

Exploring the diversity of participants with dementia taking part in research: A mixed methods study

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Introduction

It is estimated that 885,000 people are living with dementia in the UK which is set to double by 2040. Dementia is a degenerative condition leading to loss of function and reduced quality of life. The Promoting Activity Independence and Stability in Early Dementia (PrAISED) research programme tested a complex rehabilitation intervention for people with Mild Cognitive Impairment (MCI) and mild dementia. The PrAISED randomised controlled trial (RCT) recruited 365 patient carer dyads from Join Dementia Research register, Memory clinics and GP practices across 5 sites in England; Nottinghamshire, Derbyshire, Lincolnshire, Oxford and Bath (see figure 1). Anecdotal evidence shows the RCT was not representative of the diversity known to be present at these sites. Nationally, 3% (25,000) of people living with dementia are from minority ethnic groups this is set to double by 2026. Socioeconomic deprivation has also been linked to an increased risk of dementia.

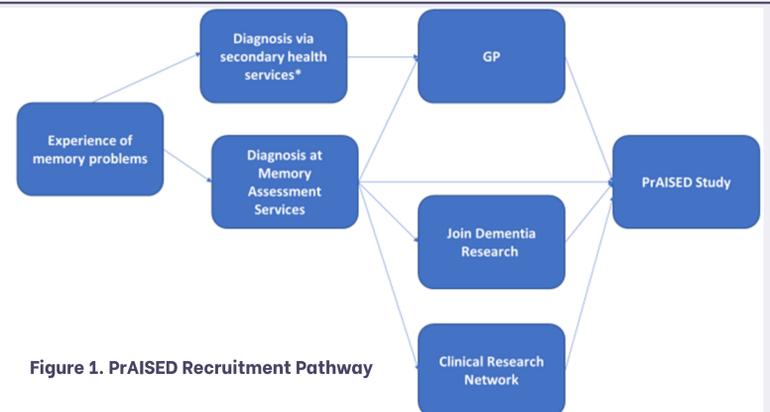


Figure 1. PrAISED Recruitment Pathway

Objectives

- Establish disparity of ethnic and socioeconomic diversity between the PrAISED cohort, recruitment pathways and the general population in England and Nottinghamshire.
- Explore factors influencing diversity in PrAISED RCT and dementia research more generally.

Methods

- Explanatory sequential mixed methods design.
- Extracted data on ethnic and socioeconomic diversity from PrAISED RCT, Nottinghamshire memory assessment services, Census 2021, NHS digital and English Indices of Deprivation 2019.
- Recruited participants through existing relationships with key stakeholder organisations and community networks
- Conducted exploratory interviews with key stakeholders (research staff and memory clinic nurses) and community representatives.
- Interviews explored barriers to accessing services and participating in research for people living with dementia from diverse backgrounds.
- Used descriptive statistics to analyse quantitative data and reflexive thematic analysis of interview data.

Results

Quantitative results:

PrAISED cohort

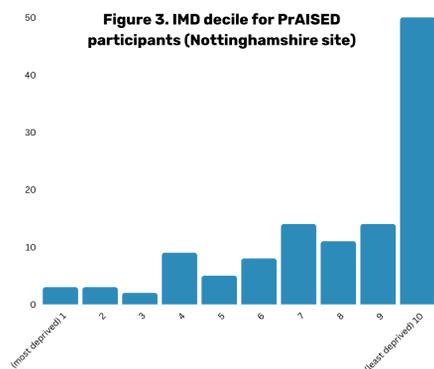
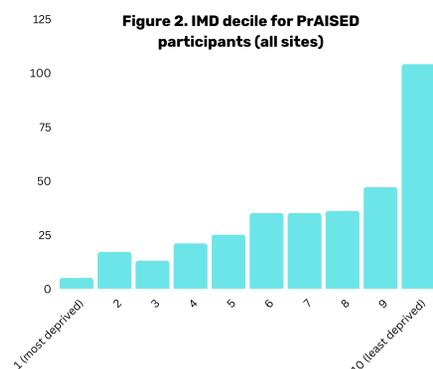
- PrAISED recruited 365 participants of which less than 2% (7/365) were from a non-white ethnic minority community.
- 28% of participants lived in the least deprived decile (Figure. 2).

