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A Report on a Survey of the Dementia Information Needs of Black, Asian and Minority Ethnic Communities

David Truswell and Dr. Jay Chauhan April 2018

INTRODUCTION

Despite evidence that people from Black, Asian and minority ethnic (BAME) communities experience discriminatory treatment with UK health services, especially mental health services^{i,ii}, these communities continue to be frequently characterised as ‘hard to reach’ or ‘seldom heard’ by health research establishments or healthcare policy makers. This continues a practice of institutional ‘othering’ of such communities that reinforces the stereotype of them as remote or estranged from health and social care research for reasons entrenched within their culture rather than any shortcomings of the research and policy engagement processesⁱⁱⁱ.



In *Dementia does not discriminate*, an inquiry report from the All-Party Working Party on dementia published in July 2013^{iv} it was estimated that there were 25,000 people from BAME communities living with dementia at the time. This was projected to rise to 50,000 by 2026. As standardised generic estimates of dementia prevalence in the general population were used to project the estimated future numbers it should be also recognised that these numbers are likely to be a significant under-estimate. There is some evidence that rates of vascular dementia and early onset dementia are significantly higher in the African–Caribbean community in the UK^{v,vi} and increasingly it has been suggested that there are raised risks of dementia for the South Asian and Irish communities^{vii}. There are also a number of barriers to accessing dementia care across a variety of BAME communities^{viii}. The *Dementia does not discriminate* inquiry report concluded that “*there is an urgent need to increase awareness of dementia among BAME communities*” (p5).

A basic premise underpinning health and social care provision in the UK is that services have a responsibility to deliver care equitably^{ix}. It is important that in the case of dementia, there are robust, targeted efforts made to ensure advice and information on prevention, support and treatment within BAME communities is achieved in an equitable manner, as there is clear evidence of some communities being at higher risk for the development of the condition. Also, a better understanding of the drivers underpinning these higher risks and improved approaches to interventions that reduce risk in these populations will be valuable for developing risk reduction strategies across the general population.



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The Dementia Alliance for Culture and Ethnicity (DACE) www.demace.com and the Dementia Diversity Xchange Network (DDXN) www.ddxn.org.uk are grassroots organisations committed to raising awareness about dementia in BAME communities and also improving understanding of cultural issues for dementia service professionals. They aim to do this by improving knowledge and encouraging cooperative working through developing partnerships between people living with dementia, their carers, communities, dementia service professionals and commissioners.

DACE and DDXN believe that cooperative developments to improve information and services must include the views and perspectives of people from BAME communities living with dementia, their carers and families and the wider members of BAME communities. The scale of the Dementia challenge across the whole of society means that research organisations, commissioners and policy makers need to involve BAME communities in finding much more imaginative and effective ways to understand and support people living with dementia and their carers together with enabling better access to dementia information and support from dementia services. Good dementia care includes information and support for the whole community that reflects the diverse nature of the UK older population. The full range of that diversity must be included in the conduct of research and the development of support and services. The characterisation of under-served groups as ‘hard to reach’ and ‘seldom heard’ presumes a homogeneity and civic isolation across such communities that can encourage stigma and marginalisation.



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THE SURVEY

1. Methodology

DACE and DDXN used a commercial, low cost public domain survey tool, Survey Monkey, to create a short questionnaire for distribution via social media within a wider programme of national awareness-raising on dementia in Black, Asian and minority ethnic communities conducted by the Race Equality Foundation in late 2017/early 2018. Survey Monkey is a tool developed from market research principles and includes a number of in-built features for analysing responses with available on-line support for those conducting the survey. This approach was taken to contain costs and administrative management of the survey.

The authors developed a short questionnaire for the survey that was intended to be completed by responders in less than five minutes. Questions were developed by the authors that reflected their joint experience over the last two years with giving awareness-raising presentations to a variety of community groups and discussions with people from BAME communities living with dementia, their carers and members of the wider BAME communities. This experience has included awareness raising work with the African-Caribbean, South Asian, Irish and Chinese communities as well as with professionals and commissioners working with dementia services provided to BAME communities. The survey questionnaire and accompanying introductory text can be found in the **Appendix**.

The survey was disseminated through social media network links available to the Race Equality Foundation, DACE and DDXN. The main social media channels were Twitter and Facebook and online newsletters or website current information pages. Many community groups operating in the UK have information websites, electronic newsletters and social media feeds as standard components of their communication and marketing activities. These are often regarded as valued and trusted information sources by the communities they serve.

