Birmingham Health Partners
Collaboration. Innovation. Application.

Patient and Public Involvement and Engagement (PPIE) Case Study

Interventions for antipsychotic-induced weight gain in people with severe mental illness (SMI) - The Resolve Study – Prof. Ian Maidment, Aston University - with McPin Foundation

Aim

Embed the lived experience of patients with SMI at every level of the study. Patients to be active members of the project team to shape the research design including a co-applicant.

12 public contributors involved

Methods

25 Online meetings (Jan 22 – April 25)

In-person meeting

Best practice

- Lived experience representation was present at every level throughout the study from the very start
- Mix of embedded PPIE roles in project team and a structured Lived Experience Group (LEG) for day-to-day decision making and focused contributions at key points
- Allowed plenty of time to prepare patients for involvement activities, offer feedback and sense check the study
- PPIE recognised nationally with a team member receiving the Association for the Study of Obesity Ken Clare Award in recognition of best practice.

Involvement included

- Patients attended project meetings, shared lived experience to shape research direction, key areas for focus and how it was conducted.
- Reviewed language in all materials and outputs to ensure it was clear and non stigmatising
- Contributed to discussions on data collection and co-designed research questions to reflect the realities of living with antipyschotic-related weight gain.
- Patients advised on the data interpretation to ensure this was relevant to them
- Co-designed dissemination of study results including reaching a diverse audience. Contributed to recorded interview sessions, blog series and social media quotes.
- Co-presented at national and international conference and a webinar
- Patients challenged assumptions within the research team

Impact of PPIE

- Patients shaped interview questions to ensure a non-blame approach was used in all language and a holistic approach to the interviews was adopted for e.g. considering issues such as hospital food.
- Patient input led to changes in focus of study such as double stigma (e.g. the SMI and weight gain and the impact on service users).
- Patients flagged the lack of existing literature on intense food cravings and binge eating which led to changes in the search strategy and interview guides to ensure those issues were explicitly explored.
- LEG members noted that antipsychotic-related weight gain was rarely discussed in routine care, prompting targeted interview questions about these conversations and their impact on access to support.
- PPIE had impact on personal empowerment – one patient won a prize for presenting a conference poster
- Patients felt reassured this was seen as a real issue, not a result of poor behaviour choices and that others were in the same position.