Co-producing a dementia research funding application with a diverse lived experience group

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UCL

Co-production

Principles: power sharing, joint ownership decisions, valuing unique skills, reciprocity, relationships

Equality Diversity Inclusion (EDI): white middle-class (Russell et al, 2020)

Co-production in dementia research: Developing interventions (e.g., Lord et al; 2022), data analysis (e.g., Dooley, 2020) reflecting on experiences (e.g., Gordon and McKeown, 2019)

Less written about co-producing a dementia research funding application

The lived experience group

Funding:

NIHR Dementia Career Development Award

Broad research idea:

Developing primary care workforce communication skills training for delivering personalised dementia care planning

Membership calls:

Social media and national dementia organisations

Representation

Lived experience:

1 person with dementia, 4 carers, 1 former carer.

2 of group experienced significant visual difficulties

Ethnicities:

Asian British (Indian) x2, White Irish, White Scottish, White English, Mixed (South Asian and Black)

Region of UK:

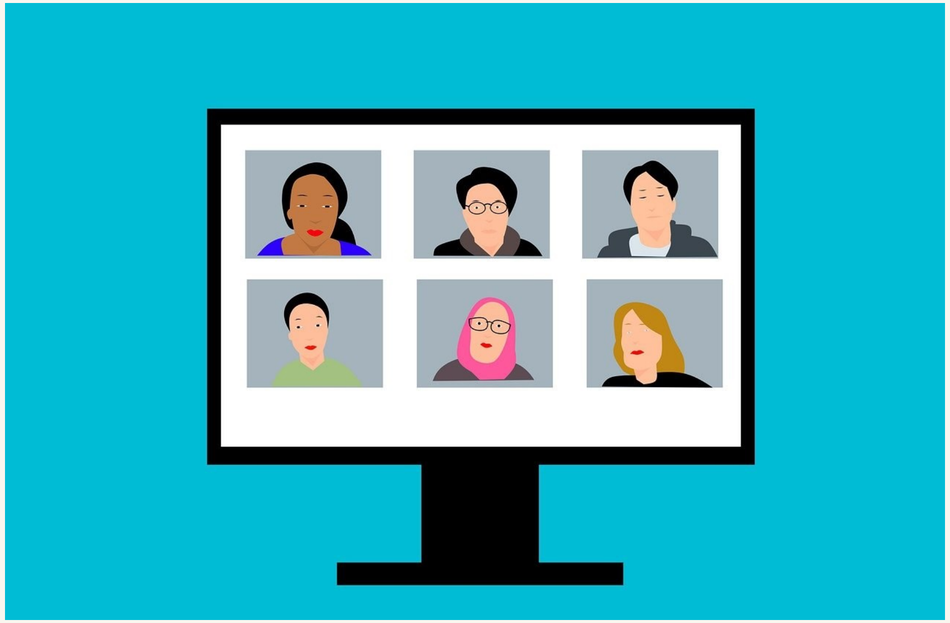
London, the Midlands, North England, Scotland

Group sessions: practicalities

8 x 90 minute monthly virtual meetings, according to funding timeline

Tried to include one ‘in person meeting’

Two co-leads



Strategies to support engagement: Scheduled breaks, clear agendas, hard copies in large print, pacing of sessions, limited screen sharing, time to build relationships, use of zoom chat, Padlet, email and google docs.

Meeting	Topic	Application timeline
1	• Purpose of group, co-creating ground rules, • **What does co-production mean to us?** • **What does personalised care mean to us?** • **Which professionals should be focus of research?**	Submission stage one – Much earlier than expected.
2	• Discussion stage one proposal • **What constitutes good and bad practice in care planning conversations?**	Successful outcome stage one
3	• Discussion/scrutiny of proposed research methods • Co-production of research title • **Discussion on inclusion of under-represented groups** in dementia research, to inform 'EDI strategy'	
4	Discussion/feedback on refined lay summary	Submission stage two
5	Literature review discussion: developing a search strategy, discussing papers retrieved from initial scope.	Invited to interview
6	Presentation and **mock interview practice**	Interview + outcome
7	Planning **co-written reflective journal article**	
8	Refinement of draft journal article	Article submission

Reflections: Diversity and inclusion

Co-lead involvement inclusive + democratic

Involved in creating something

Virtual meetings increased inclusivity

Inaccessible remuneration systems – support valued BUT feelings of being undervalued/unequal

Having a person of colour as co-lead was a signal that representation was going to be taken seriously.

It's been exciting to help create something. Normally we are just quotes in a paper.

Some studies take a long time to pay you. When you're properly paid in a timely fashion, you feel valued.