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The survey ran for a two-month period from mid-December 2017 to mid-February 2018, its distribution supported by the Race Equality Foundation’s information dissemination for its short programme of raising awareness events about dementia in BAME communities. The Race Equality Foundation’s programme of locality-based dementia information sessions for local communities and dementia professionals ran from November 2017 to March 2018. DDXN also disseminated the survey with its publicity materials for its own independent programme of awareness raising events and DACE disseminated the survey via its own and the Twitter feeds of DACE member organisations. After an initial circulation of the survey link with a short explanatory comment, DACE refreshed the Twitter circulation at approximately fortnightly intervals accompanied by a picture ‘meme’ intended to encourage re-circulation by Twitter followers. This had a degree of success in stimulating new responders but over time the effectiveness of this as a stimulus for encouraging new responders declined.

Figure 1 shows examples of the picture memes used to encourage circulation of the survey link.

Figure 1



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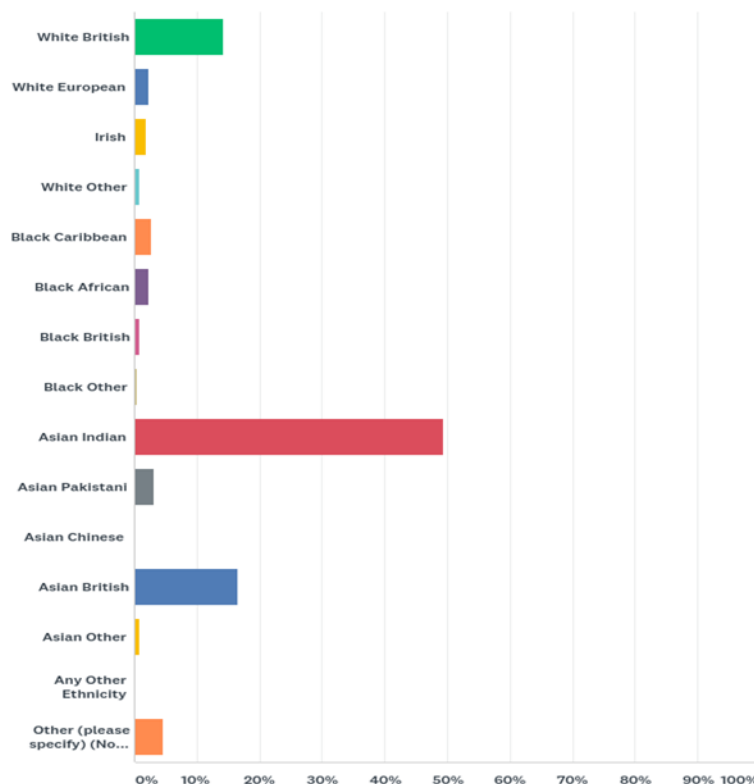
RESULTS

2.1 Ethnicity

219 people responded to the survey. All respondents completed the survey in full taking an average of two and a half minutes. 85.84% of responders defined themselves as having Black, Asian or minority ethnic origin. A breakdown of ethnicity of responders is given in Figure 2.

Figure 2

Q1 What ethnicity you regard yourself as being (Categories used here are from UK National Census)?



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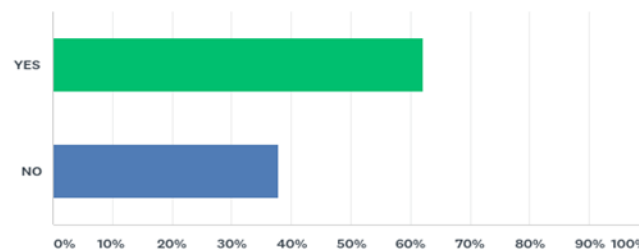
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2.2 Personal familiarity with the issues

62.1% of responders said they personally knew someone from a BAME community living with dementia or caring for someone living with dementia.

Figure 3

Q2 Do you personally know anyone from a Black, Asian or minority ethnic community living with dementia or caring for someone living with dementia?

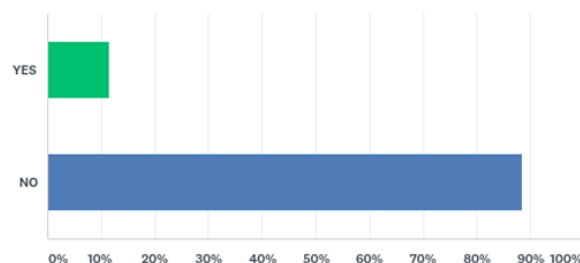


2.3 Current information needs

88.58% of respondents did not feel they had enough information on the specific needs of people living with dementia from BAME communities.

