

# INCLUSION OF PEOPLE LIVING WITH DEMENTIA IN RESEARCH: FINDINGS FROM THE PRIDEM FEASIBILITY STUDY

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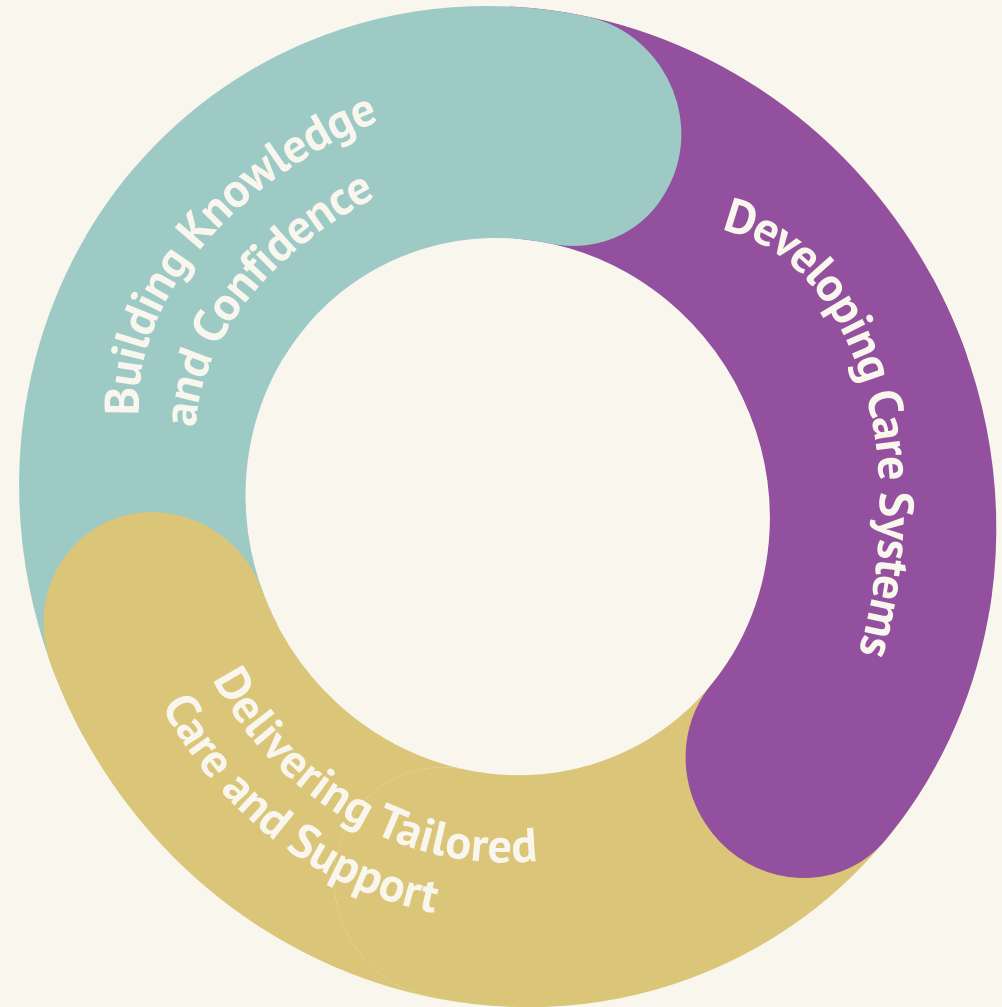
# Background

