

The background of the slide features a stylized illustration. At the top, there are two large, tangled balls of yarn, one in a golden-brown color and the other in a darker brown. From these balls, numerous long, thin strands of yarn extend downwards, creating a complex, web-like pattern that fills much of the upper and middle sections of the slide. In the bottom right corner, there is a cartoon illustration of two people. The person on the left is a woman with long, wavy brown hair, wearing a brown top, and she is smiling while giving a thumbs-up. The person on the right is a woman with short brown hair and glasses, also wearing a brown top, and she is pointing her index finger upwards. To the left of the woman with glasses is a speech bubble containing a large black exclamation mark. The entire scene is set against a solid grey background.

Messy, meaningful and designed together

Reflections on involvement of the public in PhD research

Tristi Brownnett – May 2026

Introducing me

- Theme Lead - EIW
- RN, SCPHN (OH)
- Public Health Lecturer
- Wellbeing Researcher
- PhD Candidate: The CLIO Study - cancer-related loneliness
- Chair: Participatory project to address help seeking behaviours for early lung cancer screening and diagnosis
- Future Plans: Co-design loneliness interventions with stakeholders



Some key terms:

- **Participatory approaches** - research approaches where the people affected by the issue are actively involved in the research process.
- **Co-creation** – Open-ended and flexible, engages participants throughout the different stages of research(Chastin *et al.*, 2025)
- **Co-production** – Typically, shared governance but focuses on implementation of a predetermined initiative (Vargas *et al.*, 2022)
- **Co-design** – Tends to be focused on designing something specific, usually in workshops to generate ideas, interventions, prototypes etc. (Vargas *et al.*, 2026)
- **NIHR have principles**: Shared power, includes all perspectives and skills, equity, reciprocity, building and maintaining relationships
- **PPIE** – Public Patient Involvement and Engagement

Where my
research
began



Problem: *The loneliness of cancer is a profound and isolating state that is difficult to articulate, insufficiently understood by others, and frequently overlooked within the design and delivery of formal services and charitable support.*