Figure 4

Q3 Do you feel you have enough information on the specific needs of people living with dementia from Black, Asian and minority ethnic communities?



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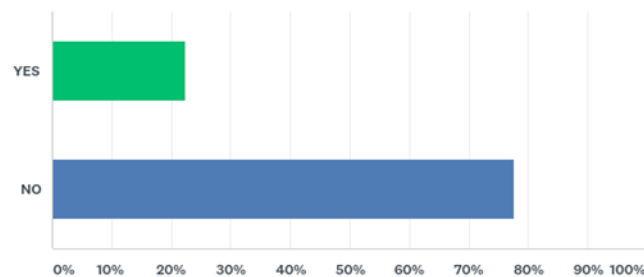
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2.4 Current involvement with BAME organisations providing dementia support

22.37% of responders were directly involved with an organisation providing help and support to people from BAME communities living with dementia.

Figure 5

Q4 Are you directly involved with an organisation providing help and support to people from Black, Asian or minority ethnic communities living with dementia?

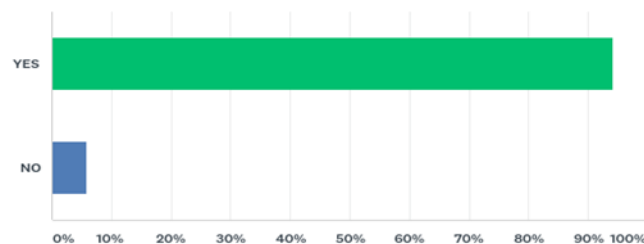


2.5 Support for increased funding to BAME organisations working in dementia field

94.06% of respondents would like to see more funding for community organisations helping people living with dementia from BAME communities.

Figure 6

Q5 Would you like to see more funding for community organisations helping people living with dementia from Black, Asian and minority ethnic communities?



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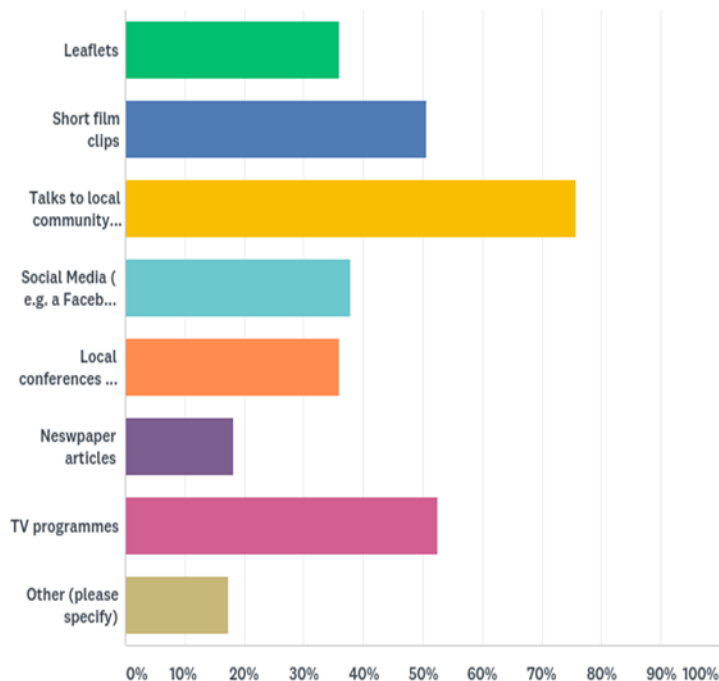
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2.6 Preferred method of information sharing

The results of offering respondents a choice of selecting up to three options for preferred routes for receiving information are shown in Figure 7

Figure 7

Q6 What do you think is the best way to raise awareness about dementia within the Black, Asian and minority ethnic communities (Choose up to 3 options from the list provided)?



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2.7 Additional ‘free text’ responses.

93 responders also provided additional responses to the final open question (Question 7) inviting responders to suggest other ways of receiving information. 73 of these responses were further suggestions or developments from the list of options in Question 6.

Of these 73, 48.7% of these referred to improving publicity about dementia for BAME communities; 14.1% thought this should directly involve BAME community organisations and 6.4% also thought this should directly involve faith groups or religious leaders. 10.2 % of responders highlighted the issue of language barriers and 15.4% of responders highlighted the need for cultural sensitivity training for staff. Specific communities that were highlighted by the responders were South Asian communities, the Irish and Gypsies and Travellers. There were also responders who offered to help with raising awareness, supporting further research or disseminating the survey results.

