

ILD ECA network steering members

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Dr. Charmaine Brown (ECA Lead-School of Education)

Dr. Tiffeny James (ECA Lead-ILD)

Dr. Yemi Onilude (ECA Lead-School of Health Sciences)

Dr. Marianne Markowski (ECA Lead-School of Health Sciences)

Prof Andrew Clark (ECA Champion)

Prof Claire Monks (Deputy Director ILD)

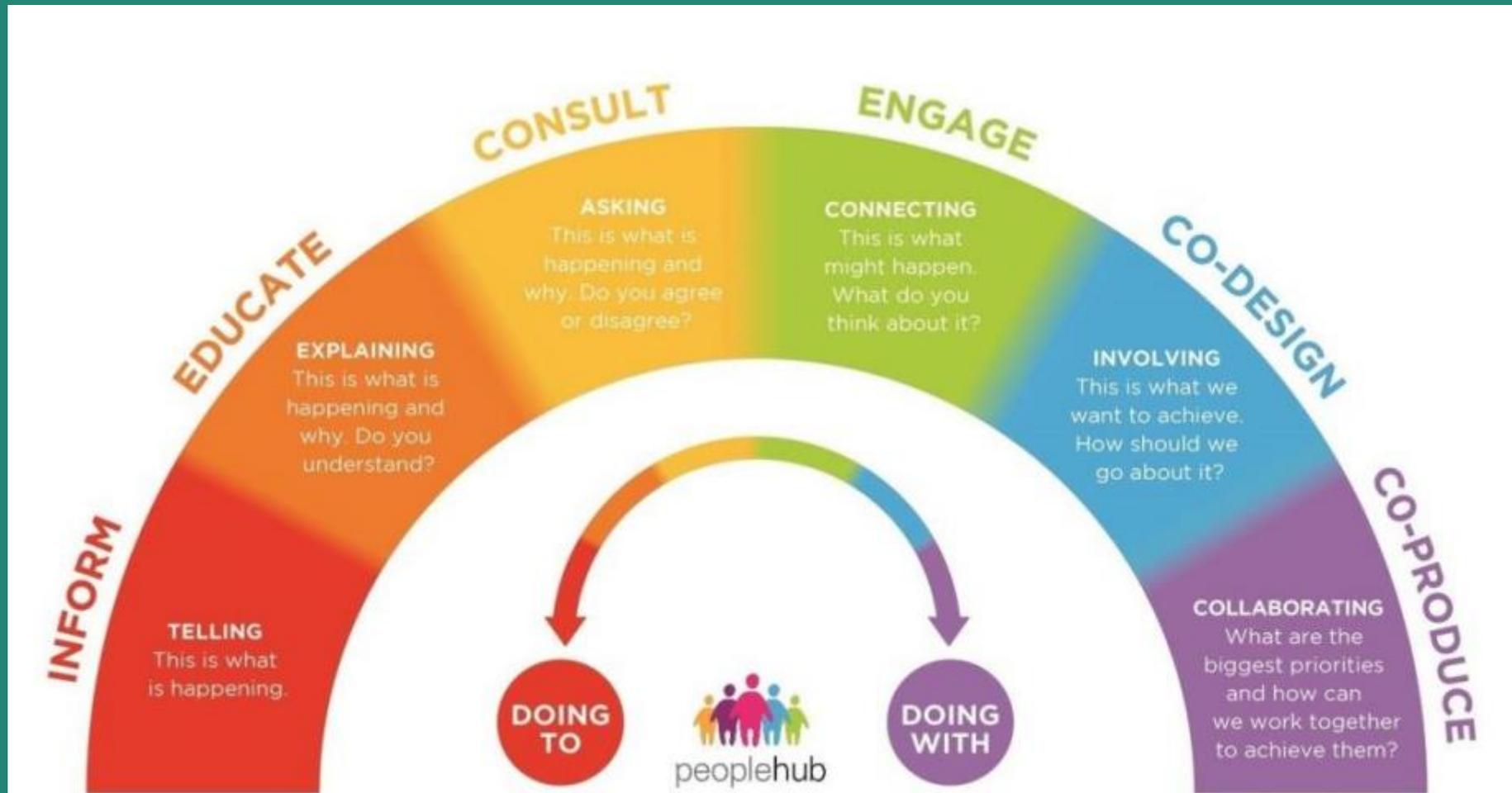
Prof Rosanna Pacella (Associate Dean Research and Knowledge Exchange, Director ILD)

What does co-production mean to you?



