“Patient and Public Involvement (PPI) can often be something bolted on to research in a way that fits with the existing research plan. This makes research much easier to press ahead with, as the conflicting and changing opinions of the public do not need to change the planned course of progression. Unusual then, that PPI was considered to be an integral part of Power Up, and awarded time, resources, and influence. The young people who were involved have made great use of this newfound power. The Power Up app is fantastically tailored to the target audience because the target audience made it. The novel approach to PPI used in the project was important in hearing and using the young people’s views...I would urge future researchers to consider PPI as a vital part of research proceedings, as it has been in Power Up.” Project worker, Power Up

The Power Up study, supported by NIHR CLAHRC North Thames, has made the involvement of young people an integral part of the research process in work to develop an app to support shared decision-making in mental health. Power Up is a four-year research project to develop an app for young people to use from their first assessment with Child and Adolescent Mental Health Services (CAMHS) to empower them to be actively involved in decision-making.
Young people were active participants in taking the concept of a shared decision-making tool through design, prototype, and testing through three different types of involvement: governance of the project; needs and environment analysis; and detailed input for the development of the intervention.

PPI was embedded into the project model from the outset, to be iterative and cyclical informing the development and direction of the digital tool at each stage. Involving service users resulted in the identification and implementation of multiple changes to the app, both conceptual and tangible. Several challenges associated with PPI were also encountered, warranting future research and discussion.

The team has published their involvement experience in a paper published in special themed edition of the Journal of Health Design entitled Patients as co-designers to improve the quality of care.
Power Up: Patient and public involvement in developing a shared decision-making app for mental health

Chloe L. Edridge, Julian Edbrooke-Childs, Kate Martin, Louise Delane, Pheobe Averill, Amy Faltham, Jessica Rees, Grace Jeremy, Louise Chapman, Michael P. Craven, Miranda Wolpert

1. Evidence Based Practice Unit, UCL and the Anna Freud Centre, London, United Kingdom
2. Common Room Consulting Ltd, London, United Kingdom
3. NHR MindTech/ModTech Co-operative, Institute of Mental Health, University of Nottingham
Innovation Park, Nottingham, United Kingdom


Corresponding Author:
Chloe L. Edridge
Evidence Based Practice Unit
UCL and the Anna Freud Centre
London, United Kingdom
chloe.edridge@ucl.ac.uk

SUMMARY
Young people as active partners in the design of interventions is increasingly considered an integral part of research. In this project, young people were co-designers in a digital intervention for shared decision-making in mental health services. They were involved in three ways: governance of the project, needs and environment analysis, and detailed input into the development of the intervention. From the outset, the project model was intended to be cyclical, allowing for it to be built into the project plan and to identify and implement seven key themes of change.

Key Words
PPI; app; MHhealth; shared decision-making; co-design

ABSTRACT
Background
The importance of patient and public involvement (PPI) in designing interventions to support young people's mental health is becoming a central tenet of the research process. Existing research has indicated that co-design with service users may help to engender multiple improvements in research projects, from design through to applications of study findings.

Aims
The aim of this study is to examine our experience of making the involvement of young people an ongoing part of the research process. We report on PPI in relation to a feasibility trial of the development of an app called Power Up, which is designed to support shared decision-making in mental health.

Method
Young people, carers, and clinicians were involved in each aspect of the project from governance, needs and environment analysis, to development and revisions of the Power Up smartphone app intended for use within child and adolescent mental health services. Involvement was achieved through ongoing contributions to steering groups, co-design workshops, and interviews. The project model was approached as a cyclical multidirectional process of ideas, PPI input, reflection, and alterations.

Conclusion
PPI was embedded into the project model from the outset, to be iterative and cyclical informing the development and direction of the digital tool at each stage. Involving service users resulted in the identification and implementation of multiple changes to the app, both conceptual and tangible. Several challenges associated with PPI were also encountered, warranting further research and discussion.

BACKGROUND
Mental health problems are one of the main causes of overall disease burden worldwide. Statistics show that lifetime DSM-IV disorder prevalence estimates are 18.1–36.1 per cent. Furthermore, it has been shown that half of all lifetime cases of mental illness begin by age 14, providing support for continued research into mental health intervention and support.