DISCUSSION

The authors do not contend that the survey provides any more than an investigatory pilot study exploring the views of people from BAME communities about their information needs in relation to dementia. However, the results do provide a number of important indicators that could stimulate further research work and strategic thinking including investment in the development of plans to raise awareness about dementia with BAME communities in the UK. In this instance the use of a simple market research tool has captured a number of useful points for consideration for a modest outlay that benefitted from a nuanced understanding of the target audience.

The methodology captured the views of a primarily ethnically diverse group of responders as was intended (85.84%). A substantial proportion of responders had direct personal knowledge of someone from a BAME background living with dementia or caring for someone living with dementia (62.1%). As only around a fifth of responders (22.37%) were directly involved with BAME organisations working with dementia, this suggests that there may be a significant number of the people from a BAME background living with dementia who do not get support from BAME community organisations. This is an area that would be useful to explore in more detail.

A substantial majority of responders, including those of white UK ethnicity, expressed an interest in knowing more about dementia in BAME communities (88.58%) and that more should be done to support funding for BAME community groups working with dementia (94.06%).

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Information talks for community groups had a clear lead as the main preferred method for raising awareness about dementia, but the use of video-based information was also strongly supported by about half of responders. Of interest was that the use of leaflets and social media had very similar levels of support from responders, about a third of responders in both cases. This would normally encourage researchers to use a combination of communication and engagement tools to maximize take up and involvement. Free text responses revealed a variety of further options, either on developing further detail based on the options selected from the list in the survey or by making new suggestions or commenting on the survey itself.

Health researchers and policy makers can fail to engage with a diverse representation of those using dementia services, their carers or others involved personally with their care and support. The authors would contend this is less a result of some essential characteristic of these under-served groups but more often can reflect the rigidity of research engagement practices. More creative and flexible engagement with the recruitment of BAME communities into research, for example that shown by recent work in Bristol⁸, continues to be the exception rather than the rule. Developing further research to explore either at scale or in finer detail some of the findings from this survey would require a more substantial financial investment.

However, financial or resource constraints should not be a barrier to an initial and local exploration of concerns regarding dementia information and services with local BAME constituencies in a granular way modelled on the methodology outlined here. This could easily be adapted to elicit input for example into local Joint Strategic Needs Assessments (JSNAs).

It would be relatively straightforward and low cost to replicate this survey method on a regional or local basis with the support of local community groups and the utilisation of the current communications systems readily available at Trust or local authority level anywhere in the UK. Currently the BAME dementia research narrative can be paralysed by inaction with concern about the difficulty of achieving adequate and proportional responses from the so-called 'hard to reach' groups. The survey results here suggests this does not reflect the willingness of BAME communities and other under-served groups to engage with research inquiry. A significant and useful level of response was achieved by this pilot study disseminated in an online format in English, generating a nuanced level of responses from a community of largely BAME responders. Those that replied were ready to respond to an accessible approach and their answers showed a wide-ranging understanding of contemporary information media and communication methods.

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The survey demonstrates the success of a more thoughtful appreciation of communication channels currently in use across a number of BAME communities. The inquirer's information request was embedded within the existing features of these channels providing a vehicle for collecting useful and nuanced information. This approach has captured information that could be further developed both at scale and in depth with BAME communities to support effective dementia awareness raising with preventative benefits.

A clear implication from the responses to this survey would be the need for a multi-faceted approach to meeting BAME dementia information needs. This approach would appreciate a variety of modalities that are readily used by BAME communities, ranging from interpersonal methods and discussions to written information and contemporary digital technologies. This also shows the challenge involved in improving whole community health awareness rather than focusing on a demographic sub-set of BAME communities that may only normally access specific information or media.

LIMITATIONS OF THE SURVEY

A sub-set of the full set of the 2011 Census categories for ethnicity was used and a number of organisations and individuals that contributed to the dissemination of the survey felt that a larger set of the Census categories should have been used.

Financial constraints meant the option of 'boosting' the Facebook posting of the survey link was not undertaken and this will have significantly limited the number of responders.

Although one of the authors is a carer of someone living with dementia, it is anticipated that any future iterations of the survey would be supported by a small advisory group also including people living with dementia to guide the development of questions and format.