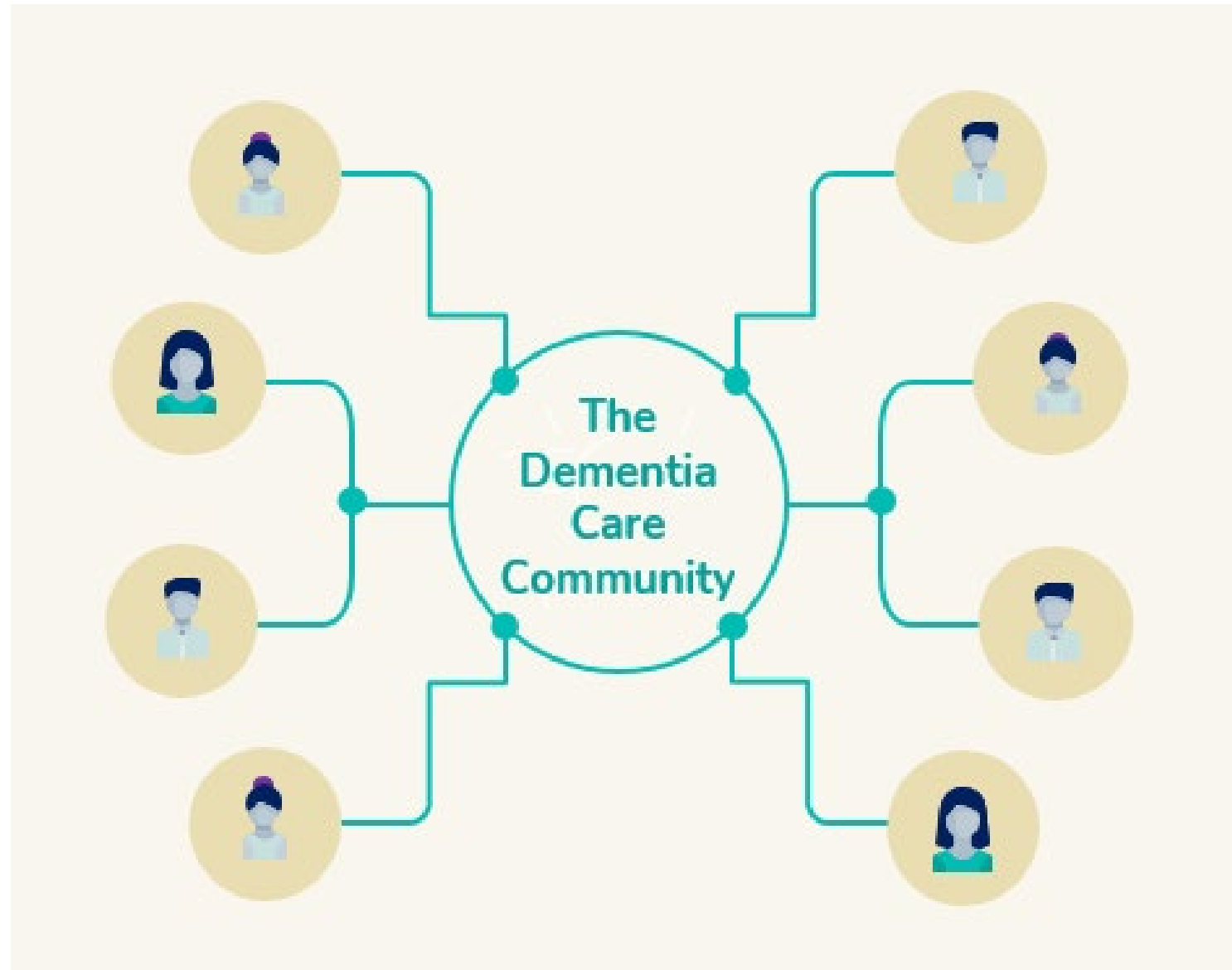
- People with dementia underrepresented in dementia care research
- Those included tend to be individuals in early stages/ those with informal carer to support inclusion. (Brooks et al; 2017, NICE Dementia guidelines, 2018)
- **Significant gap in evidence base and need for strategies to support inclusion**

# PriDem Programme background (2018-2023)

Developed evidence-based primary care led approach to post-diagnostic dementia care

Clinical Dementia Lead (CDL) supporting general practice staff to deliver three intervention strands





