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

Griffiths, S., Spencer, E., Wilcock, J., Poole, M., O'Keeffe, A., Hunter, R., Flanagan, K., D'Andrea, F., Walters, K., Robinson, L., and Rait, G. on behalf of the PriDem Study project team

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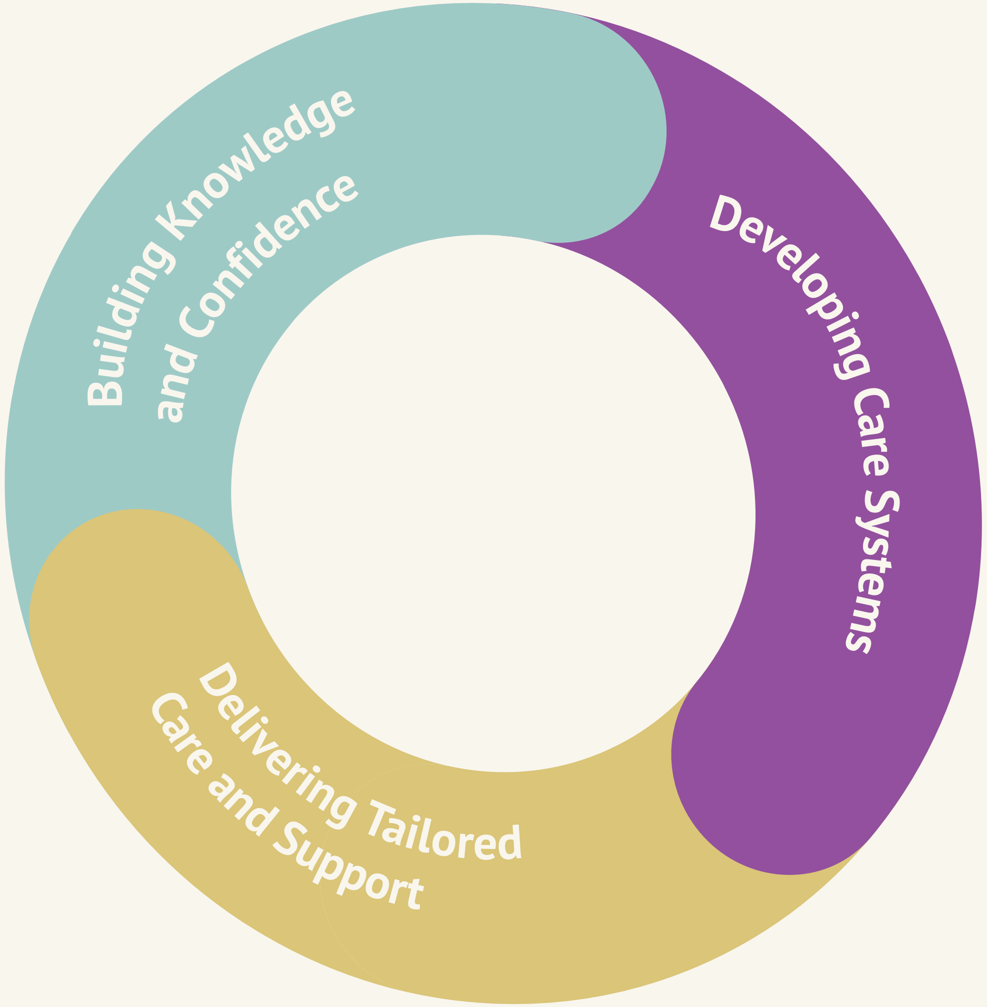
Background

