



Leave no-one behind

Improving pathways to dementia information, early assessment, and support for older people from minoritised and racialised backgrounds in Wales



Research Briefing Paper

Evidence Review & emerging research priorities

July 2021

Acknowledgements

Diverse Cymru is a pan-Wales equality and diversity charity – working to ensure equality for all. Diverse Cymru’s vision is to help create a nation without prejudice or discrimination, where every person is equal and diversity is celebrated, and our mission is to eliminate discrimination and inequality. We have a staff team of experts and are supported by a strong board of trustees. Diverse Cymru specialises in several fields:

- BAME Mental Health Projects (adults, children and young people)
- BAME Workplace Good Practice Certification Scheme
- BAME Dementia (Policy)
- Advocacy
- Direct Payments support
- Community engagement, research and consultancy

Suzanne Duval, Diverse Cymru’s BME Mental Health Manager has been conducting pioneering work in BME dementia in Wales for the last three years and this Brief has been shaped by her vision, passion and stewardship. Drafted by Dr Roiyah Saltus (University of South Wales), who has worked and conducted research with Suzanne Duval in the field of mental health for nearly 20 years. The Brief also benefits from discussion with and invaluable input by Dr Sofia Vougioukalou (Cardiff University). Professor Mark Johnson (Bradford University) provided specialist advice and expertise in terms of reviewing the draft. Lastly, we thank all those who have helped and supported us over the last 3 years for sharing their experiences and adding their voices, talents and knowledge to the Black Asian and Minority Ethnic dementia arena in Wales. We acknowledge and owe a debt of gratitude to:

Faith Walker & FW Consultancy

Aisha Jenkins

Humie Webbe

Jacqui Ayres

Anne Mears-Rees

Shelagh Maher

David Truswell

Mohammed Akhlak Rauf

Councillor Daniel De’Ath

Gaynor Legall

Zoe King

Samira Salter

Kay Denyer
Helen Joy
Nubian Life
Dementia Alliance for Culture & Ethnicity
The Yemeni Community Centre
Travelling Ahead – Gypsy, Roma and Traveller Advice and Advocacy Service
Nexus
Cardiff and Vale Action for Mental Health (CAVAMH)
Race Council Cymru
Public Health Wales
Social Care Wales
Alzheimer’s Society
3 Nations Dementia Working Group (3NDWG)
Mark R D Johnson, Emeritus Professor of Diversity in Health and Social Care at
De Montfort University Leicester UK

Download

This document is available to download as a free PDF and in other formats at:

[XXXX](#)

Citation: If you are using this document in your own writing, the preferred citation is:

Saltus R, Duval S & Vougioukalou S (2021) Leave No-one Behind: Improving pathways to dementia information, early assessment, and support for older people from minoritised and racialised backgrounds in Wales – Research Briefing Paper. University of South Wales, Pontypridd

©2021 Diverse Cymru

Leave no-one behind

An estimated 25,000 people of Black, Asian and Minority Ethnic (BME) origins live with dementia in the UK – a number which is expected to increase sevenfold by 2051. People from many minoritised communities experience dementia in a markedly different way to their white British counterparts. The fight for a myriad of effective information pathways, quick diagnosis, and person-centred care systems that address the health as well as psychosocial support requirements of those with dementia has long been a research, practice and policy priority. We need to build our understanding of how best to improve the lives of people living with dementia and their families and carers. Understanding the ways BME people living with dementia and their carers seek information, and how they experience the assessment process, and live with dementia is a critical step. In the coming decades the UK's older demographic will increasingly become more diverse and thus the need for dementia services to improve how people access their screening and assessment services, to enhance their models of early intervention and to develop meaningful messaging and information platforms will become that more pressing.

Moreover, the pandemic has raised the spectre of health inequalities and the disproportionate impact of dementia on population groups – not least those from Black and Minority Ethnic backgrounds where the existing evidence base is patchy and nascent. In order to (i) capture the accelerated interconnections across sectors, (ii) draw on the impact of the overhaul of existing systems and process, that cross many boundaries, and (iii) move forward, rooted in the learning and innovation that is taking place in ways that address social and health care issues exacerbated by the pandemic crisis, such work is needed. Given the Welsh Government commitment to deliver a new 10-year dementia action plan in the coming two years, not to gather necessary evidence may lead to the further cementing of health and social inequalities in the field of dementia. This work needs to be done now. In Wales, the work to be done must be noted, alongside the need for work in this area to accelerate. This report provides a (i) scoping overview of the evidence base (ii) summaries of recently completed scoping studies and engagement work undertaken by Diverse Cymru and (iii) proposed research programme to be taken forward.

