

The Youth PPI Cafe

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Sussex Partnership's Youth PPI Café is a hugely successful project that is engaging 'hard to reach' young people. The Youth PPI Café offers a youth-led space for **those aged 16-22 yrs old** to be heard, working alongside dedicated **clinicians and researchers to take local research and service development projects forward**.

Our innovative project has generated a lot of interest from young people interested in mental health research and service users; researchers; individual clinicians and CAGs; NHS managers; ARC; PPN; 3rd sector organisations such as McPin; and other NHS Trusts.

What is the Youth PPI Cafe?

The Youth PPI Cafe **supports and empowers** more young people to not only become involved with research, but to be part of the co-development process of growing our work and steering research questions, and service development. The PPI café can really be part of an individual's recovery and as an **agent of change** within research culture - **putting the voices of young people at the heart of every decision being made**. We have shown through the pilot and unforeseen world events that the PPI café model is incredibly adaptive and responsive to need.

The young people that make up the group come from a **range of backgrounds**, and were recruited through ChYPs & CAMHS services, local schools, colleges and charities working with young people. Optional **inductions** are set up, and led by the team to ensure new members are comfortable in joining.

Sessions are held **once a month**, and each session explores a different area of research deemed important by the group. As members of the Youth PPI Café, young people are awarded the title of **"Research Advisor"** which can be used on CVs and in references. They are also **paid for their participation**. The Youth PPI Cafe network is now made up of **more than 100 young people**.

Outside of sessions, young people can get involved in writing for our newsletter, about an area of mental health research they are passionate about, posting on our Instagram, joining in with feedback sessions to shape the group, and taking part in events.

"Again, I'd like to extend my thanks. The input of those in the group has been incredibly valuable and I'm super appreciative of it. [...] The young people were incredibly thoughtful in relation to my project, and I can tell that they have a lot of empathy and compassion for others who may be involved in research." - Researcher who attended the Youth PPI Cafe

"I'm unbelievably grateful to you all for all your work on this. I've written so many drafts and sent them to so many different researchers and clinicians, and by far this is the best feedback I've had" - Researcher who attended the Youth PPI Cafe

A network of over 100 young people

Background and Context

A wider pilot PPI Café project (for all ages) was funded by an Innovation Grant from Heads On (2019 to 2021). Our desire was firstly to **increase the diversity of the people that get involved with research** in Sussex Partnership NHS Foundation Trust (SPFT), and secondly, to **go out into the community** instead of expecting people to come to hospital settings to talk about research. SPFT's Youth PPI Café was established to specially facilitate the engagement of young people in research across a number of topic areas.

The Youth PPI Cafe was **formed collaboratively**, based on preliminary discussions held with a panel of approximately 20 young people in January 2020. These discussions formed the basis of many of our approaches in setting up the Youth PPI Café, particularly around the format of the virtual sessions, and effective methods of outreach and engagement.

The Youth PPI Cafe launched in May 2020, with the following aims: to ensure that **young people can be actively involved in decisions on a range of research** relating to children and young people, and use their **unique lived experience** to refine service development.

"Young people working together for useful causes is a lovely thing to see and be a part of" - Youth PPI Cafe Member

"This group is interesting and worthwhile" - Youth PPI Cafe Member

Our Impact

Since its launch, The Youth PPI Café has contributed to a wide range of research, from differing stages of development and differing researcher backgrounds. These include:

- **The DisCOVeRY Study - Exploring the psychological impact of COVID-19 on young people.** Led by the University of Sussex, funded by ARC KSS
- **An algorithm to determine those most at risk of developing psychosis: the ethics.** Led by Prof. Kathryn Greenwood – Awarded NIHR ARC KSS Funding
- **BAME Representation in research.** Sussex Partnership NHS Foundation Trust Research and Development Team - reports produced for clinic leads

In November 2020, members of the Youth PPI Cafe identified the following research priorities: Preventative research into supporting young people before their mental health becomes debilitating; Early intervention in anxiety and social anxiety; Support in schools, and education; Childhood abuse and trauma.

All those involved in the Youth PPI Cafe have seen first-hand the impact that this group has had, and has the potential to have on research, clinical practice and service development going forwards. The results have far surpassed even our wildest expectations as a group.

Young people want to join in the conversation; they want to be a part of research, and they want to work towards improving services, even on a voluntary basis. They just need to be treated appropriately and given the space to be heard.

We hope to continue our work, placing the voice of young people at the centre of research.