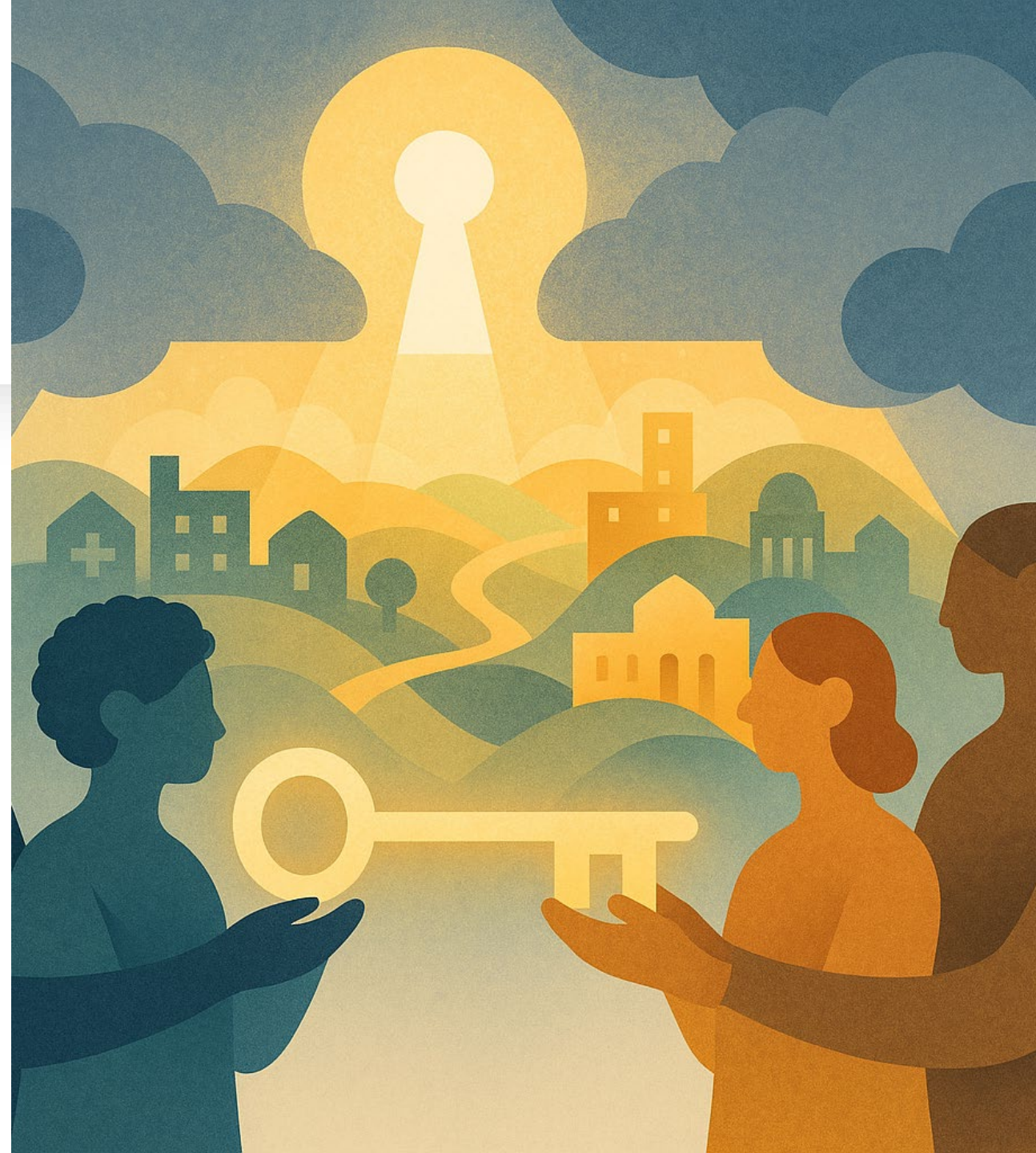
Why I wanted to work with PPIE

- Experts by experience
- Diverse and complex lives with realities that I can't imagine
- Others who could sense-check my ideas and understanding
- Others who may have better ideas
- I hoped it would improve the quality and impact of the research
- It felt right and I wanted to try it



Issue 1: Getting Connected

- KSS ARC conversations
- Local third sector organisations
- NHS R&D
- Learning about how to involve PPI more
- **Learning point:** Be prepared to do the leg work – go to where people are!



Issue 2: Tensions I experienced working with PPIE

- This is my PhD – It has to bring a unique contribution
- I have no funding
- Slow pace of research
- Achieving equity in the group
- Managing diversity of voices and experiences
- Treating PPIE fairly and meeting their needs
- Making them equal partners in research
- **Learning point:** Have reflective conversations often