Co-creation of project name

CAPPD: Communication **A**spects of **P**ersonalised care **P**lanning in **D**ementia

Reflections: Reciprocity

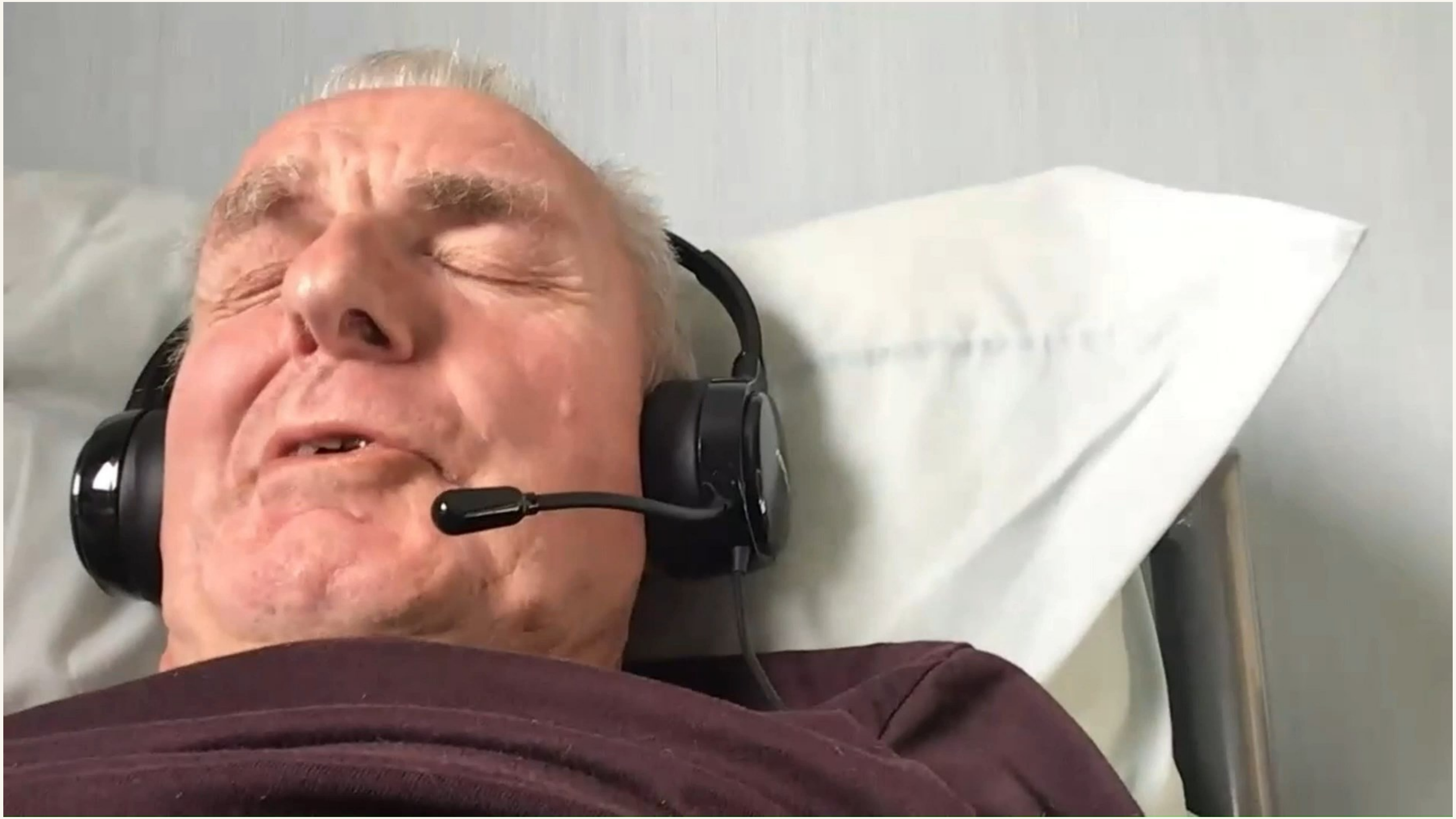
Learning from each other: ‘catnip to the brain.’

Developing knowledge and skills

Reawakening parts of self and feeling valued

Opened door to other opportunities and relationships

As a carer you can lose your sense of self…..this reminded me of my former qualification as an Occupational Therapist and makes me feel good about myself. My experience is valuable and is recognised by the group.



Reflections: challenges

Virtual meetings: less natural for turn taking/demonstrating empathy

Equality Diversity and Inclusion (EDI) discussions:

- Experiences of marginalisation individualised and emotive
- Competition about representation of marginalised communities
- Ideas for better facilitation

Researcher reflection: One member told us about how he has supported a relative in care planning conversations with a health care professional. The relative was a devout Muslim woman. When she requested support with meeting her spiritual needs, the professional responded there was nothing that could be done about that and rolled her eyes…..we talked about what an alternative personalised response might look like:

'Let me try and understand more…Let's work out how we can make that happen.'

Conclusions

It doesn’t matter if initial idea is vague. Come with open mind.

In future- increased representation of people with dementia and those from other under-represented groups within dementia e.g., LGBTQ+ community.

People with dementia can be role models and advocates - challenging binary narrative: tragedy or living well (Ward and Sandberg, 2023)

Conclusions

Cost in time for relationship building. Research culture needs to be kinder and more focused on building relationships (Staniszewska et al; 2022)

Did we do co-production?

Create through combined talents = ‘critical mass’

Accessible, streamlined and flexible remuneration systems = equality of opportunity

> ‘…ensuring everyone can take part in the elements they choose to be included in, and support and training is provided for any elements that may require this’
> (Warren et al, 2023)

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Thank you for listening!

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