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Pushing the boundaries in research: Patient and Public Involvement in PrAISED

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NHS

National Institute for
Health Research

PrAISED

Promoting Activity, Independence
and Stability in Early Dementia

This describes independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research (RP-PG0614-20007). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.



- What is Patient and Public Involvement (PPI) in research?
- What is co-research?
- PPI in PrAISED
- Co-researching in PrAISED process evaluation
- Impact of co-researching in PrAISED
- Impact of co-research beyond PrAISED





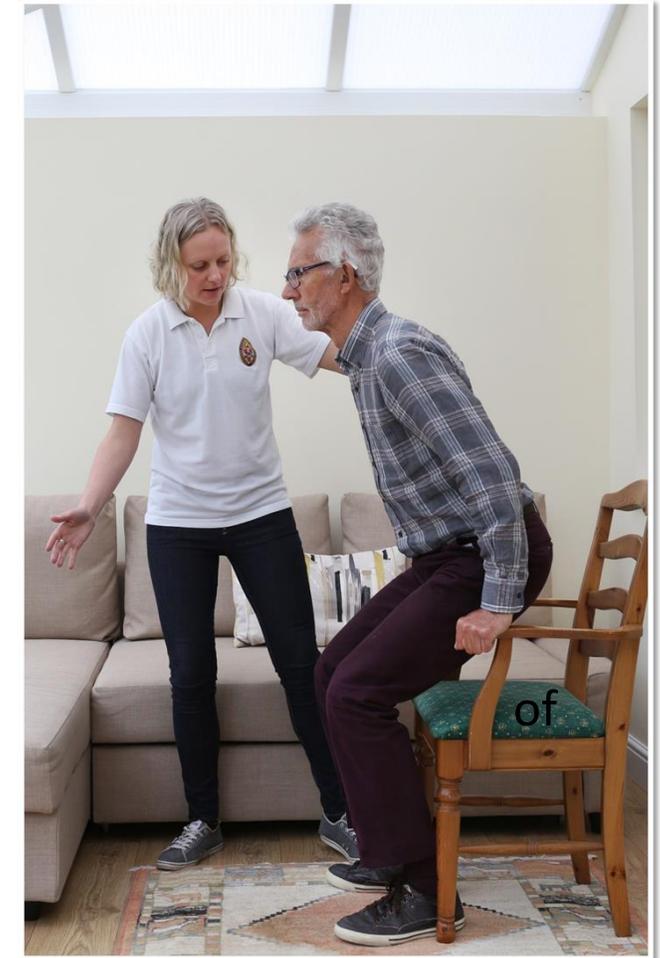
What are PPI and co-research?

- It is research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them
- It aims to align research more closely with patients' and the public's needs, to **increase success and cost-effectiveness**
- The NIHR mandates that funded research include PPI activities
- It ranges from advisory roles to more active participation in research
- Co-research is **steered and conducted by people with lived experience** together with academic researchers





- There has been great emphasis on PPI in PrAISED from day one
- All Work Packages team have collaborated with two PPI contributors with lived experience of caring for a person living with dementia
- Examples of PPI activities in PrAISED:
 - Developing study protocol
 - Refining language in participant documents
 - Modelling for exercise photos and videos
 - Promoting acceptability, relevance and understanding intervention procedure and materials
 - Assisting with interviews with therapists delivering PrAISED
 - Writing papers





- In the process evaluation workstream, we aimed to progress/innovate the practice of PPI by doing co-research
- All study phases were co-steered and co-produced by the PrAISED research team and our PPI contributors:
 - Developing research documents, e.g., study protocol, topic guides for the qualitative interviews
 - Collecting data, e.g., interviews with participants and caregivers, note taking/observations post-interview
 - Analysing data, e.g., annotating interview transcripts, generating themes, adding a PPI dimension to interpretation
 - Disseminating findings, e.g., co-authoring papers, developing posters, co-delivering presentations synthesis





- Maureen, and I were of a similar age to the participants and could identify with their experiences
- By combining Maureen's personal experience as a carer and my own, we were able to make carers and participants feel at ease
- We could show by reflective listening and empathising (eye contact and body language), the supportive and enabling nature of the study
- As volunteers with lived experiences and by being less formal, we could tap into the wider aspect of participants' quality of life
- By talking to participants and carers, we realised how important social interaction and support were for both the carer and the participant
- We were unsure whether opening up about our similar journey was beneficial
- In suggesting options, we might have given examples which the participants may not have been interested in



- Co-researcher's prompts for participants and responses to their remarks were more relevant to their human experience of dementia
- Seeing someone on a similar journey made participants relaxed to open up
- It also set the ground for an equal relationship in the interview session
- More balance in gender and age in the research team (more relatable)
- Extra resources are needed (travel, funding for PPI members)
- Potential power differential for person with dementia, if co-researcher is a carer
- The carer might reveal relevant information outside of the interview (in confidence to the co-researcher)
- Risk of emotional impact on PPI members when hearing participants' difficulties
- Added logistics: Finding suitable times, locations, travelling arrangements

