible and original ways (or methodology) of hearing from Black, Asian and other minority ethnic (BME) people on a health topic which holds stigma across a range of communities: dementia. Despite the short 8 month time-frame of this study and the fact that only 1 part-time researcher was employed to gather people's perspectives and experiences, a considerable number and range of people took part, from communities often assigned the homogenous label 'hard to reach'. Our approaches to encourage and enable people's participation are arguably of value to share with other researchers, as BME people are frequently invisible in research including clinical research, unless that research has a specific 'race equality' or 'diversity' theme to explore.

The report of this research study was published in February 2017: "*Dementia experiences of Caribbean, Chinese and South Asian people in Bristol*". Available from:

<http://www.bristolhealthpartners.org.uk/health-integration-teams/dementia-hit/research>

#### Background

There are an estimated 25,000 people of Black, Asian and other minority ethnic (BME) origins with dementia in UK; with a forecast seven-fold increase up to 2051, compared to a forecast two-fold increase of white British people with dementia (Jutlla, 2013). Evidence shows that people of BME origins experience dementia in markedly different ways from white British people. For example: diagnosis is more likely to occur at an advanced stage of the illness; the availability of culturally-aware support after diagnosis is variable; and there is lower take-up of mainstream dementia services (APPG 2013; Moriarty, Sharif, Robinson, 2011).

Bristol has a culturally diverse population which is set to increase: 22% of residents are of BME origins (Bristol City Council, 2016) and 50% of children in Bristol nurseries are of BME origins (BME Voice/Voscur, 2017). There are an estimated 2,130 people aged over 65 years of BME origins living in Bristol (Bristol City Council, 2016). Approximately 150 of this cohort are likely to have dementia; under 50% are registered with Bristol Dementia Wellbeing Service. It must be noted that this roughly corresponds with the percentage of the total estimated number of people with dementia in Bristol who are registered with Bristol Dementia Wellbeing Service. This has important implications for local dementia care currently as well as for future strategic planning.

The 8 month research study focused on people of Caribbean, South Asian and Chinese origins in Bristol. I was employed as a Research Associate by UWE in February 2016, to gather the main body of qualitative research evidence for this study which was funded by Public Health/Bristol City Council. The research was carried out on behalf of the '*BME people and dementia in Bristol*'

Steering Group which included representatives from local BME-led voluntary and community sector organisations (VCSOs) Alzheimer's Society; Bristol City Council; UWE; and Bristol Dementia Wellbeing Service. Professor Richard Cheston of UWE (Head of Dementia Research) was my supervisor during this study.

### Key Points

I offer four key points for consideration, regarding how to encourage and enable people from more diverse communities to be research participants:

1. There were already firm foundations of partnership working and support from BME led VCSOs prior to funding being secured to actually carry out the study. This significantly enhanced my opportunities, as soon as I was in post, to raise awareness of the research study and to seek to recruit participants for one-to-one interviews and to establish focus groups. In effect, many doors were already open to me. **This is the first key point: fact-find and develop partnerships as much as possible before funds are secured and/or a researcher employed, to be able to recruit research participants as smoothly and quickly as possible, therefore making more time available for actually hearing from participants.** A referral process was also agreed with several key BME led VCSOs for them to directly pass on contact details of interested potential research participants to me, with consent given from the individuals.

2. The Steering Group had already decided to gather evidence via one-to-one interviews and focus groups. Ethics approval was given by UWE. The Steering Group agreed to focus this study on 3 BME communities, given the 8 month time-frame. Caribbean and South Asian people are the largest groups of older people in Bristol and the UK. People of Chinese origins have hitherto been particularly invisible in other qualitative dementia research studies about BME people and dementia in UK; this was a gap that the Steering Group wanted to try to address. Focusing efforts on 3 BME communities made more effective use of the available time. As soon as I was in post, I visited local BME-led VCSOs, which particularly provide support and services to people from the three targeted BME communities, to introduce myself and the research study; and gain an understanding of ways dementia might be talked about in different communities where English is not people's first language. This undertaking helped me learn around six different linguistic terms for dementia or dementia-like symptoms in Cantonese, Punjabi and Urdu. Using these terms helped me to recruit participants. For example: I visited a local Gurdwara twice which allowed for introductions and some familiarity, as well as the chance to learn some Punjabi words/phrases that could be used to describe typical symptoms of dementia. As a result, six older Sikh men of Indian origins came forward to be interviewed. It is worth noting that although I speak some other languages in addition to English, none of these languages are spoken by the 3 targeted BME groups involved in this study- so I had to learn these words/terms for dementia or dementia-like symptoms.