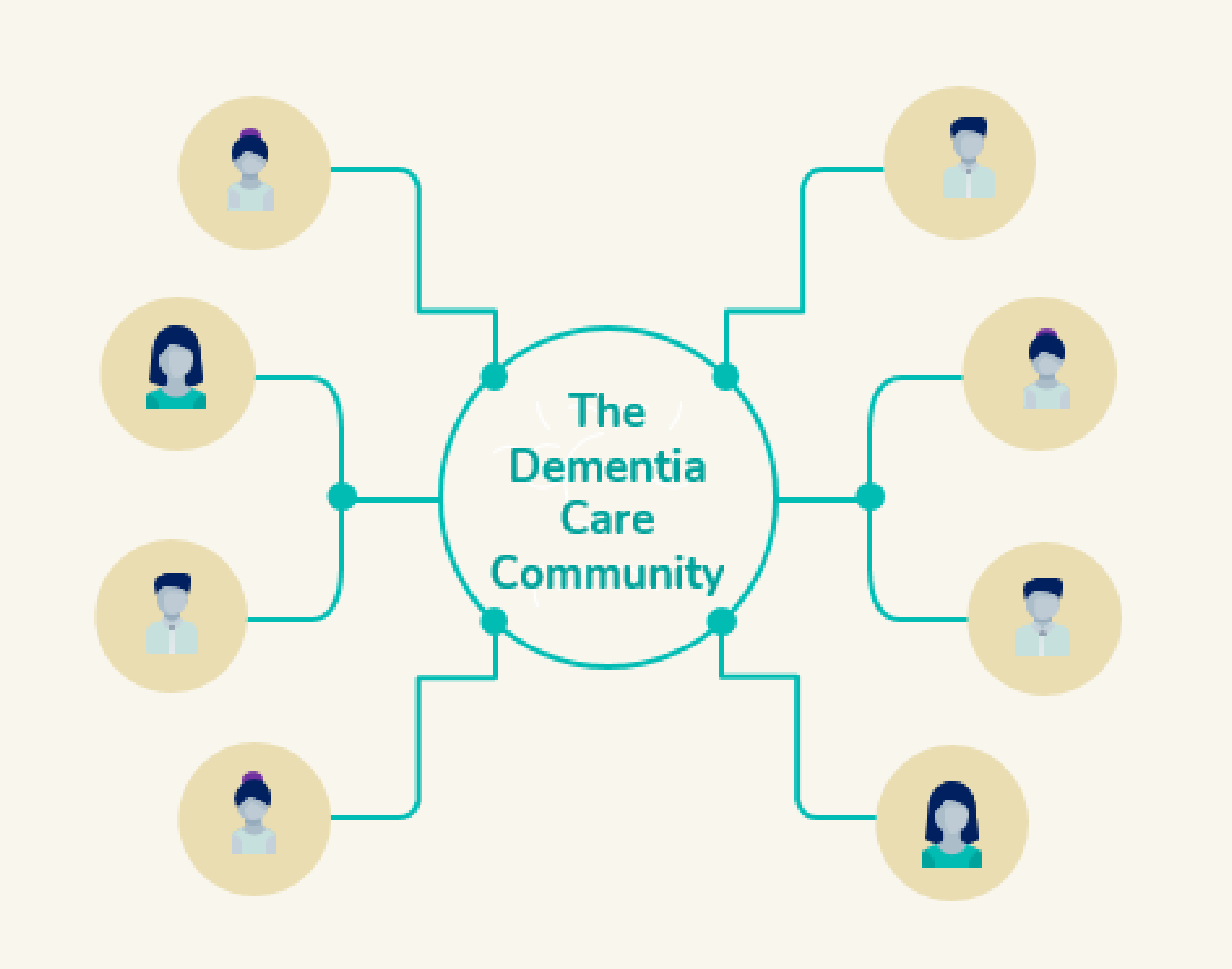
- People with dementia underrepresented in dementia care research
- Those included tend to be individuals in early stages/with informal carer to support inclusion. (Brooks et al; 2017, NICE Dementia guidelines, 2018)
- **Significant gap in evidence base. Need strategies to support inclusion**

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




The Dementia Care Community

PriDem Feasibility study (2022-2023)

