

NIHR SPCR Masterclass

Let's talk dementia: Supporting
communication in research partnerships
involving people with dementia

17/02/2026

Sarah Griffiths (Primary care and population health, UCL)
Martin Robertson – Lived experience lead

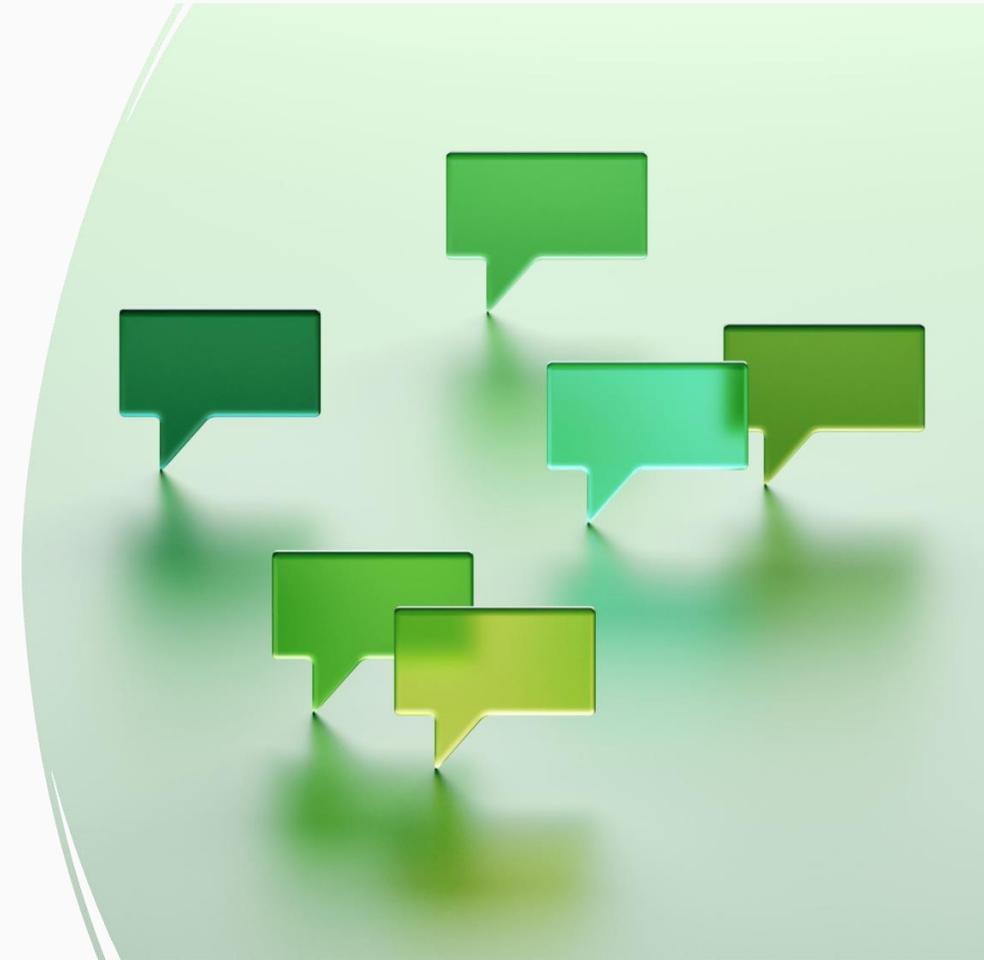


Background to the project

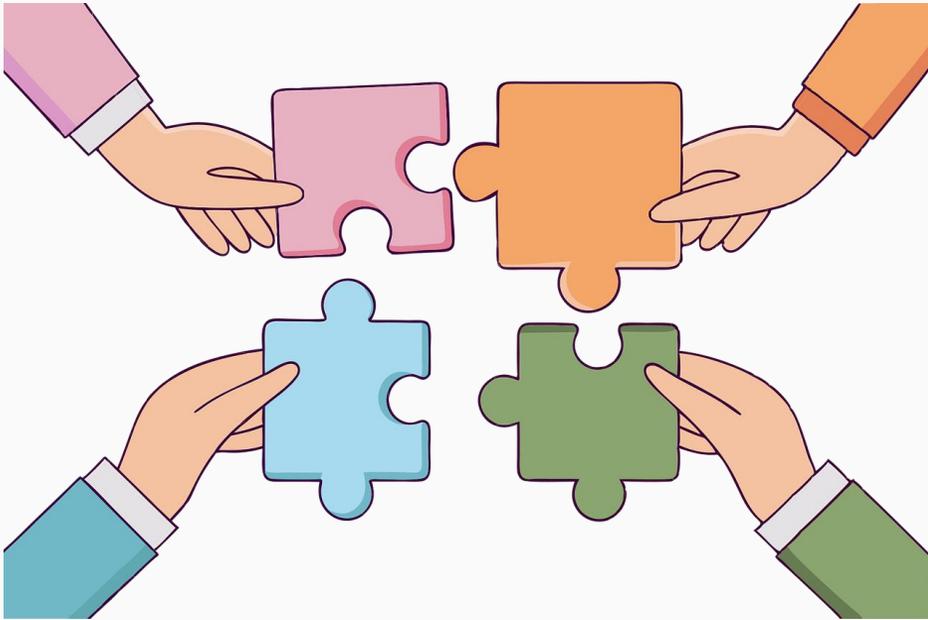
- Dementia is an urgent global health issue
- Research is essential to improve care, services, and policy
- People with dementia are under-represented in research
- This includes roles that help shape and guide research
- Use of Patient and Public Involvement (PPI)



- Communication changes in dementia can create barriers to research involvement
- Researchers report difficulty recruiting and retaining public contributors with dementia
- Clear need for person-centred communication approaches in public involvement
- Existing guidance and evidence are limited and often exclude people with dementia



Aims of project - October 2024 – March 2026



Co-produce communication guidance video

- With people with dementia and their supporters
- Practical communication strategies for research involvement
- Build researcher confidence in dementia PPI
- Support contributors to negotiate communication needs
- Improve PPI access, engagement, and retention

The team

PPIE co-applicants

Martin Robertson and
Manoj Mistry

Martin Robertson



Community co-applicant
Innovations in Dementia

Rachael Litherland



Designer

Rasmus Klastrup



Sarah Griffiths

Emily Spencer

Greta Rait

Megan Armstrong

Researchers

University
College
London
(UCL)



What is co-production?

Working together to create something

Many overlapping 'co' approaches

Shared principles

- Shared decisions & dialogue
- Respect for lived experience
- Relationships & reciprocity
- Flexibility & reflection
- Meaningful not identical involvement
- A critical mass

Co-production is a kind of revolution. It requires research to be more relational, inclusive and humane.

Staniszewska et al., 2022

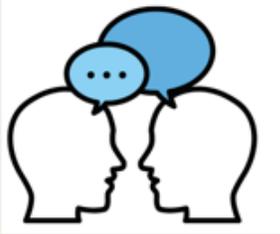
