

Experiences and understandings of dementia among Black, Asian and Minority Ethnic (BAME) Groups in Wales: community individual and intergenerational perspectives.

<https://neurodegenerationresearch.eu/survey/experiences-and-understandings-of-dementia-among-black-asian-and-minority-ethnic-bame-groups-in-wales-community-individual-and-intergenerational-perspectives/>

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Experiences and understandings of dementia among Black, Asian and Minority Ethnic (BAME) Groups in Wales: community individual and intergenerational perspectives.

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Research Abstract

This research will explore the experiences and understandings of dementia of people from BAME communities. It will consider: community responses, experiences of people with dementia and their carers, social networks and social support, interactions with formal care, access to services and intergenerational relations. Whilst there is a growing literature on the health needs of BAME older people, research on dementia remains sparse. However, we know that minority groups are underrepresented in dementia services. The existing literature points to lack of awareness about dementia; lack of or late diagnosis; stigma; inappropriate service provision; and assumptions about the caring capacity of extended family networks. Existing research stresses a need to understand the ways in which BAME communities conceptualise and understand dementia in order to provide more relevant services and to train providers.

The numbers of older BAME people in Wales will grow substantially in the future. This will translate in to higher demand for health services generally and accordingly greater numbers of people with dementia and at risk of dementia in these groups.

This research will adopt a 'grassroots' approach, undertaking community based research in South Wales (Cardiff, Swansea and Newport) working with Community Groups and Services, Third Sector Organisations and Places of Worship. We will undertake focus groups in these settings, exploring issues relating to ageing, health and social needs in general and dementia in particular. Where individuals in these locations identify as having dementia, one to one interviews will be arranged to build up more detailed explorations of conceptualisations of dementia and experiences of care. We will also interview younger family members to examine the impact of dementia on intergenerational relations. Where formal care services are involved we will interview care providers to build up a full picture of care provision.

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