



# Patient and Public Involvement (PPI) in the Promoting Activity, Independence and Stability in Early Dementia (PrAISED) Randomised Controlled Trial (RCT).

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## Introduction

- The PrAISED programme is a person centred activity and exercise intervention aimed at maintaining activity and independence in people with dementia.
- The Intervention is delivered by National Health Service (NHS) professionals.
- A Randomised Controlled Trial (RCT) is underway to test the PrAISED intervention.
- Patient and Public Involvement (PPI) is instrumental in all stages of the 'research cycle' and the development of the PrAISED intervention and RCT.

### Evaluate and recommend

– explore what has/has not worked and why

- Can lead to larger studies or trials.
- Provide recommendations for future research.

The PrAISED RCT was developed based on recommendations from the feasibility RCT and real world experience of PPI members.

### Idea/concept

– PPI involvement in early stages of research

- PPI representatives can help researchers identify service issues and problems.
- PPI representative can help researchers prioritise their research topics.

PPI representatives (Maureen and Marianne) advised the PrAISED team on the shape and focus of the RCT.

### Disseminate

– sharing findings with stakeholders

- PPI representatives give advice and support dissemination to a diverse audience.

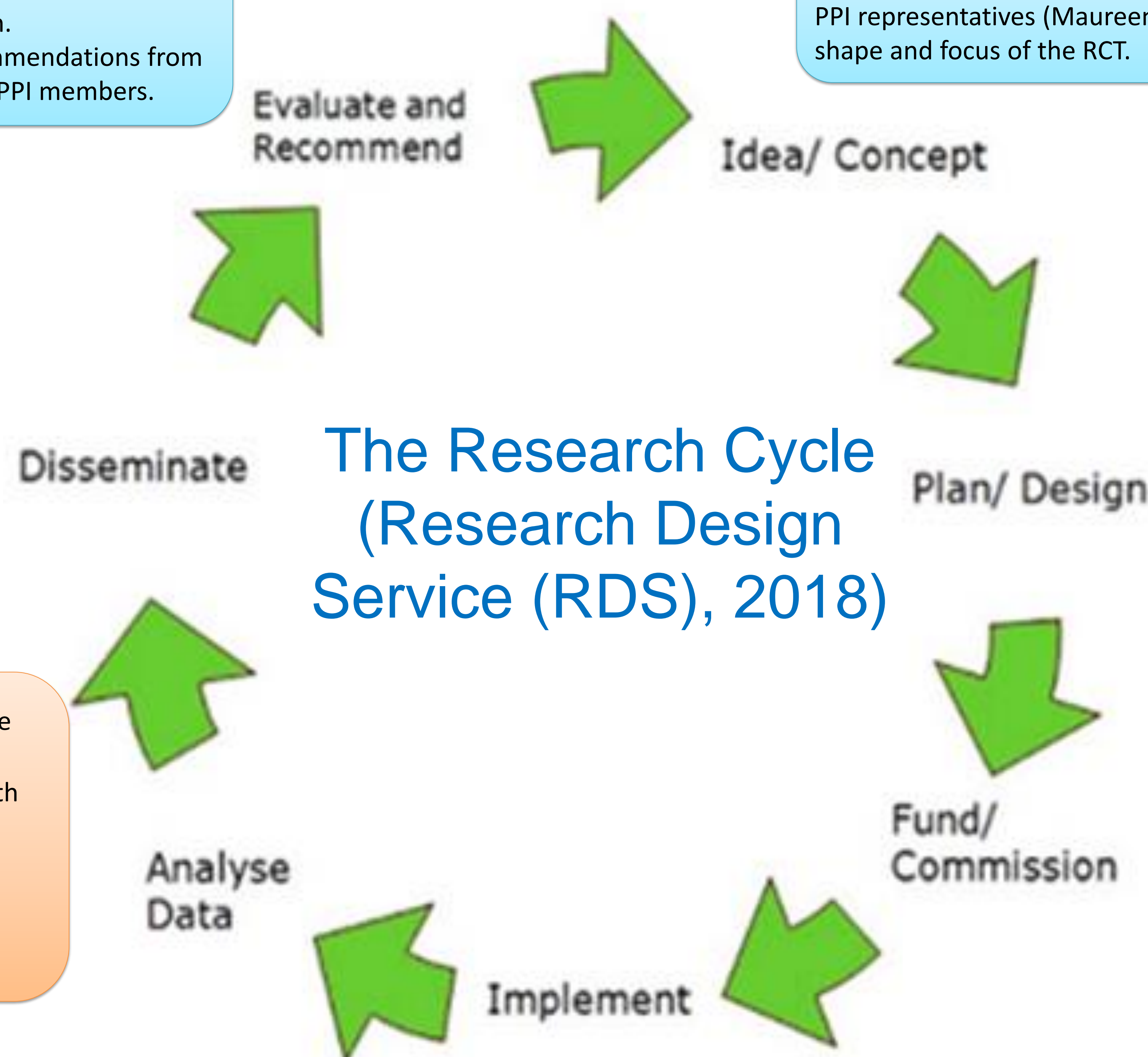
PrAISED PPI representatives (Maureen and Marianne) have presented to academics and have co-authored academic papers.

