BAME Vision – BRAVO VICTOR Insight meeting introduction summary

Your voice matters – Visual impairment in minority ethnic communities in the UK

1. Who are we?

BAME Vision is a volunteer led committee made up of people from both the eye health and sight loss sectors, as well as those with lived and learned experience. You can find out more about BAME Vision and the work we do, by looking through our website – www.bamevision.org. Our mission is - To tackle the inequalities which prevent ethnically diverse communities from making informed choices relating to their sight by empowering, engaging, and connecting with all stakeholders. Our Vision is - Ethnically diverse communities can make informed choices about their care and wellbeing relating to their vision.

Our key priorities we are focussing on are:

Lack of engagement from professionals and organisations claiming ethnically diverse communities are "hard to reach".

Lack of access to eye care information in a format and language ethnically diverse communities understand, from point of diagnosis onwards.

Negative attitudes and cultural barriers to sight loss within all communities.

Gaps in data about eye care, eye health and sight loss in ethnically diverse communities.

BRAVO VICTOR is a research charity which conducts biomedical, innovation and social & welfare research for the benefit of people living with visual impairment. We are a sister charity in the Blind Veterans UK Group.

2. Project background.

BAME Vision formed in 2020 and soon discovered that there was either no data or only anecdotal data relating to eye conditions, service use and other factors concerning blind and partially sighted people from minority ethnic communities. For example, we found no evidence concerning prevalence of eye conditions and vision impairment among different communities, or, even how many blind and partially sighted people from a particular community had accessed a particular pathway service. There was nothing to push for better outcomes, services or provision. We knew really fast that this had to change.

In 2022, BRAVO VICTOR and BAME Vision joined forces to conduct a rapid evidence review of academic and grey literature to explore the experiences of people from minority ethnic communities who have a visual impairment in the UK. As part of this, we screened 969 academic articles, only 8 of which were included in our final review article and a further 3 were found when reading these articles. We also searched the websites of charities and organisations in the visual impairment sector for relevant research reports. For the purpose of the article, we excluded research which presented findings relating to prevalence and/or risk of visual impairment and children because of the different needs of children. A final peer-reviewed article was published in 2023 in Frontier in Public Health summarising findings relating to everyday experiences, experiences along the eyecare pathway and support needs

drawn from In 11 academic articles and 4 charity reports:
https://www.frontiersin.org/articles/10.3389/fpubh.2023.1119540/full.

3. What did we find?

1. There are substantial gaps in the evidence relating to everyday experiences of living with visual impairment, experiences along the eyecare pathway and support needs among different ethnic communities in the UK.

2. Much of the available evidence was older and/or anecdotal.

4. What next?

To fill some of the gaps identified in the review we applied for funding and have received ethical approval for a research programme on "Visual impairment in minority ethnic communities in the UK".

The aim of this programme of research is to explore the everyday experiences of living with visual impairment, experiences along the eyecare pathway and support needs of adults from different minority ethnic communities in the UK.

Data will be collected initially in a series of semi-structured interviews. These will be followed by a survey to reach a wider group of people.

To ensure this research is relevant and appropriate:

1. We will focus on individual communities and treat each community as a separate research project
2. We are inviting input from members of the communities into the topics to explore and how best to engage with their communities
3. We will recruit community partners to lead on participant recruitment and data collection
4. We will offer the research in different languages

There are limitations on the languages we will be able to offer. This will be driven by the languages spoken by the community partner. There are further limitations on the communities included in this research. This will depend on the funding we can secure and successful recruitment of community partners.

5. Example: Visual impairment in Chinese communities in the UK.

Recruitment is due to start on a pilot project on visual impairment in Chinese communities in the UK (https://www.bravovictor.org/participateinresearch-visual-impairment-in-chinese-communities-in-the-uk)

Community partner: Yanan Yu is a Research Assistant Intern at BRAVO VICTOR. She is originally from China and has a visual impairment. Yanan is responsible for participant recruitment and data collection and was involved in developing the interview schedule and other materials.

Languages: All materials have been translated into Chinese (simplified) and Yanan is able to conduct the interviews in English or Mandarin.

Recruitment: Community organisations supporting older Chinese adults and those living with visual impairment have been identified to help with recruitment.

6. Q&A.

What are the topics we should explore in the interviews and survey?

What is the best way to engage with members of your community?

7. Next steps.

We now need to recruit community partners. They will ideally have research experience, speak at least one of the main languages other than English spoken in their community and have a visual impairment themselves.

We will also need to source funding to be able to add multiple communities to this research programme.

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