Six people with dementia and six supporters

Activities	Date	Details
Workshop 1	April 2025	Generate ideas: communication tips
Sarah meets with designer	May 2025	Develop draft content for video
Workshop 2	June – July 2025	Discuss and refine ideas
Sarah meets with designer	July 2025	Designer develops storyboard
Workshop 3	August/September 2025	Discuss storyboard and refine
Sarah meets with designer	Sept/Oct	Finalise video

Engagement outside workshops – DEEP newsletter, visiting PPI groups, inclusion of people with different types of dementia including Primary Progressive Aphasia

What do we mean by communication?

How people convey and understand messages and build connections with each other – in person/online



Speaking, listening,
understanding



Tone of voice/loudness



Reading, writing, drawing



Eye contact



Facial expression



Body language/gestures



Technology (remote meetings,
emails, post, phone calls...)

+ more

There is a lot of advice out there on general communication tips for dementia

We are interested in **communication specifically for doing PPI**

What are your good and bad experiences of communication in PPI meetings? Think about:

- In person meetings and remote meetings (e.g., via Zoom)
- Researchers helping people with dementia to understand things in meetings
- Researchers making it easier for people with dementia to communicate in meetings

What are your top communication tips for researchers doing PPI work with people who have dementia?

Guidance and video can be found [here](#)



Let's Talk Dementia:

Supporting communication in research partnerships involving people with dementia

Guidance for researchers

We are a group of people with dementia, their supporters, and researchers. We have created this guidance on how to communicate in a way that is accessible to people with dementia, as partners in research. By partners we mean people with dementia acting as advisors or collaborators rather than participants in research. We have also created a video of top tips for communication which can be found [here](#).