1. Introduction

There are several reasons why a programme of dementia research with a focus on older people from minority ethnic backgrounds living in Wales is urgently needed. First, dementia is a global public health priority. In 2015, dementia overtook heart disease and stroke as the UK's biggest cause of death and in 2017 it was one of the top four causes of death (along with heart disease, stroke and lung cancer).¹ Second, as will be explored in further detail below, BME² people in the UK are more likely to develop certain dementias than white ethnic groups, but they're much less likely to be diagnosed and get support.³ It is estimated that in the next 40 years that there will be a 7-fold increase in the BME population and only a 2-fold increase in the White community⁴. However, despite the rapidly ageing population and a predicted sevenfold increase in the prevalence of dementia in minority ethnic communities, people from these communities remain under-represented in specialist dementia services⁵.

Lastly, dementia is the most common pre-existing condition for people who are dying from Covid-19 and for the 25,000 people from Black, Asian and minority ethnic (BAME) backgrounds living with the condition across the UK, the social restrictions imposed during lockdown have made an already

¹ <https://www.alzheimers.org.uk/blog/research-dementia-UK-biggest-killer-on-the-rise>
Accessed: 6/01/2020

² The use of the term 'minority ethnic group' emphasises three things, namely that everyone is from an ethnic group, that some ethnic groups are smaller than others and that the impact of minoritisation (and with that racialisation) means that many people from minority ethnic backgrounds face a host of intersecting social inequalities that impacts on all aspect of their lives. Mindful of the ongoing contestation around terminology we will refer to these grouping as minoritised, and also when referring to specific groups we will use the term racialised. We will also use the term Black and Minority Ethnic (BME) people, communities and populations with the clear understanding that lived experiences, life outcomes and perceptions between and among individuals and groups will vary.

³ Health and Social Care correspondent, Victoria Macdonald report 8 August 2018 - <https://www.channel4.com/news/black-people-more-likely-to-develop-dementia-than-any-other-ethnic-group-study-shows>

⁴ The All-Party Parliamentary Group on Dementia (2013) https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg_2013_bame_report.pdf Accessed: 6/01/2020

⁵ Parveen, S., Peltier, C., & Oyebode, J. R. (2017). Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. *Health & Social Care in the Community*, 25(2), <https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12363> . Accessed 26/04/2021

challenging time even more difficult⁶. COVID-19 has disproportionately affected those of a Black, Asian and minority ethnic (BAME) backgrounds in the UK, with members of these populations dying from COVID-19 at twice the rate of the White population, as well as contracting COVID-19 at higher rates. COVID-19 has also had a disproportionately high effect on older adults, including those with dementia. As of February 2021, Wales and the rest of world remains very much in the grip of the Coronavirus pandemic. However, there is an urgent need to begin now to plan for how best to move out of national lockdown and to a post-pandemic world. This will coincide with the new Dementia strategy to be developed over the next two years. The Dementia Action Plan for Wales 2018 – 2022 made no detailed action plans or decisions for BME people and their carers living in Wales, despite very clearly indicating that all social groups need to be considered in all aspects of planning and delivery.⁷ That is, that no-one would be left behind. With a specific focus on people from minoritised and racialised backgrounds, the work currently being conducted by Diverse Cymru is seeking to build a strong platform in which to shape dementia policy, practice and research in Wales.