“Nothing about us without us”

Slogan popularised in the UK in the 1990s by the book written by James Charlton



Source: [People hub – Co-production-a-new-defintion.pdf](#)

Participatory
Research (PR)

Action Research
(AR)

Co-Creation

Co-Design

Participatory Action
Research (PAR)

Community-based
Participatory
research (CBPR)

Co-production

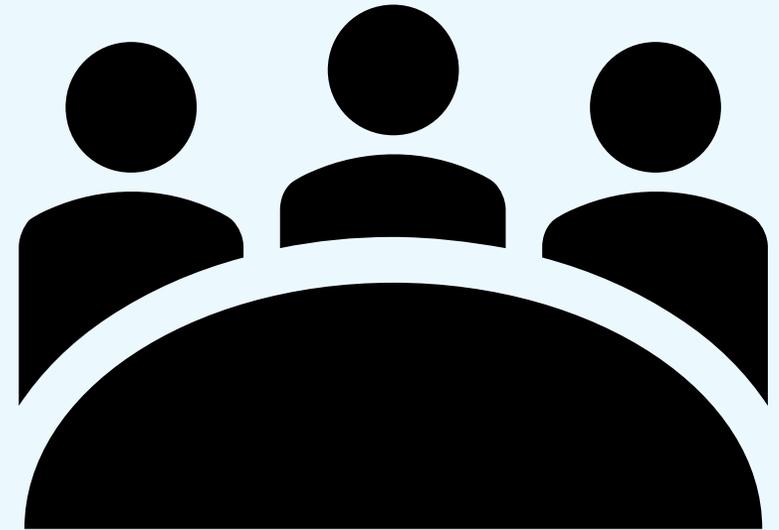
Emancipatory
Research

Inclusive
research

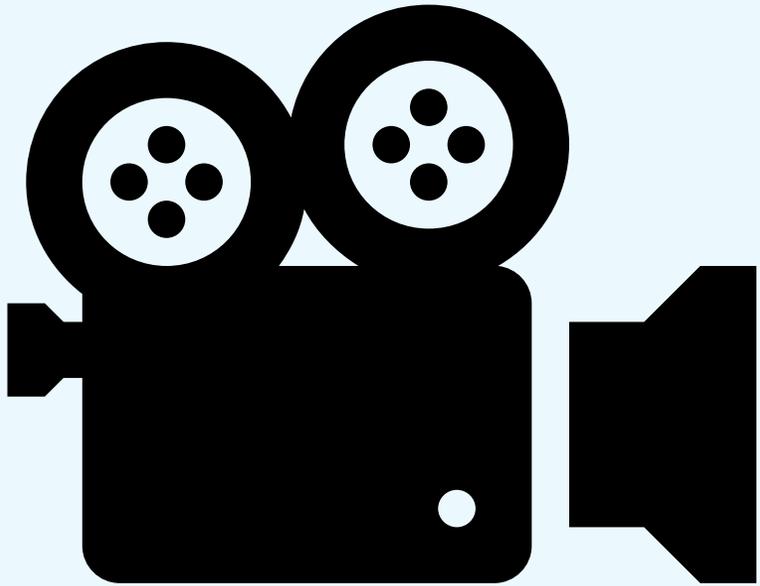
Patient and public
Involvement (PPIE)
or (PPI)

Working with a Group

- For the past three years, I've worked with Bexley Mencap in Bexleyheath in London, United Kingdom.
- This is a group of people with learning disabilities who advocate for themselves.
- We have met several times, to talk about their ideas about how people with learning disabilities can be healthier.

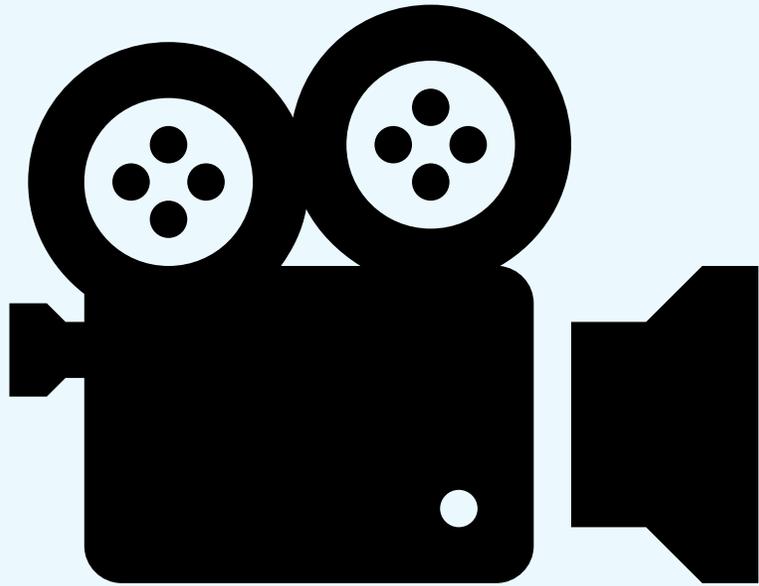


Making a Video



- Some of the group members suggested making a video about bowel screening.
- This is because not everyone who needs a bowel screening kit does this.
- There are many reasons why someone wouldn't do a bowel screening kit.