In total, 48 people were interviewed during April to Aug. 2016. This is the second key point: allowing some time in relevant settings for potential participants to become familiar with a researcher and vice versa can eventually widen the pool of participants.

3. Eight focus groups were held; all based within BME led VCSOs. When interpreting was needed, staff/volunteers at these organisations provided this skill. **Here is the third key point: situating focus groups in venues familiar to people, during regular sessions, opened up access to participation.** This is particularly helpful when trying to hear views on a health topic such as dementia which is often not known or understood and/or has stigma attached to it. Again, I used the terms I had learnt during my outreach phase as well as the English word 'dementia' to encourage people to share views. The focus groups and interviews were all recorded, with consent gained beforehand. In general, the feedback from leaders of BME-led VCSOs indicated that money was better spent on paying for interpreters rather than translating written information materials, if budgets are limited.

4. A mid- point review identified two significant gaps: the views of Caribbean men and of people of Chinese origins. To address the latter deficiency, Bristol and Avon Chinese Women's Group (BACWG) were commissioned to translate the recruitment flyers, participant information and consent forms; funds had been allocated in the small budget from the start specifically for interpreting and translating needs. BACWG made extra efforts once the translated materials were available, to contact potential participants, share the information, and refer to me. Eleven participants of Chinese origins for one-to-one interviews were recruited this way. BACWG were commissioned to provide interpreting for these interviews.

I sought advice from a fellow race equality activist in Bristol - a man of Caribbean origins - about places older men of Caribbean origins might spend time and be comfortable to share views. One suggestion was to seek out certain barbers' shops in 2 parts of Bristol with large Caribbean populations: Easton and St Paul's. With endorsement from Professor Cheston from UWE, I tested this approach, to hear more informally from people hitherto missing in the research evidence. I established connections with three barbers' shops which opened a rich seam of qualitative evidence: opinions, experiences and suggestions from Caribbean men on the topic of dementia.

A similar method was used to hear from more people of Chinese origins: by attending a local Mahjong group twice. The busy activity and noise in this setting ruled out running a formal focus group but I was still able to gain a lot more knowledge about views of people of Chinese origins on this topic. Interpreting was provided voluntarily by the Coordinator of the group, largely because she wanted to access training and skills on this topic herself.

**This is the fourth learning point: the value of pausing during the evidence-gathering stage to reflect on who has or has not been heard from thus far. The ability to admit when gaps do exist; to adapt methodology approaches; and have adequate budget to draw upon if necessary were all vital here.**

Hearing from the two groups cited above brought depth to this small-scale research study as both these groups (Caribbean men and people of Chinese origins) are noted as being less likely than other groups to seek medical help on or to contribute to research related to mental health.

## Some key findings and ideas for action

Briefly, some of the research's findings include: knowledge of dementia varied across these 3 BME communities. For example: Caribbean women were more likely to be knowledgeable about dementia; and had a more flexible attitude towards seeking relevant support and services, than Caribbean men. Older people of Indian origins seemed more open to talk about the topic both with the researcher and each other, than many people of Chinese origins. There was stigma around symptoms of dementia as well as around taking-up of mainstream dementia services. VCSOs led by older people of BME origins play a vital role in educating their members about dementia; signposting to relevant agencies; and providing ongoing support and care of people with dementia and their carers.

Some ideas for action: more sustainable and equitable resourcing of these VCSOs would prepare local dementia care to meet increasing future needs of people of BME origins with dementia. New approaches to share information about dementia risk factors and 'living well with dementia' with BME communities are necessary and were strongly requested by contributors.

## References

1. Jutlla, K. *Ethnicity and Cultural Care in Dementia: a review of the research*. Journal of Dementia Care, 12 (2), April/May 2013
2. APPG (All-Party Parliamentary Group) on Dementia *Dementia Does Not Discriminate. The Experience of Black, Asian and Minority Ethnic Communities*. London: Alzheimer's Society, 2013.
3. Moriarty, J., Sharif, N. and Robinson, J. *Black and Minority Ethnic People with Dementia and their Access to Support and Services*. London: Social Care Institute for Excellence, 2011.
4. Bristol City Council, *Population of Bristol*, July 2016
5. Bristol BME Voice/Voscur, *Manifesto for Race Equality (Batook's Blueprint)*, 2017.

**Subitha Baghirathan**, Research Associate: BME people and dementia, University of the West of England.

For more information about this project email Subitha Baghirathan at [Subitha.Baghirathan@uwe.ac.uk](mailto:Subitha.Baghirathan@uwe.ac.uk)