Examples from guidelines

Importance of silence

Be aware of fluctuations

Speed controls - video/
audio clips

Some people supported by
lip-reading

What co-production looked like in practice



- Project name
- Phil doing the video voice over
- Fun and laughter

https://www.dropbox.com/scl/fi/5qbhf36zkqlcrx6coi34o/LTD_Animation_Final.mp4?rlkey=wpxyh4qf689kxpn4ibq4eed28&st=ifq9b819&dl=0



<https://www.dropbox.com/scl/fi/wqz1yxikojkimatnlwueo/Martin-final.mp4?rlkey=oo9y720ut5951p983c7w34rk8&st=vnyo6zdy&dl=0>

REFLECTIONS FROM CONTRIBUTORS

I felt heard, listened to, informed, and like a real part of things

It's nice to have been involved from step one, not just at the end

I like that this output challenges the assumption that people with dementia can't do things

Good that at times you have done the same meetings at different times of the week to suit the varying commitments of us all

One thing we should try to change is that it's always the same pool of people coming to these types of meetings. That's not the fault of this project, but something we could highlight and work to change as a group

Learning

- Balancing two different audiences
- Experiences of supporters
- Co-production within real world budget constraints
- Co-production and leadership
- Researcher support needs

Key Recommendations for Future Projects

- Ensure early involvement
- Maintain strong communication
- Include in person meetings
- Recognise and budget for costs
- Diversify participation
- Acknowledge contributions
- Continue challenging assumptions



- Impact
- Future observational study
- Long-term potential – collection of resources

We want your feedback!

Email Sarah with feedback:

s.a.griffiths@ucl.ac.uk

OR anonymous feedback:

[LET'S TALK DEMENTIA RESOURCES FEEDBACK - Researchers and students – Fill in form](#)

[LET'S TALK DEMENTIA RESOURCES FEEDBACK -General – Fill in form](#)

Links to further information

Alzheimer Europe's position on involving people with dementia in research through PPI (2018):

<https://pubmed.ncbi.nlm.nih.gov/28513210/>

Methods and approaches for enhancing communication with people with moderate-to-severe dementia that can facilitate their inclusion in research and service evaluation (2022): <https://pubmed.ncbi.nlm.nih.gov/35156412/>

Planning and enabling meaningful patient and public involvement in dementia research (2019):

<https://pubmed.ncbi.nlm.nih.gov/31306247/>

DEEP guidance

[https://www.dementivoices.org.uk/wp-](https://www.dementivoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf)

[content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf](https://www.dementivoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf)

NIHR brief guide to public involvement in funding applications

<https://www.nihr.ac.uk/documents/a-brief-guide-to-public-involvement-in-funding-applications/24162>

<https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/co-production>

NIHR ARC Blog: [https://arc-sl.nihr.ac.uk/news-insights/blog-and-commentary/emotional-side-ppi-understanding-its-impact-and-how-navigate-](https://arc-sl.nihr.ac.uk/news-insights/blog-and-commentary/emotional-side-ppi-understanding-its-impact-and-how-navigate-it#:~:text=To%20harness%20the%20positive%20emotional,can%20help%20navigate%20emotional%20challenges.)

[it#:~:text=To%20harness%20the%20positive%20emotional,can%20help%20navigate%20emotional%20challenges.](https://arc-sl.nihr.ac.uk/news-insights/blog-and-commentary/emotional-side-ppi-understanding-its-impact-and-how-navigate-it#:~:text=To%20harness%20the%20positive%20emotional,can%20help%20navigate%20emotional%20challenges.)

Emotional impact of PPI on contributors: <https://pmc.ncbi.nlm.nih.gov/articles/PMC10951420/>

Emotional impact of PPI on researchers: <https://hexi.ox.ac.uk/patient-public-involvement-researchers/Feelings-about-involvement-and-emotional-impact>

Thank you for listening

**This guidance was funded by
NIHR School for Primary Care
Research and created by:**

Project lead - Sarah Griffiths; University
College London

Lived experience leads - Martin Robertson,
Manoj Mistry

Researchers - Emily Spencer, Greta Rait and
Megan Armstrong; University College London

Collaborators – Rachael Litherland;
Innovations in Dementia, Anna Volkmer;
University College London

Co-production workshop contributors: Philip
Angrave, Geoff Andrews, Wayne Easton,
Winnie Henry, Farzana Kausir, Manos Kumar,
Anne-Marie Norris, Francesco Palma, Reshma
Pubjabi, Debs Smith, Wade Tovey, The East
Kent 'Forget me nots'.

With support from Innovations in Dementia

*The views expressed are those of the
authors and not necessarily those of the
NIHR or the Department of Health and Social
Care*