It would have been useful to ask responders to identify gender and age cohort information to provide more detailed information regarding preferred information routes.

We need to test the value for respondents in providing the survey in alternative languages and formats. Comparative sample groups of modest size would be one way to explore whether this would result in a significant difference in preferred information routes.

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SUMMARY

This survey of the Dementia Information Needs of Black, Asian and Minority Ethnic Communities used a readily available commercial survey tool, Survey Monkey, to explore the views of people from BAME backgrounds regarding their information needs with respect to dementia and its impact on BAME communities. Responses indicate that while people from a BAME background would, overwhelmingly, like more information that they have currently, a majority would prefer to have the information provided through personal presentations to local groups. However, responders also indicated that a wide range of information approaches from print based to digital social media would also be considered beneficial. While the survey provides a pilot study of the views of a largely BAME population of responders it is recognised further work needs to be done either at scale with the same methodology or in detail with smaller groups. It will be important to test alternative versions of the survey that could be more accessible to the target groups.

The success of the survey in reaching its target population despite its modest financial and resource outlay reflects the use of existing digital communication routes that are now standard for routine information exchange by many members of the BAME community. This suggests that the characterisation of BAME communities as ‘hard to reach’ is an unhelpful distortion of the willingness of the communities to respond to creative attempts to explore their views on dementia. The approach taken could usefully form the baseline for a regional or local iterative approach to exploring local BAME communities’ dementia information and support needs.

Currently the limited exploration to enhance understanding of the information and support needs of BAME communities with regards to dementia fails to address inequity in provision. This is despite the evidence that some BAME communities have higher risk of dementia than the mainstream population. As this higher risk involves vascular dementia, a form of dementia with well accepted and advocated preventative strategies, these persisting inequities need to be urgently addressed. The current limitations at the research and policy level to address this inequity should be challenged, and a programme for widening involvement developed in order to provide more accessible services that are more likely to reach people from BAME communities who may be at risk from Dementia or experiencing the signs or symptoms, and their families and carers.

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ABOUT THE AUTHORS

David Truswell is an independent writer and researcher on dementia and its impact on Black, Asian and minority ethnic (BAME) communities with over 30 years’ experience in mental health services encompassing the voluntary sector, local authorities and the NHS. He is a Trustee of Culture Dementia UK, an organisation that provides information, support and advice to people living with dementia and their carers in the Black, Asian and minority ethnic communities. He is also the founder and Director of the Dementia Alliance for Culture and Ethnicity (DACE), a support, advice and information hub for community organisations providing dementia support services to BAME communities.

Dr. Jay Chauhan is a Doctor of Philosophy and Director of AmbaCare Solutions CIC linking health and social care, housing and regeneration and is the founder of Dementia Diversity Xchange Network. He is a highly skilled professional, with extensive senior management experience within the statutory, public and voluntary sectors. He has developed general and special needs housing and social care schemes across the West Midlands. For the past 14 years, Jay has worked in the NHS across both the Acute and Primary Care settings and was involved in developing and supporting a number of acute and community-based initiatives. He has extensive experience and understanding of the needs of BAME Communities. He is seeking to develop an Integrated BAME Mixed Tenure Health & Social Care Housing Village, which will include dementia units for BAME communities.

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APPENDIX

Introductory Text

Dementia Diversity Xchange Network (DDXN) and the Dementia Alliance for Culture & Ethnicity (DACE) are hub organisations committed to helping all community groups raise awareness about dementia in Black, Asian and minority ethnic communities. We are working together to make the case for better public recognition of the information and support needed by people from Black, Asian and minority ethnic communities living with dementia and their family carers. You can help us make our case to central government to improve information and support by completing our survey on information needs

Survey Questions

Q1 What ethnicity you regard yourself as being (Categories used here are from UK National Census)?

Q2 Do you personally know anyone from a Black, Asian or minority ethnic community living with dementia or caring for someone living with dementia?

Q3 Do you feel you have enough information on the specific needs of people living with dementia from Black, Asian and minority ethnic communities?

Q4 Are you directly involved with an organisation providing help and support to people from Black, Asian or minority ethnic communities living with dementia?

Q5 Would you like to see more funding for community organisations helping people living with dementia from Black, Asian and minority ethnic communities?

Q6 What do you think is the best way to raise awareness about dementia within the Black, Asian and minority ethnic communities (Choose up to 3 options from the list provided)?

Q7 Do you have any further suggested information or comment on the survey (word limit 100 words)

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