

Understanding participation benefits to Patient and Public Involvement as an enabler to engagement in Clinical trials: Reflections from the STADIA Trial

Colleen Ewart¹, Youth Lab², STADIA Parents and Carers², STADIA TSC PPI representatives², Kirsty Sprange³, Ellen Bradley⁴, Laura Wyatt³, Kristina Newman^{4,5}, Alexandra Lang⁶, Kapil Sayal⁴

¹Patient and Public Involvement lead, Institute of Mental Health, University of Nottingham/Nottinghamshire Healthcare NHS Foundation Trust, ²STADIA Patient and Public Involvement Groups and members, ³Nottingham Clinical Trials Unit, School of Medicine, University of Nottingham, ⁴Institute of Mental Health, University of Nottingham/Nottinghamshire Healthcare NHS Foundation Trust, ⁵Psychology Department, Nottingham Trent University, ⁶Faculty of Engineering, University of Nottingham

Background

To deliver and implement clinical and cost effective health care it is essential to engage patient and public collaborators.

Our Patient and Public Involvement (PPI) team have evaluated a range of feedback from our PPI contributors and developed thematic headlines of mutual benefits that are not always recognised by research teams.

Better identifying and understanding these mutual benefits could assist with recruiting and retaining PPI partners to influence research and improve inclusion and diversity represented in PPI and trials.

We reflect on our experience of PPI involvement in the NIHR Funded STADIA Trial; an RCT investigating a standardised diagnostic assessment tool for children and adolescents with emotional difficulties.

Methods

To engage PPI contributors with differing backgrounds and experiences of PPI a wide range of accessible methods have been used to encourage participation, develop working relationships and elicit input from people in different ways [1]. Such as:

- ❖ Varied ice breaker activities
- ❖ Interactive and multimodal workshops
- ❖ Collaborative work exercises
- ❖ Surveys
- ❖ Creative design
- ❖ Debrief sessions & 'thought tree' (Fig 1)



Figure 1: Thought tree

Results

The following depicts the major enablers to engagement experienced by a range of PPI contributors to STADIA. Inclusive of STADIA PPI Co-Investigator, STADIA YouthLab members, STADIA Parent/Carer PPI Team.

| | |
|----------------------|--|
| Upskilling | Upskilling in digital collaborative working (teams, online whiteboard, surveys, polls) |
| | Upskilling in research methods (data analysis, qualitative methods etc) |
| | Development of transferable skills, leadership, project management. |
| | Learning about research processes |
| Research Community | Continuity of inclusion from start |
| | Feedback loop to ensure participants are informed about value of their contribution |
| | Continuity of communication |
| | Creative licence in workshop activities |
| Shared experience | Shared sense of ownership in the STADIA project |
| | Social side to involvement and meeting others in similar situation |
| | Mutual support, learning and sharing coping strategies |
| | Meaningful and valued contribution |
| Personal development | Confidence building |
| | Increased resilience |
| | Documented recognition of achievement and skills |
| | Personal ambitions and future opportunities |

Figure 2: Key factors in developing and maintaining engagement in PPI activities



Conclusions/Discussion

To improve meaningful and diverse engagement in clinical trials, it is essential to understand the wider benefits of participation. A more in-depth understanding of these benefits could facilitate a positive cycle of co-creation and development of true research partnership.

Benefits of participation could be valuable in PPI recruitment and retention to improve inclusivity and diversity should be further explored.

[1] Furniss D, Lang AR & Ewart C (2021) Enhancing Patient Ergonomics with Patient and Public Involvement in Research Projects. Ch13. In The Patient Factor: Theories and Methods for Patient Ergonomics (1st ed.) Eds Holden RJ & Valdez RS. CRC Press, Boca Raton.