Nottinghamshire memory assessment clinics

- 4910 referrals to Memory Assessment Services within Nottinghamshire (excluding Bassetlaw) were made between October 2018 and June 2021.
- 92.7% were white, 2% were Black (African, Caribbean, or Mixed White and Caribbean) and 2.5% were South Asian (Indian, Pakistani, Bangladeshi, or other).

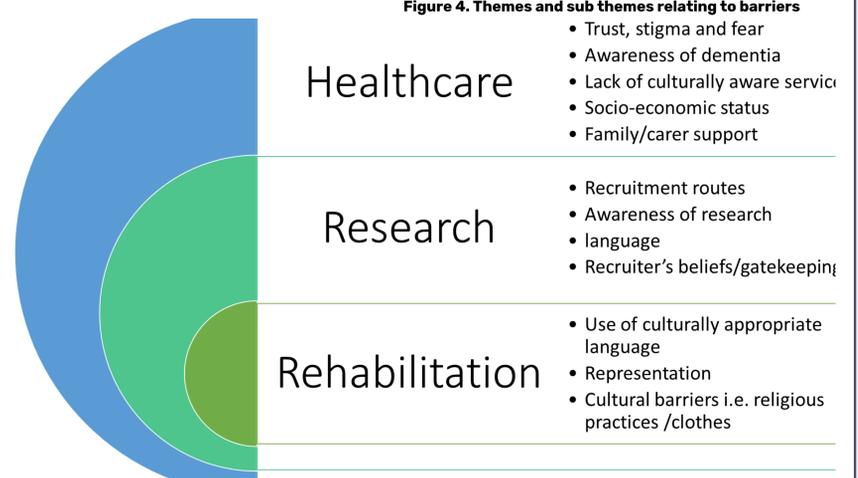
PrAISED Nottinghamshire site

- 113 identified as white, 3 identified as black and 2 identified as south asian and 1 identified as asian.
- 42% (50/119) of participants recruited lived in the least deprived decile (Figure. 3).



Qualitative results:

- Participants interviewed included 2 memory assessment nurses, 2 researchers from the Nottingham Clinical Research Network and 4 community representatives.
- The community representatives were from the the Jamaican community, Pakistani community, Indian muslim community and Sikh community.
- The identified communities had many barriers to accessing research, including distrust of healthcare services, concerns about the stigma of a dementia diagnosis and a lack of culturally appropriate services.
- It was felt that using healthcare as a route to research recruitment limits access and awareness to research, as does limitations on language.
- Accessing rehabilitation research had further barriers related to feelings of a lack of representation and interventions that accommodate cultural requirements (see figure 4).



"We used to do a recruitment process called Living Well with Dementia...And I would say the majority of people who attend the Living Well groups are relatively, I don't want to say affluent, but they've got money to spend on taxis, they've got money for bus fares, they were independently mobile, or their partner had got a car. So you're already looking at quite an able-bodied catchment before you even got to talking about any of the studies. And then from that the participants who went forward to say yes, 'I'd really like to do PrAISED,' again were coming from that already quite time rich, motivated, access to mobility catching group" (MAS6).

Conclusion

- Representation of minority ethnic groups and socioeconomic diversity was lacking across the PrAISED population.
- In Nottinghamshire inclusion of minority ethnic groups was better however there was little socioeconomic diversity.
- Interviews highlighted that the barriers to research were multi-level starting with barriers to accessing healthcare services.
- Recruiter's beliefs and gatekeeping in research warrants further exploration.

Recommendations

- Representation
- Building trust
- Accessible information
- Recruitment strategies
- use of familiar venues
- Build long term relationships with communities
- Renumeration
- Flexibility