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Designing research through lived experience of young people across Sussex

Sixteen young people with lived experience of mental health got together in May to help design a research study into the psychological impact on Covid-19 on young people in a project led by the University of Sussex and funded by NIHR Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS).

Led by Dr Sam Robertson, Lead for Patient and Public Involvement and Team, at Sussex Partnership NHS Foundation Trust, the aim of the meeting was to explore, identify and consult on different research questions, survey styles and methodologies.

The hour long session, which took part at the [Virtual PPI Youth Café](#), a space where young people, with lived experience, can learn about mental health research and get involved, was led by Abigail Thomson and two research assistants, Elise Armsby and Amy Pound, from the Research and Development Team at Sussex Partnership NHS Foundation Trust.

Abigail Thomson, PPI Youth Café Session Co-Ordinator and Community Outreach, said: "Our Virtual Youth PPI café is a collaborative peer-based network where those aged 16-22, with lived experience, can come to learn about, and be involved in research that impacts them. This space is entirely youth-led and gives young people the opportunity to tell us what they feel is important to them, using their unique experience to guide researchers who are carrying out research centred around children and young people. It aims to improve youth involvement in research, by involving young service users from start to finish."

Professor David Fowler, Starting Well Theme Lead ARC KSS, said: "The PPI Youth Café has been a great way for us to talk to young people with lived experience and bring a fresh perspective and invaluable to our research methods."

"Members of the Youth Cafe who took part were invited to look the research questions aimed at young people to find out what their experiences they are having as we come out of lockdown and they had as a result of the pandemic. They were asked to think about how the question were phrased and worded and to share their thoughts on some of the resources and handouts available. Their feedback, creative ideas and individual contributions will now help us to tailor our research study to meet the needs of young people."

The PPI Youth Café is part of a continuing drive towards ensuring that patient, public and carer involvement is more meaningful and more representative of the community that we serve. There are physical cafes in community settings and also virtual cafes that reach out to communities who are underrepresented in research, such as young people, BAME communities, as well as people with dementia and their carers.

Anybody looking to get involved in the Youth PPI Café, or find out more can email InvolvementInResearch@sussexpartnership.nhs.uk