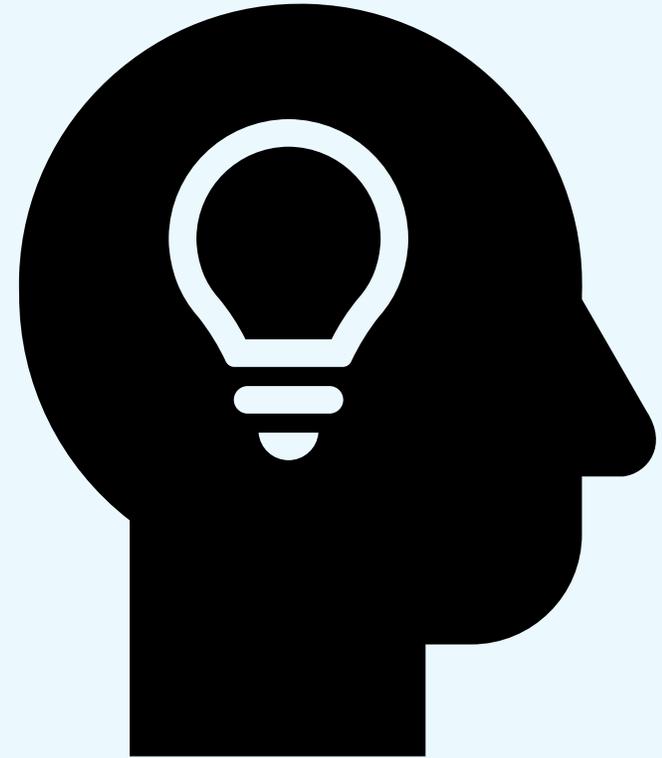
Making a Video



- In May and June 2024, we met to talk about what would go in the video on bowel screening.
- Once we agreed what would go in the video, we met in July 2024 to film the video.
- We finished the video in July 2024.

What we learned

- Making the video was a bit hard, and both the self-advocates I worked with and myself learned a lot about how to work together.
- We want to share this video to encourage other people to get bowel screening.
- We are making more videos about different health topics, such as what doctors and nurses should know when providing care to patients with learning disabilities.



Thank you!

**G.Breau@
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- The members of the Friday Respect group at Bexley Mencap
- Jane Menzies and Steve Grimsey (staff at Bexley Mencap)
- Sarah Haddou (the research assistant who edited the video)
- The University of Greenwich (for providing funds to create the video through the ECA Pilot Project Fund in 2024)

CONSIDER study

18-month study

Advisory group 1

Advisory group 2

Advisory group 3

WP1: Situational analysis

- Scoping review of existing literature
- Mapped policies, legislation, guidance
- Audited 152 UK local authorities
- Identified major gaps in information and support
- 12 Interviews with staff and volunteers (upcoming)

WP2: Qualitative Interviews

- 24 interviews using photo elicitation
- People with dementia and family carers (n = 12) and homecare professionals (n = 12)
- Exploring experiences and good practices around distance care

WP3: Two co-production workshops

- Distance carers, homecare staff, and others (n = 12)
- To develop 3 key outputs**
- ✓ Tips for distance dementia carers
 - ✓ Guidance for homecare workers
 - ✓ Priorities for research and policy

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Co-production

A partnership approach where researchers, practitioners, and people with lived experience **share power and responsibility throughout the entire research process**—from agenda setting to dissemination. It emphasises reciprocity, mutual respect, and shared ownership.