Issue 3: Building and formalising PPIE

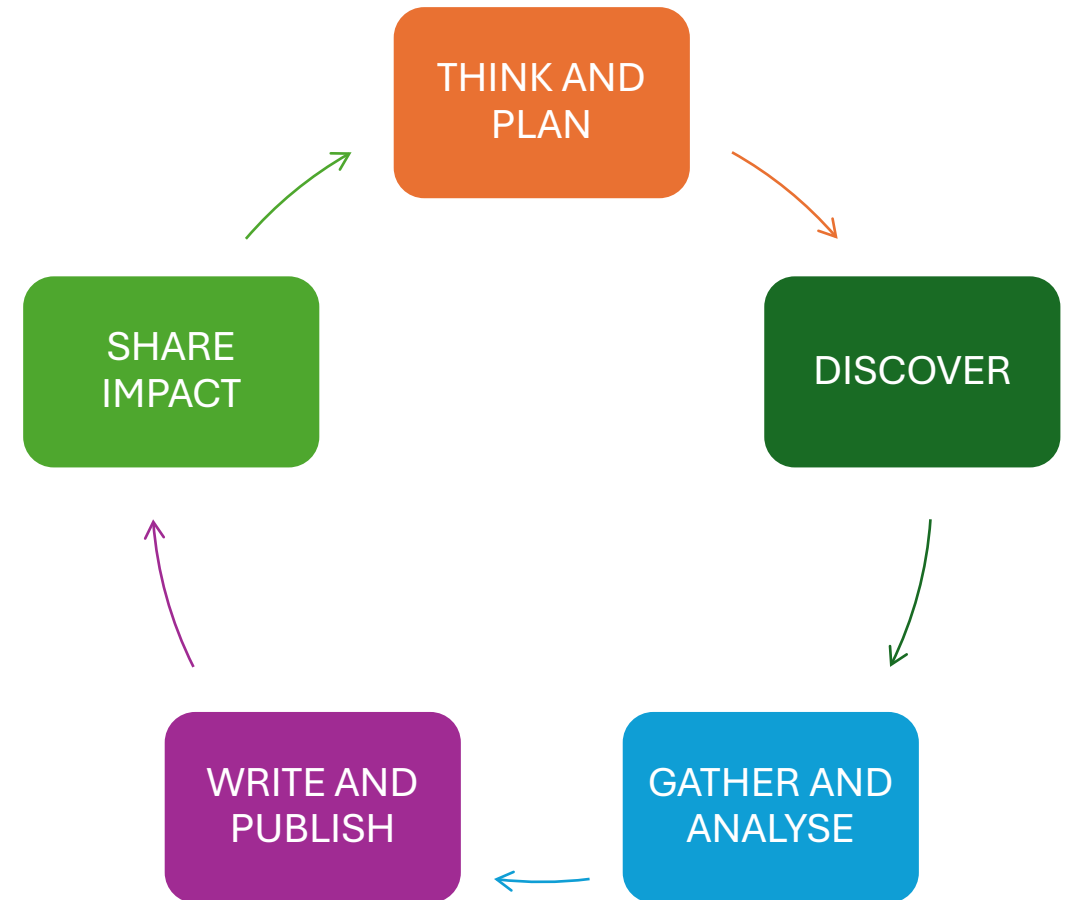
- They don't know each other
- Building trust and sense of security
- Keeping them in the loop even when there was nothing to tell
- 'Deciding' where they could bring meaningful contributions and check expectations
- Formalising the group with a terms of reference
- **Learning point 1:** Be patient! working in groups takes time.
- **Learning point 2:** Being clear about where you are heading and what contributions each person brings
- **Learning point 3:** Recap and take stock to check group alignment often



Doing research with the public is easier than you think...

PPIE group actively involved in developing research materials:

- Contributed to interview design, questions and pilot testing
- Advised on language and structure of interview questions
- Helped create plain English summaries and recruitment materials
- Shaped interview approach to ensure participant comfort and inclusion
- Supported writing and reviewing of NIHR funding application
- **Learning point:** Don't assume digital literacy!



Would I do it again?

- They shaped the research
- They shared the load and the journey prior to my collecting data
- They helped me make sense of some things that were basic for them and helped be informed e.g., survivorship, story/journey

They told me about:

- The importance of having somewhere to be
- To not be surprised if people tell their whole story
- To not do research on Teams and instead invite people to the university
- To be mindful of hidden disabilities that influence loneliness, and responding to distress
- To recognise that participants may cancel at short notice but leave the door open for them



Did I learn anything else worth sharing?

- I would do more leg work at the beginning as it does take a huge amount of time to get the right people, arrange, and facilitate.
- PPIE Members were generous with their time, insight, and honest about their vulnerability - facilitation and group bonding is important.
- Try to get funding to cover the costs of running PPIE, lunch, car parking, travel, postage etc.
- It was a good experience for me but not without tensions:
 - For example, some members expressed a strong desire for the study to prove that their loneliness exists and to demonstrate that the system does not adequately meet their needs.*
 - For example, it's my PhD and I am responsible for its delivery, ultimately there are limits to how much I can expect from them and things I must do for myself.*

Thanks for
listening

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References

- Chastin, S., Smith, N., Agnello, D., An, Q., Altenburg, T., Balaskas, G., et al. (2025) 'Principles and attributes of evidence-based co-creation: From naïve praxis toward a trustworthy methodology - A Health CASCADE study', *Public Health*, 248, 105922.
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