15-month mixed methods, feasibility study

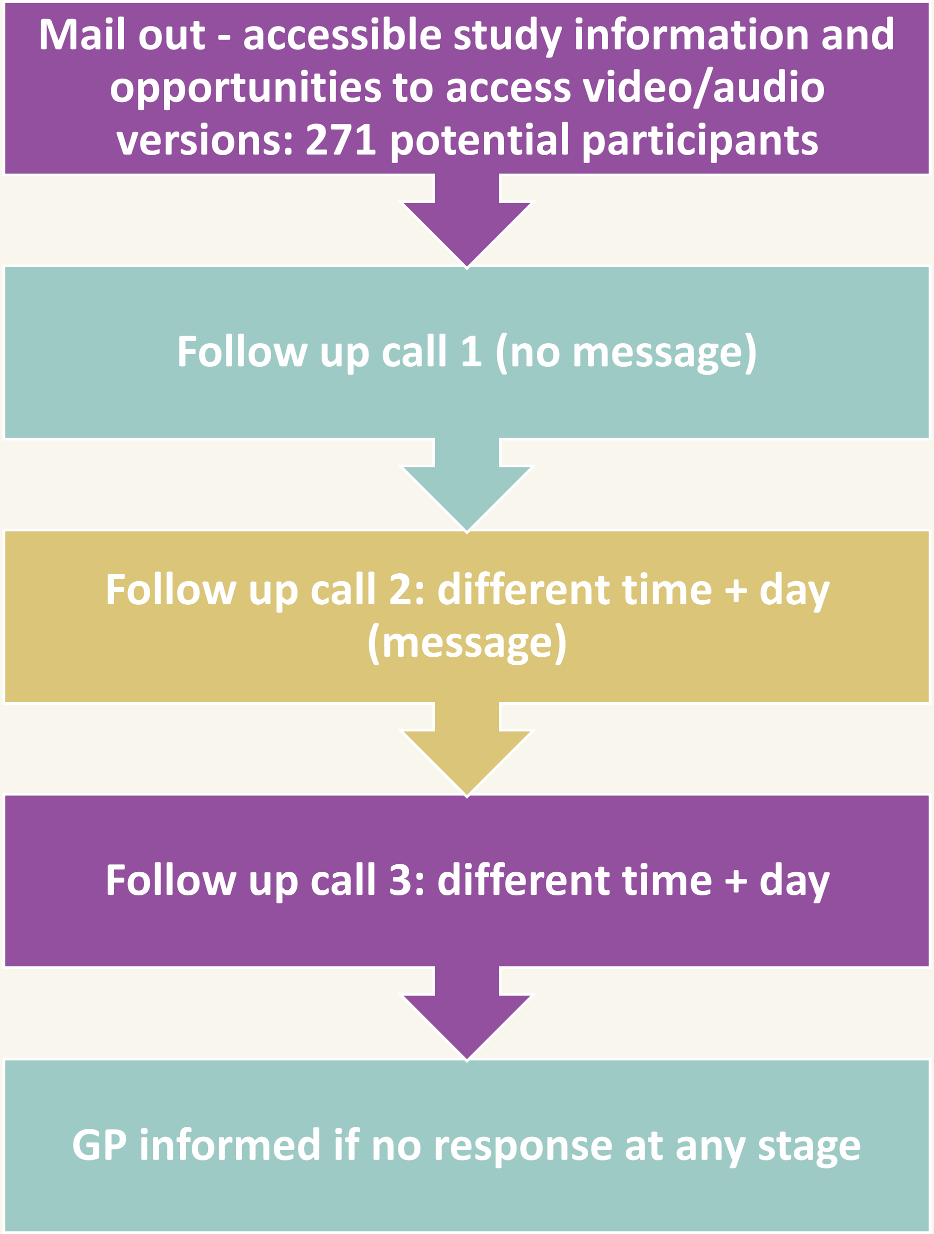
- Testing the intervention and the methods for supporting inclusion of people with dementia in the study

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, staged approach
- Flexible scripts developed with DCC



Mail out - accessible study information and opportunities to access video/audio versions: 271 potential participants

Follow up call 1 (no message)

Follow up call 2: different time + day (message)

Follow up call 3: different time + day

GP informed if no response at any stage

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)

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

44.8%

Recruited via consultee

25.9%

Living alone

15.5%

Participated without carer participating alongside

10.4%

Ethnicity non-white (22.4% carers)

17.3%

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 doesn’t want to talk about dementia

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
Upset with GP surgery	**1**
Died	4
Carer felt continued participation would be too stressful for person with dementia	1
Found to have no diagnosis at analysis stage	1
Total withdrawals	**14**

Learning: Recruitment

- Funding for replacement care
- Enhanced accessibility of study information
- ‘Service level’ intervention hard to understand.
- Cynicism - strategies to support engagement?

