

Barriers and solutions for recruiting and conducting dementia research with British ethnic minorities: A systematic review



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1. Background

Ethnic Minorities in the UK

- 14% of the UK population belong to an **ethnic minority**¹- predicted to rise to 20% by 2051¹
- There is an **increasing ageing ethnic minority population**²:
 - Migration to the UK between the 1950s and 1970s as young adults
 - Older ethnic minorities choosing to stay in the UK permanently
- Predictions say up to 29% of ethnic minorities will be over the age of 65 by 2051⁴.

Dementia in Ethnic Minorities

- Ethnic minorities account for **25,000+ dementia diagnoses**⁵- expected to double by 2026⁶.
- Ethnic minorities show **high susceptibility for receiving a dementia diagnosis**^{7,8}:
 - Higher prevalence of risk factors eg. vascular diseases, diabetes, obesity
 - High prevalence of dementia in those who don't speak English
 - Inaccessible information on dementia and preventative measures

Despite this, ethnic minorities are underrepresented in UK based dementia research...



2. Aims

How can we improve ethnic minority representation in dementia research?
Identify issues recruiting, including and retaining ethnic minorities in UK based dementia research and solutions to these issues:
A qualitative systematic review

3. Methods and Search Results



4. Findings

The themes allowed us to identify **3 areas** that are **responsible for intervening and improving these issues: community and patient education, health services, and researchers.**

Community and Patient Education

1. Attitudes and beliefs about dementia in ethnic minority communities



Health Services

- 2a. Recruitment Process – Determining a Diagnostic Label for Dementia
- 2b. Recruitment Process – Defining and identifying ethnic minorities



Researchers

3. Data Collection

- Mismatch of language and culture in testing
 - Poor quality translation
 - Communication issues due to language and cultural barriers
- Solutions:
- Cultural adaptation of materials
 - Hiring qualified translators
 - Hiring and training interpreters according to cultural differences



4. Practical Issues

- Lack of financial resources
 - Low socioeconomic status
 - High mobility
 - Difficulty in committing time
- Solutions:
- Arrange for transport
 - Arrange for child minding services
 - Multiple visits
 - Persistent contact
 - Conduct research at place of residence or community location



5. Researcher Characteristics

- Gender discrepancy
 - Age related issues
 - Struggle to interpret data due to cultural differences
 - Participants reluctant to work with researchers from their community
- Solutions:
- Gender matching
 - Cultural sensitivity training
 - Data analysis by an individual from the same ethnic group



6. Paucity of literature on dementia research within ethnic minority groups



5. Discussion

This Research

Our review lists **existing issues in recruiting, including and retaining ethnic minorities within UK dementia research.**

- It covers **research stages**, highlighting barriers that emerge not just during the research process but before .eg. *Beliefs in the community that prevent recruitment.*
- It also highlights problems that can arise when recruiting ethnic minorities to any health research.
- Some of these problems may also apply to other disadvantaged or low socioeconomic groups.

The themes act as a check and guide for future dementia researchers when designing their studies.

Future Directions

- Authors of the publications should be contacted to explore the solutions they used in case they did not report this in their publications.
- The areas responsible for intervention act as a precursor for identifying new and improving existing solutions.
- Researchers should incorporate the solutions pertaining to them.

6. References

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