Researching together

Putting PPIE co-researchers at the heart of research

Background

- Creating a new treatment pathway for people with type 2 diabetes (T2D).
- Delivered by trained coaches currently delivering TDR interventions.
- To be succesful the pathway must reflect the experience living with T2D and work for as many different people as possible.
- **Aim**: incorporate public involvement to ensure NewDAWN pathway is person centred and grounded in the lived experience of T2D.

Participant agrees to take part, is randomised by GP

Gold standard NHS treatment (Low cal diet)

NewDAWN service

Call/text from coach and referral to weight loss programme(s)

Regular support to help find suitable programme

NewDAWN

Approach

- PPIE is required by funders but can be tokenistic commenting on research... as a "necessary nuisance".
- **How can we put PPIE at the heart of developing the NewDAWN serivce?**
- From researcher and PPIE perspectives, we considered: What does meaningful, PPIE-led, involvement look like? And what worked/did not work well in our approach?

WP1

Interview design → Sample design → Interview recruitment → Interviewing participants → Descriptive coding → Identify patterns and learnings → Develop training recommendations → Translate recommendations to aide memoire for coaches

Evaluation

PPIE Co-researcher

- Recognition of expertise and experience
- Common ground experience with study participants
- Being 'offered' > applying
- Less time than expected - could do more?
- Research skills courses not designed for the public

Study researchers

- Enhanced quality and acceptability by the public
- Improved relevance and impact of findings
- Shine a light on possible blind spots
- Difficulty managing levels of research expertise
- Co-researcher's time + meaningful involvement

Conclusion and Implications

- Including a PPIE co-researcher firmly cemented the patient view at the heart of the NewDAWN programme.
- Difficulty achieving parity between meaningful co-researcher involvement, need for research skills training, and managing PPIE co-researcher time with demands of the research.
- Meaningful involvement means facilitating co-researcher input throughout and having co-researcher led decisions.
- Proactive researchers encourage PPIE involvement by valuing their expertise and experience.
- Democratising research is gold standard practice and co-research is one step in that direction.

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