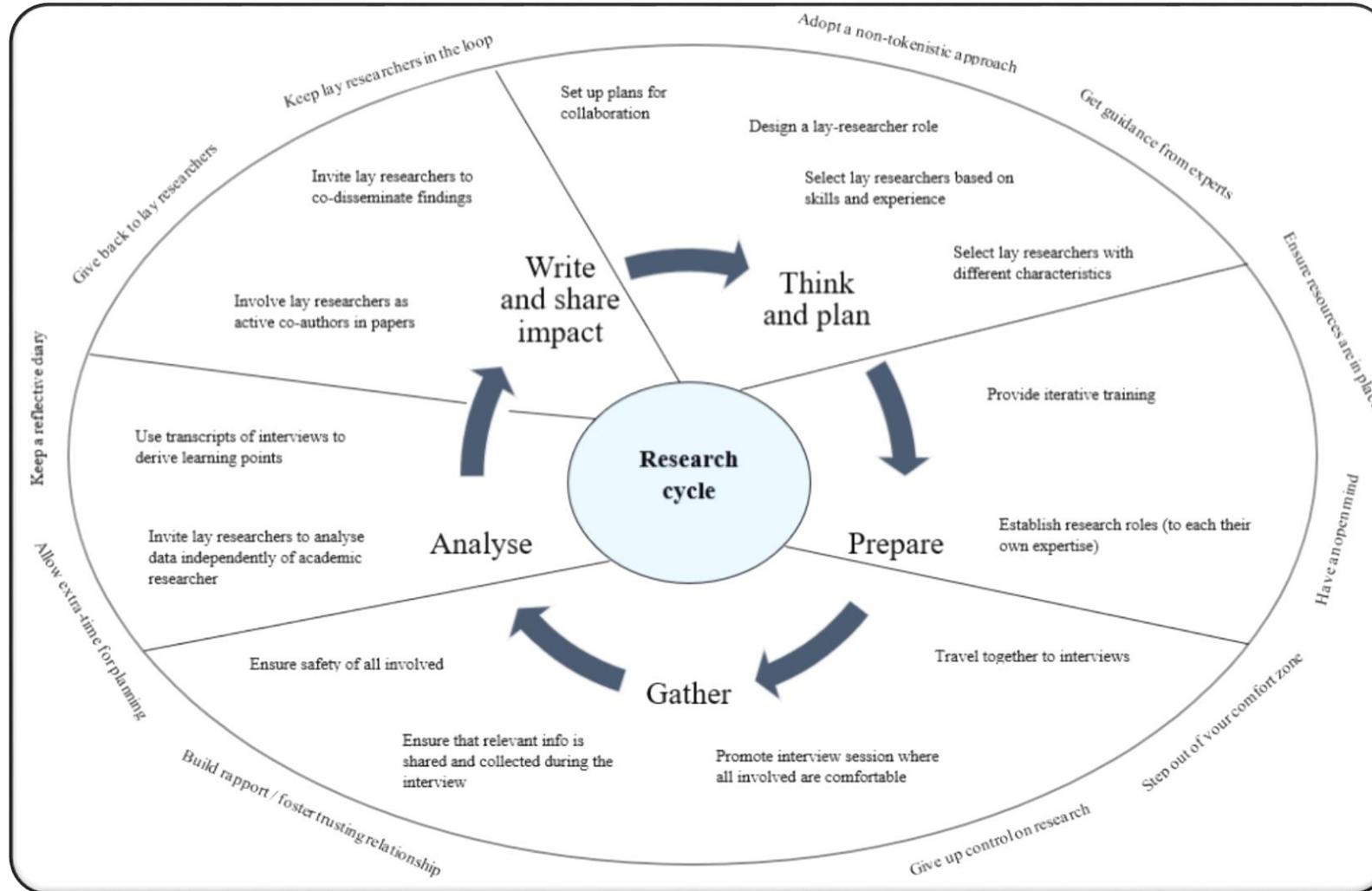
- We co-produced a methodological paper on doing co-research to advance this method and promote good practice
- Aims: To advance this method in research by reporting and synthesising the personal reflections of the academic and lay researchers around the methodological issues, benefits and challenges of co-research
- The paper has won first prize of the INTERDEM publication award 2021: <https://interdem.org/?p=7530>

ORIGINAL RESEARCH PAPER

WILEY

Adding to the knowledge on Patient and Public Involvement: Reflections from an experience of co-research with carers of people with dementia

Claudio Di Lorito PhD, Research fellow¹  | Maureen Godfrey BA Hons, Patient and Public Involvement representative¹ | Marianne Dunlop Dip, Patient and Public Involvement representative¹ | Alessandro Bosco PhD, Research fellow² | Kristian Pollock PhD, Professor³ | Veronika van der Wardt PhD, Senior Research fellow⁴ | Rowan H. Harwood MD, Professor³



- We showcased our experience of co-researching at conferences, e.g., Alzheimer Europe, Alzheimer Association International Conference

- We recorded a podcast on PPI in research for the Institute of Policy and Engagement at UoN:
<https://knowledgeengaged.buzzsprout.com/1870242/10906022-representation-in-research-matters-w-claudio-di-lorito?t=0>

Public Involvement in research: Co-researching with carers of people with dementia in the PrAISED study
Claudio Di Lorito, Maureen Godfrey, Marianne Dunlop, Victoria van der Weijl 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 purpose 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

Maureen Godfrey
• Member of the public
• Named co-applicant
• Helped develop research documents
• Attended management and ethics committee
• Modelled for intervention

Marianne Dunlop
• Member of the public
• Named co-applicant
• Supported Maureen in PI role documents
• 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
Think & Plan
Training for qualitative interviews
Administering interviews to participants with dementia and carers
Analyzing transcripts
Write & Publish
Disseminating findings
Writing papers / reports
Setting up strategies for continuing collaboration
Share Impact
Research Cycle

What 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 participant" (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 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

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- PPI activities and inclusion of PPI members in PrAISED was successful
- It has generated benefits to researchers, PPI members, research participants and research
- It has been rewarding on a personal level
- It has enhanced research data and outputs
- It has furthered methodology and science
- The challenges and practicalities have required extra resources, and the sustained commitment of the study team
- Culture change and support from institutions and funders is key to promoting successful future implementation of PPI in research



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Thank you for your
attention. Any
questions?

For further info:

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