### Analyse data

- quantitative and qualitative analysis of study data

- PPI representatives can assist researchers with data analysis.
- Can add a patient/carer/member of public perspective when interpreting the data.

This approach will be adopted during the analysis/interpretation of PrAISED RCT data.



### Plan/Design

– how best to conduct the research

- Develop clear, focused research questions to solve problems and improve practice.
- Carefully consider the method and approach to effectively answer the research questions.
- Identify the best way to carry out the research to ensure accuracy of results.

PPI representatives helped the PrAISED research team to develop clear research questions and reviewed patient facing documents to assess appropriateness.

### Fund/Commission

– applying for research funding

- Gaining funding/commissioning to conduct research.
- PPI involvement is an essential funding criteria.

PPI representatives were co-applicants on the PrAISED funding applications and co-authors of interim project reports.

### Implement

- PPI representatives help maintain research focus.
- Communicate study updates to PPI friendly audiences.
- Assist researchers in presenting findings to academic/clinical audiences.

PrAISED PPI representatives have been involved in delivering poster/verbal presentations at conferences and co-authoring journal articles.



*“Always thinking ‘what can I do’ led me to offering myself and husband to be models for the series of exercises and tasks to be used for the study implementation work package. We modelled as the dementia patient and carer, and effectively exercised for eight hours whilst a professional photographer took 1900 shots. These have been used for leaflets and work sheets.”*

## Maureen's experience of involvement in PrAISED

*“The recognition I am part of the team came when I attended the International Geriatrics Conference in Rotterdam. I was surprised to learn the PPI role was not as well developed in many European countries.”*

*“There is no doubt that the PrAISED clinicians have been instrumental in making Marianne and myself feel highly valued. For me, and I believe Marianne, the surprise is that in retirement we are able to experience the most rewarding volunteering role.”*

*“We are encouraged to contribute to every stage of the research process. I believe we have actively helped shape, refocus and practically follow through the implementation and will continue. This has resulted in some surprising and possibly unique experiences.”*

*“Marianne and I role played the patient and carer, again from memories of lived experience, to assist with the writing of the intervention manual. As part of the team we were able to be constructively honest and our colleagues used our suggestions and openly credit us. We have responded to all requests. Marianne has been a valued contributor to an interviewing panel, we have contributed to training sessions, attended the Ethics committee.”*

Reference: Research Design Service [RDS] East Midlands. (2018). Public Involvement Research Cycle. [https://www.rds-eastmidlands.nihr.ac.uk/resources/RDS\\_PPI%20Handbook 2014\\_v6%20FINAL.pdf](https://www.rds-eastmidlands.nihr.ac.uk/resources/RDS_PPI%20Handbook%202014_v6%20FINAL.pdf)