1.1 What we already know

People from many BME communities experience dementia in a markedly different way to their white British counterparts. For instance, diagnosis is more likely to occur at an advanced stage of the illness, while there is a lower take-up of mainstream dementia services^{8,9}. There is evidence that ethnic

⁶ Race Equality Foundation (2020) <https://dcan.org.uk/news/race-equality-foundation-covid-dementia-projects-coming-to-an-end/> - Accessed: 6/01/2020

⁷ The Dementia Action Plan for Wales 2018 <https://gov.wales/sites/default/files/publications/2019-04/dementia-action-plan-for-wales.pdf> - Accessed: 6/01/2020

⁸ All-Party Parliamentary Group on Dementia (2013). Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities. <https://dementiaroadmap.info/resources/dementia-does-not-discriminate/#.YlabhC1Q2gA>

Also Parveen S, Peltier C, Oyebode JR. (2017) Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. Health Soc Care Community. 2017 Mar;25(2):734-742. doi: 10.1111/hsc.12363. <https://pubmed.ncbi.nlm.nih.gov/27278859>

⁹ Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P., & Currie, K. (2018). A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished. Dementia, <xocs:firstpage xmlns:xocs=""/>. doi:10.1177/1471301218804714

minority groups seek less support from services.¹⁰This may be due to increased stigma, alternative health and religious beliefs, reduced knowledge about dementia and a perceived lack of culturally tailored care.¹¹ For example, a recent study that explored perceptions of dementia in British Indian, African and Caribbean, and East and Central European communities in UK revealed the need to be attentive to the role of religion (as opposed to medical healthcare services), as a form of personal and treatment control, limited knowledge awareness of services, and culturally specific barriers such as language revealing – as some many studies have shown across the gamut of health issues facing BME groups in the UK - the ongoing need to focus further on reducing barriers to accessing services¹².

Challenges related to the provision of intercultural care and support include:

- Lack of relevant information about dementia and services and its dissemination
- Stigma and shame – both societal and on a community/sub-group level
- Outdated perceptions including that “they look after their own” and do not want support
- People with dementia from minority ethnic groups are absent from research.
- Failure to reach carers
- Insufficient focus on religion and spirituality or everyday patterns of care and life
- Multiple jeopardy based on intersecting oppressions (e.g., linked to the stigma of dementia and to actual or perceived racism, sexism, sexuality, ageism, prejudice against migrants, health literacy and lower socio-economic status). Prior experience or the expectation of discrimination and prejudice, and prior experience of poor-quality care
- Lack of cultural competence of health and social care professionals

¹⁰SCIE Research briefing 35: Black and minority ethnic people with dementia and their access to support and services. (Research Briefings). Social Care Institute for Excellence. https://kclpure.kcl.ac.uk/portal/files/13501330/SCIE_briefing.pdf

¹¹ Daker-White, G., Beattie, A.M., Gilliard, J. and Means, R. (2002) 'Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice', *Aging & Mental Health*, vol 6, no 2, pp 101–108; Mukadam, N., Cooper, C. and Livingston, G. (2010) 'A systematic review of ethnicity and pathways to care in dementia', *International Journal of Geriatric Psychiatry*, <http://dx.doi.org/10.1002/gps.2484>

¹² Parveen, S., Peltier, C., & Oyeboode, J. R. (2017). Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. *Health & Social Care in the Community*, 25(2), <https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12363> . Accessed 26/04/2021.

In the UK, older people with Asian Indian, Black African and Caribbean backgrounds are more likely to develop dementia more often and at younger ages than their White and other minority ethnic counterparts. This is mostly likely because of migration history, the fact that these groupings having the largest proportion of older groupings. Despite this, we know very little about how Black African and Caribbean people perceive dementia, their view on receiving diagnosis and treatment or about their expectation of dementia services. Black African and Caribbean people tend to use dementia services much later, often when they are in crisis or no longer able to cope alone. They are also less likely to receive drug treatments, take part in dementia research and move into a care home¹³. This knowledge, however, is essential to ensure that dementia care is culturally appropriate – whether it is delivered in the homes of people living with dementia, GP services or care homes.

