





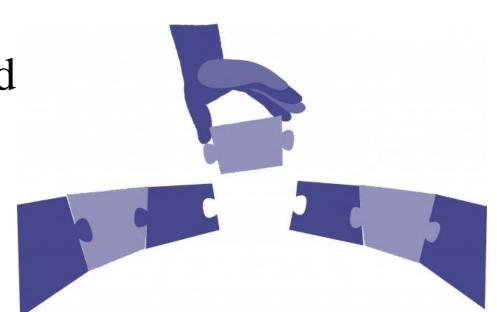
Public Involvement in research: Co-researching with carers of people with dementia in the PrAISED study

Claudio Di Lorito, Maureen Godfrey, Marianne Dunlop, Kristian Pollock, Veronika van der Wardt and Rowan H. Harwood University of Nottingham, United Kingdom

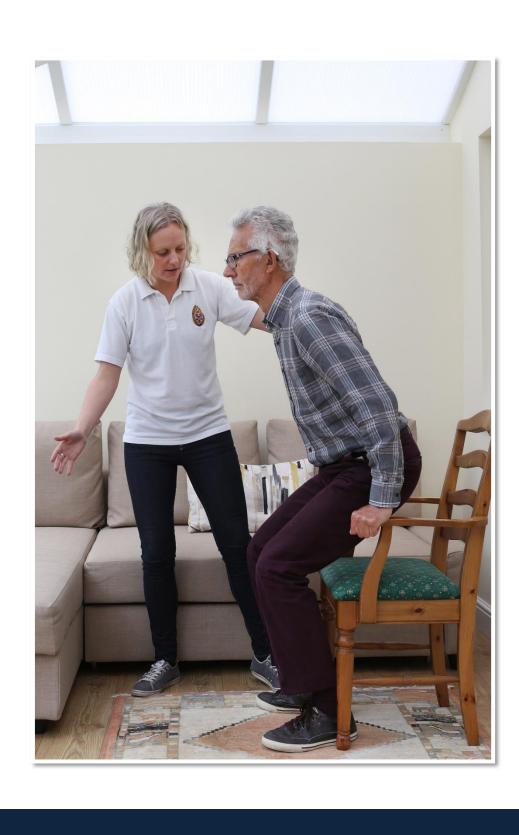
What is **Public Involvement (PI)** in research? It is research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them

What is **co-research**? It is a type of PI where research is steered and conducted by people with lived experience of the issue being studied together with academic researchers

What is **the pur**pose of co-research? To bridge the gap between academia and the public. Co-research aligns research more closely with the public's needs, thus increasing success and cost-effectiveness



What is **PrAISED**?



A multi-centre, randomised controlled trial testing the effectiveness of a home-based physical activity and exercise intervention to promote activity and independence in people with early dementia or mild cognitive impairment

Setting up strategies for continuing collaboration

Maureen Godfrey

- Member of the public
- Named coapplicant
- Helped develop research documents
- Attended
 management and
 ethics committee
- Modelled for intervention

Marianne Dunlop

- Member of the public
- Named coapplicant
- Supported Maureen in PI role
- Interviewed and recruited PrAISED therapists
- Reviewed research documents / materials

Claudio Di Lorito

- Academic Research Fellow
- Working in PrAISED process evaluation
- Leading PI in the Division of Rehabilitation,
 Ageing and Wellbeing

The co-research team



What we are doing as co-researchers?

Developing research protocol and interview topic guide

Share/Impact

Think & Plan

Discover

Research

Training for qualitative interviews

Administering interviews to participants with dementia and carers

Disseminating findings

Writing papers / reports

Write & Publish



Analysing transcripts

What we are the benefits and practicalities of co-research?

I found the interview the most rewarding piece of work. I felt so in touch with the study and it brought home a reality I share with the participants (Maureen)

I feel the empathy a co-researcher can provide is of value to the carer, they feel more able to open up to someone they do not see as a professional (Marianne)

As the volunteers with lived experience, the co-researchers could widen the scope of the interviews, ensuring that enriched narratives were gathered (Claudio)

- Being of a similar age / background as the participants, the co-researchers could better identify and empathise with their experiences
- As they are on a parallel journey, the co-researchers could share and encourage positively
- The co-researchers brought an informal dimension to the interview, where participants felt encouraged to open up



- Extra resources are needed (travel, funding for co-researchers)
- Extra time to organise appointments is required
- Good rapport between academic and co-researchers and team building is key
- Training and preparation for interviews is crucial