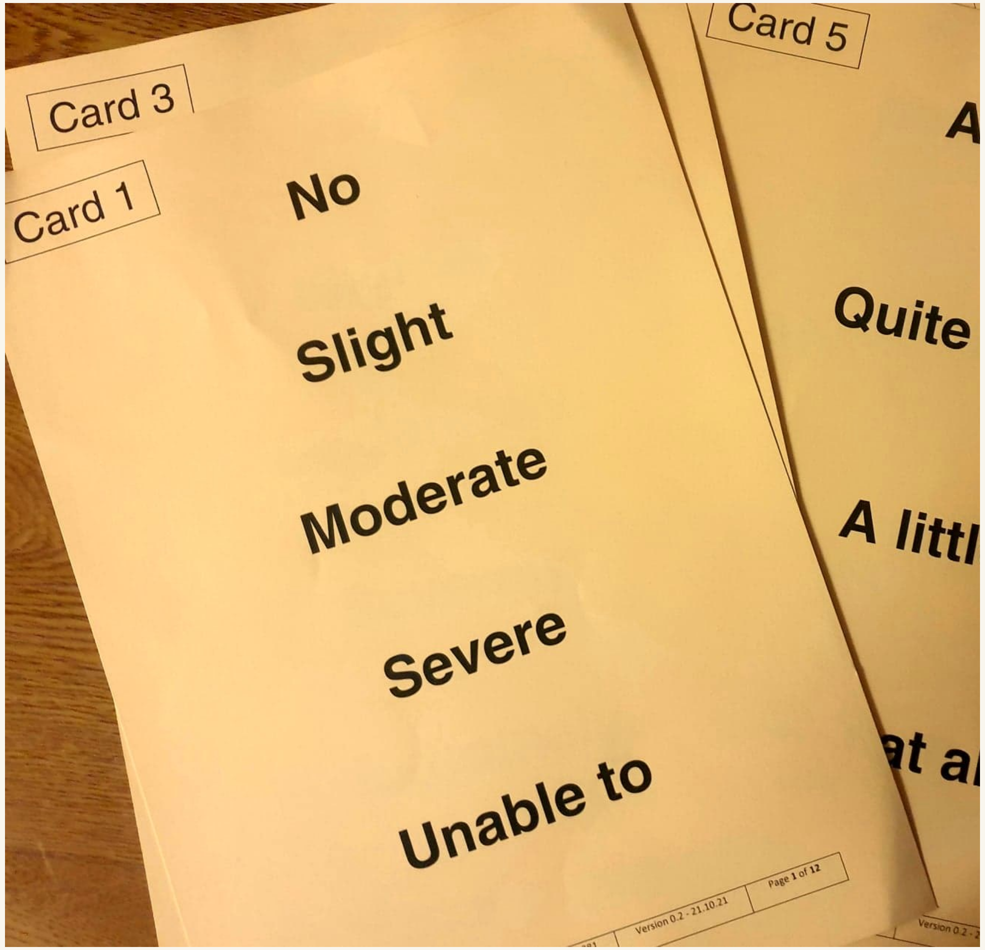
Learning: outcome measures

- 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….. I do find that helpful, just that acknowledgement. (Carer)*

Simple strategies can be powerful

- Use of visual cue cards –people with dementia and carers, recall, keeping on track, responding privately, saving researchers’ voices
- Phoning prior to scheduled visits
- Maintaining researcher consistency



Conclusions

- A future larger study is warranted – we would consider ways to enhance inclusion further
- Funding should not underestimate time and researcher capacity needed to support inclusion
- **Intensive work. Participants need time and support to engage and build trusting relationships with researchers**

Acknowledgements

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Thank You

Sarah Griffiths: s.a.griffiths@ucl.ac.uk

Twitter: @PriDemProject