One particular group of importance are those who can be identified under the umbrella term Gypsy, Roma and Traveller (GRT) communities. In ways like other minoritised and racialised populations, the traveller community experience a host of health and social inequalities and marginalisation that lead to very low health outcomes. Importantly, traveller health is worse than that of the general population or non-Travellers in deprived areas and for those who are mobile, access to health and social support is that much more difficult^{14 15}. Although there is growing evidence on traveller health, the impact of dementia on this population group is very limited. Moreover, although the life expectancy of this population grouping remains comparative low in the

¹³ Mukadam, N., Cooper, C., Basit, B. and Livingston, G., 2011. Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, 23(7), p.1070 https://www.researchgate.net/profile/Naaheed-Mukadam/publication/50195273_Why_do_ethnic_elders_present_later_to_UK_dementia_services_A_qualitative_study/links/54e327140cf2d618e195ed38/Why-do-ethnic-elders-present-later-to-UK-dementia-services-A-qualitative-study.pdf

¹⁴ Truswell D, (2013) Black and Asian Minority ethnic communities and dementia – where are we now? . Better Health Briefing 30. London. Race Equality Foundation - <https://raceequalityfoundation.org.uk/health-care/black-and-minority-ethnic-communities-and-dementia-where-are-we-now/> Accessed 26/04/2021

¹⁵ Tilki M, Curran C, Moloney K, Jones H, Rogers E (2016) Reaching out effectively to Gypsies and Travellers. *Journal of Dementia Care* 24, 5, 12-14 - https://www.dementiaaction.org.uk/news/26692_dementia_in_gypsy_and_traveller_communities Accessed 26/04/2021

UK^{16,17}, there is growing evidence of dementia in these communities. In our scoping review we found very little evidence to draw on and conclude that this group is one of particular importance in any future work in this area.

Lastly, we know that the community and voluntary sector has played a key role in the health and wellbeing of people from BME backgrounds in the UK. Recent findings on work commissioned by EYST has revealed the vital role played by the sector during the pandemic and the importance of building on the gains – the new ways of working and cross-sector connections – as we move beyond the crisis of the pandemic¹⁸. A recent study exploring experiences of caregivers for family and friends living with dementia from South Asian, African Caribbean and Chinese communities in Bristol found that there is a need to acknowledge and more equitably resource dementia care within BME-led VCISO as they were key to how people were managing their lives with dementia¹⁹. An important concept that emerged was that of the ‘fear of diminishment’ which revealed both the awareness and need for support but not at the cost of being diminished as a person. It was that fear that led some to seek support from trusted community-based, BME-led organisations.

1.2 Note on reach and impact of Pandemic

In England, research funded by the Alzheimer’s Society includes (i) the impact of Covid-19 on dementia in Black and Minority Ethnic Groups to people with dementia and to their carers, (ii) an investigation of the role of obligation, willingness and preparedness for caregiving within South Asian communities, (iii) a study exploring how African-Caribbean and Irish communities view and cope with dementia to underpin intervention models, and finally (iv) the scaling up of a longitudinal study to include people from minority ethnic

¹⁶ Ryan, L, D’Angelo, A, Puniskis, M and Kaye, N (2014) Analysis of 2011 Census data. Irish community statistics, England and selected urban areas: Report of England. Irish in Britain/ Middlesex University

¹⁷ https://www.dementiaaction.org.uk/news/26692_dementia_in_gypsy_and_traveller_communities#

¹⁸ Saltus, R (2021) Holding on to the gains. The impact of COVID-19 on the BME Communities in Wales. USW, Pontypridd. <http://www.eyst.org.uk/assets/holding-on-to-the-gains151220.pdf> Accessed 26/04/2021

¹⁹ Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P., & Currie, K. (2018). A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished. *Dementia*, doi: <https://doi.org/10.1177%2F1471301218804714>

communities on how best to live well with dementia²⁰. What is evident is a growing awareness of repeated issues facing BME groups in terms of health and social care, with this informing a list of challenges recently published in the area of dementia care (see side bar above). In Wales, evidence of the impact the pandemic is having on older BME people with dementia has yet to emerge.

The scoping body of evidence outlined above is the framing in which the current programme of work conducted by Diverse Cymru is rooted. What follows is a summary of the work undertaken by Diverse Cymru and by colleagues at Cardiff University which provides a clear steer for the next phase of research and engagement work.

Diverse Cymru's current research

The Welsh Government has funded Diverse Cymru to work on a programme of engagement and research on BME people with dementia/their carers/families, with a focus on what services they receive, if they are happy with those services and what would a good service look like to them. In terms of the current evidence compiled by Diverse Cymru, two reports have been produced.