# PriDem Feasibility study (2022-2023)

15-month mixed methods, feasibility study

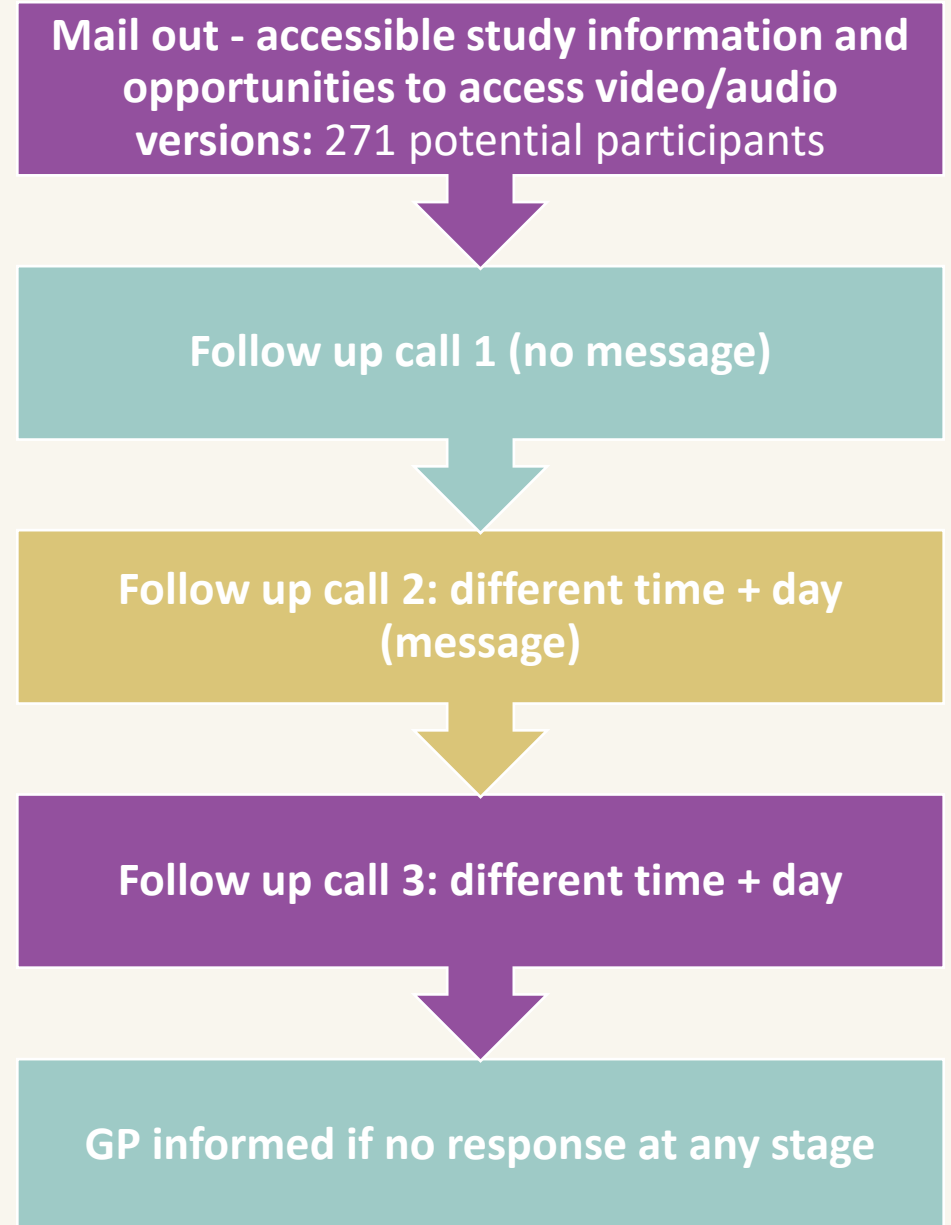
- Testing the intervention and the methods for supporting inclusion of people with dementia in the study.