Co-creation

A collaborative process in which researchers and stakeholders jointly generate knowledge, solutions, or innovations. It emphasises **shared idea generation and iterative development, often across multiple stages of a project.**

Co-design

A specific form of co-creation focused on jointly designing services, interventions, policies, or research tools. It usually involves **structured workshops or activities that bring together professionals and end-users to develop solutions.**

Example 3: Co-production In Simulation- Based Learning With Experts By Experience of MH Conditions

Lauren Philpott



Simulation for Mental Health

Project Scope: -

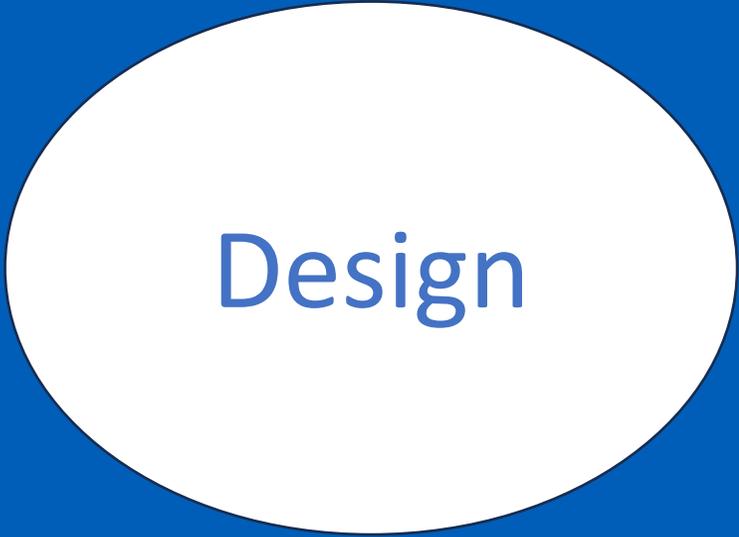
Work Alongside Experts by Experience (EBEs) to Develop, Deliver and Evaluate an Innovative Regional Programme In 3 Practice Locations

Participants:

MH nurses, psychiatrists, paramedics, OTs, police officers, GPs



Simulation for Mental Health



Design

- Three EBEs agreed to take part
- Contacted via charities, and support groups
- Initial meetings individually
- Their experience shaped topics for the simulation days
- Worked with them to design each day's activities and scenarios



Deliver

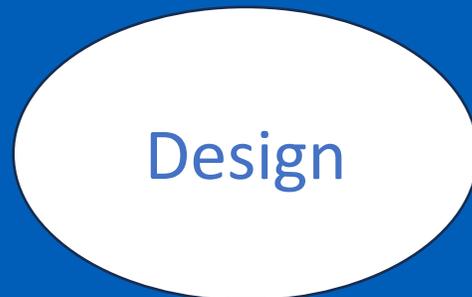


Evaluate

Simulation for Mental Health



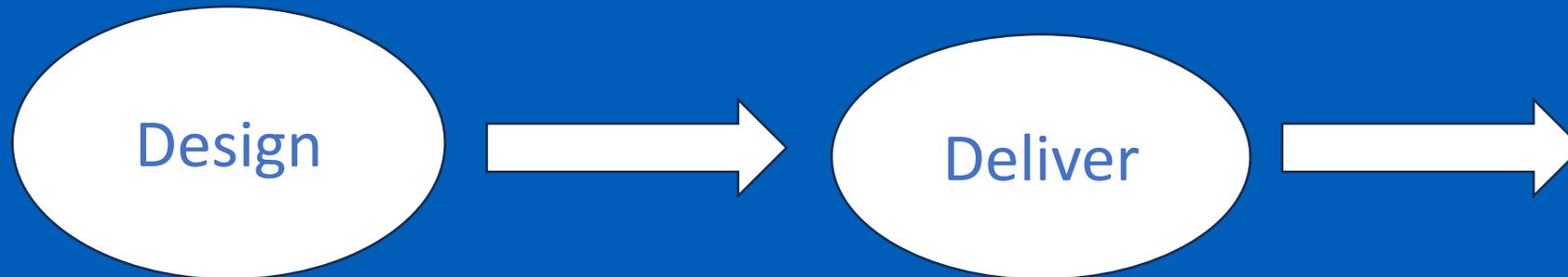
- Each day focused on different topic: psychotic disorders, depressive disorders and personality disorders
- EBEs attended, mix of face-to-face and virtual
- Where appropriate, provided insight during debriefs



Simulation for Mental Health



- Feedback from participants evaluated alongside EBE
- Themes identified
- Recommendations taken forward for the second iteration



Simulation for Mental Health

- **Further Work Involving EBEs:**

- Work written up for Journal of Healthcare Simulation
- Presented at multiple conferences
- Further iterations of the course delivered

- **Compensating the EBEs:**

- EBEs were paid for their time, using vouchers
- This was their preferred method of payment, as some were receiving benefits, so couldn't be paid using traditional methods

Any questions to the speakers

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Thank you



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