2.1 Let's Talk about Dementia – End the Stigma report (2020)²¹

World Alzheimer's Month is the international campaign every **September** to raise awareness and challenge the stigma that surrounds dementia. September 2019 was the 8th World Alzheimer's Month. On 19 September 2019, at a free event which was hosted by Diverse Cymru. Around a hundred people from across the UK gathered in Butetown Community Centre to talk about Dementia, exchange stories and experiences and foster connections between families, service organisations and commissioners.

²⁰ Policy briefing on intercultural care and support (2020) – <https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2020-Policy-briefing-on-intercultural-care-and-support/Challenges-related-to-the-provision-of-intercultural-care-and-support#:~:text=Challenges%20related%20to%20the%20provision%20of%20intercultural%20care,values%20of%20many%20people%20from%20minority%20ethnic%20groups>

Accessed 9/02/2021

²¹ Lets Talk about Dementia – End the Stigma Report (2020) <https://www.diverseecymru.org.uk/wp-content/uploads/Lets-talk-about-dementia-report-for-web.pdf> Accessed 9/02/2021

The event was hosted as part of Diverse Cymru’s BAME Dementia Project. This project was established due to anecdotal evidence that people from BAME communities are not accessing dementia services across Wales for a number of reasons. The aim was to begin to explore how best to support more families to access support and to map out gaps in information pathways, assessment, service provision and support management. Speakers shared their experiences of caring for those with dementia, the value of stories, and of family. The Lord Mayor Councillor Daniel De’Ath highlighted the importance of good service, and Stevie Wonder’s beautiful ‘Yester Me, Yester You, Yesterday’ capped off powerful stories of love, heartache, and hope delivered by three Caribbean carers. Mohammed Akhlak Rauf MBE travelled from Bradford to talk about his research, the role of culture, (both societal and service) and gave advice on the difficult conversations. Finally, the group broke into table discussions about what good Dementia care looked like, and experience of good, and poor care.

Key findings

1. There needs to be more research by service providers into how BAME people in Wales experience dementia.
2. Service provision should be patient-centred and respect the dignity of the person with dementia.
3. Information on dementia and dementia related services should be provided in a range of formats reflecting the diverse communities
4. More awareness raising and signposting around dementia and dementia services in BAME communities
5. Good practice and high-quality care for people with dementia needs to be consistent across service providers.
6. There must be more support for carers

2.3 “As I Walk the Last Mile of the Way” Report (2021)

A second report “As I Walk the Last Mile of the Way”²² has been written by Faith Walker, Consultant who is one of the three family dementia carers who attended the 2019 conference. The questions asked were taken from the All-Party Parliamentary Group on Dementia: Dementia does not discriminate (2103). The work conducted comprised face-to-face interviews, were held with 7 Caribbean individuals, one carer with an African husband and a focus group series conducted over several weeks with 8 Yemeni women. In addition, an online self-reflection interview was held also with David Truswell Executive

²² The final report was submitted in January and will be mounted on the Diverse Cymru website shortly.

Director, Dementia Alliance for Culture and Ethnicity. He has subsequently joined as an Advisor to the proposed project.

Key reflective points:

1. Greater efforts are needed to ensure that there are services that reflect the diversity of the BME communities, including age and gender
2. Diversity needs to be shown in services and leaflets/posters/communication that reflect the communities
3. Further investigation and experimentation into a culturally sensitive diagnostic framework are strongly recommended
4. Continued efforts are needed to make diversity and multi-culturalism more accessible in private, public sector and third sector organisations
5. Service provision for the African, African-Caribbean, Asian and minorities' ethnic people are made accessible, safe and culturally competent, to address the layers of complexity to the already complex and life-changing challenges facing those living with dementia and their families and carers
6. More culturally informed personal care and support services e.g., personal grooming, diet, health activities, spirituality, leisure and social activities
7. Culturally appropriate end of life care

2.4 “Dementia care experiences – understanding diversity, implementing equality, creating shared learning’ project (2019-2021)

This project was led by Dr Sofia Vougioukalou, a dementia care researcher at Cardiff University and was funded by the HEFCW Enhancing Civic Mission and Community Engagement funding stream. The researcher worked in collaboration with Diverse Cymru and Alzheimer’s Society Cymru to address the significant gap in engaging and understanding the needs of diverse under-represented communities in relation to ethnicity, sexuality and disability who receive dementia care in Wales. This project was selected by people with dementia in Wales as the winner of the Alzheimer’s Society Cymru Dementia Friendly Wales (2021) Diversity Award.