## Aims

- Test inclusivity of our approach to recruitment
- Measure recruitment and retention rates
- Assess acceptability of study procedures for people living with dementia

# Methods

- 12 months intervention: 7 general practices - Southeast + Northeast England
- Inclusion: Community dwelling, diagnosis of dementia, capacity to consent **or** consultee
- Carer participating alongside, where appropriate/wanted
- Proactive, ethical, staged approach
- Flexible scripts developed with DCC



# Methods

- Health related QOL outcome measures: DEMQOL (Smith et al 2007), EQ-5D-5L (Herdman et al, 2011) - Baseline, 4 months, 9 months.
- Carers completed proxy measures and questionnaires about own health and wellbeing.
- Qualitative interviews – acceptability of study procedures.

# Feasibility findings: recruitment

## Recruited:

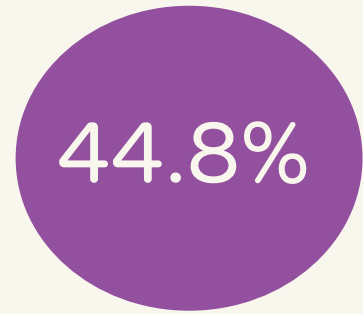
- 60 people with dementia (75% of recruitment target 80)
- 51 carers (77% recruitment target 66)

**Recruitment duration = 5 months**

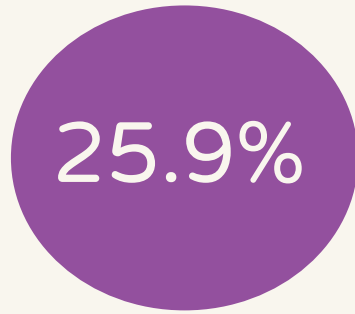
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# Inclusion of under-represented groups within sample of people with dementia



Recruited via  
consultee



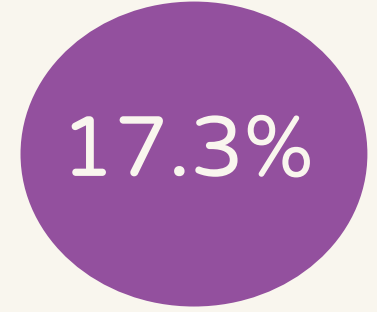
Living alone



Participated  
without carer  
participating  
alongside



Ethnicity  
non-white  
(22.4% carers)



Areas of  
deprivation\*

*\*Index of Multiple Deprivation (IMD) rankings 1 and 2*

# Reasons for opting out

## Three most common reasons (besides physical ill health)

1. Carer strain: *'Too busy doing all the dementia care.'*
2. Person with dementia gets anxious talking with new people
3. Person with dementia in denial

# Withdrawals

Reason	n =
No reason given	1
Moved to care home	4
Cognitive decline and unable to participant without support of carer (who withdrew due to own health difficulties)	1
Didn't want the bother	1
<b>Upset with GP surgery</b>	<b>1</b>
Died	4
Carer felt continued participation would be too stressful for person with dementia	1
Found to have no diagnosis at analysis stage	1
<b>Total withdrawals</b>	<b>14</b>

# Learning: Recruitment

- Funding for replacement care
- Enhanced accessibility of study information
- More explicit about eligibility of people with advanced dementia/non-English-speaking
- 'Service level' intervention hard to understand.
- Cynicism - strategies to support engagement?

*And how is this gonna help the situation? ....I want it to help people and I want it to help myself... Is it just going to be put on the back shelf? Is somebody now going to get in touch saying...I hear your mother's got dementia how can we help....or have I just wasted your time and my time and nothing's happened with it? Do you see what I mean? We don't know, do we? (Carer)*