Data was collected through interviews and engagement meetings in community settings between September 2019 and September 2020. More specifically:

- The delivery of five face-to-face engagement events in Cardiff and engaged 80 people from older BAME, LGBT and disability communities.
- 20 1-2-1/group/face-to-face or telephone interviews on dementia care experiences with under-represented groups (PLWD, carers, family members)

and dementia charity workers with a specific inclusion remit), 12 of which were with Black Asian and Minority Ethnic carers.

- The development of three collaborative performances on dementia and ethnicity, hearing loss and sexuality which are being used in dementia care education.¹⁶

The project looked at the role of kinship and identity within care settings. The analysis focused on identifying similarities and differences between the equality strands of ethnicity, sexuality and disability and subgroups within each strand. Even though people with dementia continued to understand English, their speech often reverted to their mother tongue and this caused issues when communicating with healthcare providers who could not understand them. When staff engaged with people's cultural background and language, dementia care became significantly easier for all parties involved.¹⁵

Key recommendations include:

1. Improving capacity for the enhanced supervision of people with dementia in general medical wards in hospitals by decreasing the nurse-patient ratio, involving healthcare support workers and volunteers.
2. Ensuring that all staff in health and social care have a good knowledge of cultural competence in dementia care and related communication skills.
3. Understanding and identifying solutions for the psychosocial needs of people with dementia such as using participatory arts-based activities to engage family members and volunteers in a more targeted way to provide cognitive stimulation and prevent deconditioning.
4. Engage in a more nuanced way with the mother tongue of the person with dementia as this helps prevent agitation and escalation into aggressive behaviour. When it is not possible to use interpreting services over the phone or online, bilingual communication can be facilitated by producing an inventory of additional languages spoken by staff members and deploying them accordingly. Another way is to involve carers in writing down basic words in the mother tongue of the person with dementia for staff to use. If none of the above options are possible, then using free online translation websites can provide a basic solution to communication needs, though the accuracy of the translation is not always guaranteed and might lead to miscommunication. This also applies to the Welsh language even when the person with dementia is fluent in English.

¹⁵ <https://ylab.wales/research/dementia-and-diversity>

¹⁶ <https://www.youtube.com/playlist?list=PLEPkwdTAIW1Hs7vaTZ7Fq4Y7MZKMQ3hiE>

Summary

3.1 The proposed programme of work

Based on the (i) rapid review of the evidence base and the (ii) findings from the above three studies, the following are the **ten research priority areas** in need of future exploration:

- Mapping and piloting pathways to diagnostic assessment for BME people with dementia and their carers
- Capturing the experiences, and perceptions of care and support management from a range of perspectives, with a focus on those least seldom heard as meaningful as forms of evidence, and on experiences of accumulated microaggressions and on personal capabilities and community assets that may impact on later life dementia care journeys
- Capture the support provided by first-tier community and voluntary sector organisations, with a focus on BME-led groups.
- Studies that focus on life in closed institutions such as hospital wards and care homes
- Exploring bilingualism in dementia care, as it relates to people with dementia as well as health and care professionals
- Scoping and enhancing the competencies of key dementia services
- Service delivery studies that explore and test how best to embed and evaluate culturally informed personal care and support services e.g., personal grooming, diet, health activities, spirituality, leisure and social activities
- Piloting effective dementia messaging to people from BME backgrounds
- Participatory studies that focus on the Gypsy, Roma and Traveller communities in Wales
- Studies exploring how best to provide culturally appropriate end of life care

3.2 Key framing considerations

1. The evidence we have gathered to date and those from published research findings indicate methods of data collection which are meaningful and acceptable to the group include narrative interviews, story boards, graphic facilitation, narratives and digital stories and surveying. Moreover, approaches for people with dementia are increasingly recognised as the way in which people narrate their experiences over the course of their lives, will shape their dementia journey in later life. Accordingly, our programme

of research will employ a multi- phase, multi-method design (interviews, questionnaire and consensus group work, storytelling). We will work with partners to generate a combination of quantitative and qualitative data.

2. In keeping with the policy domain in which we are working, the values and aims of Diverse Cymru and the research portfolio of the authors, we propose to conduct studies within a philosophy of community justice and cultural wealth (with its focus on rights-based and the capture of individual and community assets), the repositioning of seldom heard voices as central, the attention given also to structural inequalities, accumulated microaggressions and other issues that may led to the ‘fear of diminishment’ in seeking dementia assessment, care and support.
3. Studies and engagement work moving forward will seek views and perceptions gleaned from dementia services providing assessment and care management, and those from community link workers, community activists and volunteers, or wellbeing coordinators working in the BME voluntary and community sector.
4. In the previous scoping work, Diverse Cymru staff undertook data gathering, with aspects of the work completed by a consultancy company. Moving forward we are seeking to work with other voluntary sector organisations, to house the bulk of the study within Diverse Cymru and to employ a small team of sessional community researchers.
5. The work of the GRT community must be led ‘from within’. We will aim to work closely with and develop a research programme rooted in the known priorities, approaches and desired outputs of those already working with and trusted by members of this population group.
6. To date, the focus of Diverse Cymru’s work has been in SE Wales; we are proposing to extend the geographic remit. To date, evidence has been gathered mainly in Cardiff, Vale of Glamorgan and Newport. We are seeking to extend the reach of the project Wales-wide, with case studies from areas with comparatively large numbers of older BME people.

Diverse Cymru Resources and Publications

Dementia issues concerning Black, Asian and Minority ethnic (BAME) Communities (2019), partnership with Meri Yaadain, Mohammed Akhlak Rauf. <https://www.dementivoices.org.uk/deep-groups-news/living-in-wales-and-from-the-black-asian-or-minority-ethnic-bame-communities/>

Let's talk about dementia – end the stigma (2019) <https://www.diverseecymru.org.uk/wp-content/uploads/Lets-talk-about-dementia-report-for-web.pdf>

As I walk the last mile of the way (2021) <https://www.diverseecymru.org.uk/wp-content/uploads/AS-I-WALK-THE-LAST-MILE-OF-THE-WAY-Dementia-Report-2021-JS-Edits-Final.pdf>

Some early signs of dementia (2021) https://www.diverseecymru.org.uk/wp-content/uploads/J18528-Diverse-Cymru-A4-Flyer_v2.pdf

Recently completed research projects in Wales

Vougioukalou (2021) Dementia care experiences – understanding diversity, implementing equality, creating shared learning. Cardiff University <https://ylab.wales/research/dementia-and-diversity>
<https://www.youtube.com/playlist?list=PLEPkwdTAIW1Hs7vaTZ7Fg4Y7MZKMQ3hiE>

Welsh Dementia policy and standards

Social Care Wales (2016) Good work. A Dementia Learning and Development Framework for Wales
https://socialcare.wales/cms_assets/file-uploads/Good-Work-Dementia-Learning-And-Development-Framework.pdf

Welsh Government (2018) Dementia Action Plan for Wales (2018 – 2022)
<https://gov.wales/sites/default/files/publications/2019-04/dementia-action-plan-for-wales.pdf>

Welsh Government (2021) All Wales Dementia Care Pathways of Standards
<https://phw.nhs.wales/services-and-teams/improvement-cymru/news-and-publications/publications/dementia-standards/>

Dementia Roadmap Wales <https://wales.dementiaroadmap.info>

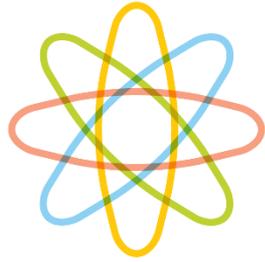
Other resources

NICE Guideline (2018) Dementia: assessment, management and support for people living with dementia and their carers.

<https://www.nice.org.uk/guidance/ng97>

Codes of practice for Registered Workforce employed in social care in Wales

<https://socialcare.wales/dealing-with-concerns/codes-of-practice-and-guidance>



diverse
cymru

Promoting equality for all
Hyrwyddo cydraddoldeb i bawb

Diverse Cymru is a unique Welsh charity committed to supporting people faced with inequality and discrimination because of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

www.diverseecymru.org.uk

© Diverse Cymru, 2021

Diverse Cymru is a registered charity (1142159) and a company registered in England and Wales (07058600).