# Learning: outcome measures

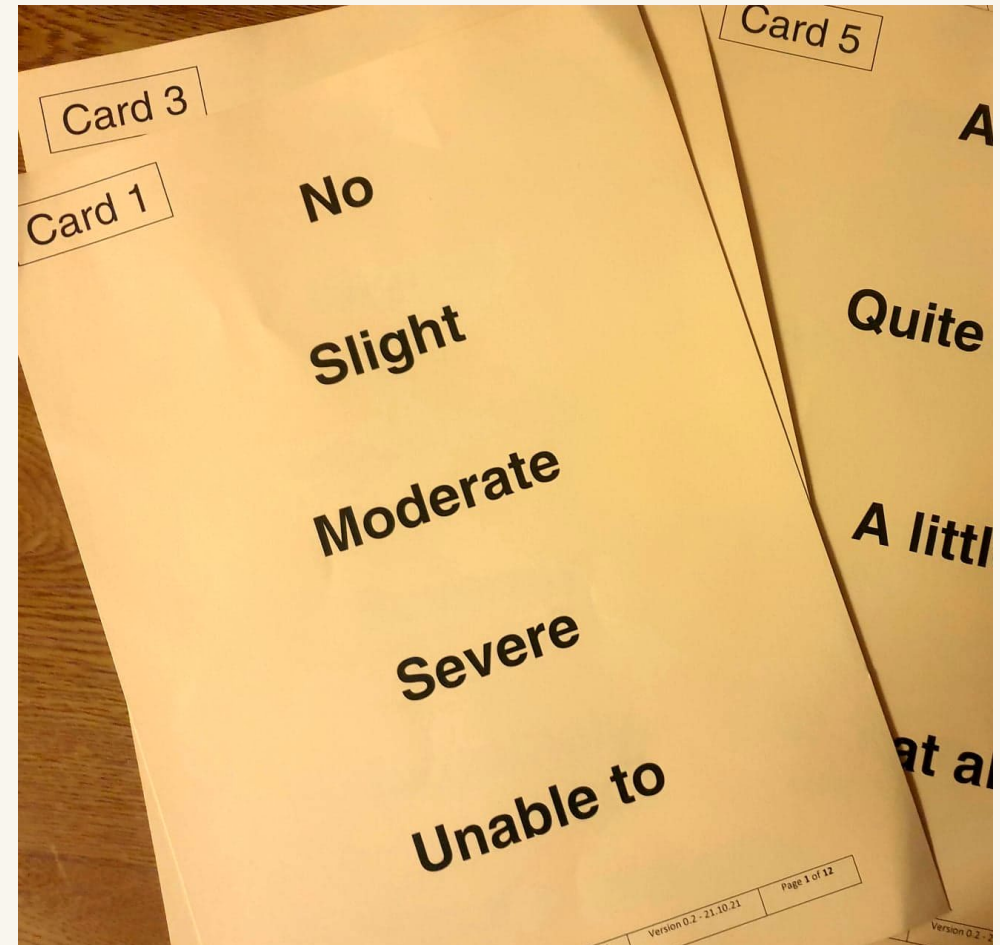
- In person contact with researchers preferred.
- Visits up to 2 hours.
- Ten carers completed some questionnaires online
- Researchers alert to fatigue/distress – handled sensitively and compassionately
- Future study – reduce measures, e.g., DEMQOL and DEMQOL Proxy least acceptable to all

*I could imagine some [researchers] might .... hold themselves outside it, 'I can't get involved'.... but actually it's such a sad and difficult thing... so if somebody doesn't say to you, "It is tough," or, "Oh yes, I can see that's tricky," whatever it might be, so I do find that helpful, just that acknowledgement. (Carer)*

- **Simple strategies can be powerful:** Use of visual cue cards even more valuable than we thought!

*To avoid it seeming in any way patronising, I will often ask if I can use the cards in order to save my voice, as it saves me from repeating the same options over and over.  
(Researcher reflection)*

- Strategies to support retention: phoning prior to scheduled visits, maintaining researcher consistency



# Conclusions

- A future study is warranted – we are learning from this experience and considering ways to enhance inclusion further
- Funding for a larger study should not underestimate time and researcher capacity
- **Intensive work. Participants need time and support to engage and build trusting relationships with researchers**

# Acknowledgements

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# Thank You

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