

COVID 19 PPI Response: PPI Café Chat and Connect



Sussex Partnership
NHS Foundation Trust

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Introduction

The **PPI Café** is an innovative project, initially funded by Heads On Charity in 2020-21 and run by a team based in the Sussex Partnership Foundation Trust R&D Involvement Office, intended to **increase diversity** in patient and public involvement (PPI) in research in the Trust.

The plan was to run 4 pop-up cafés in the community where we would offer tea, cake, peer support and some optional introductory research training to anyone who came along. These would be complemented by 4 virtual cafés for people who found it difficult to get out. The **aim** was to try to connect with more diverse populations, people who didn't normally get involved in research.

Covid changed our plans, but we responded quickly, introducing online "chat and connect" sessions within weeks of the first lockdown. Initially these were more peer support than research but we found that service users and carers wanted to talk about research anyway and so our conversations were often research focused but in a very holistic way, cross cutting the themes that traditionally boundary discussion in R&D. We've found that our community has grown and become richer and more connected as a consequence.

What we Did Pre-Covid

- Set up **fully co-produced** project management team
- Developed and delivered **co-trainer** and **co-facilitator** training
- Ran initial **PPI café workshop** (part of SPFT R&D Approaches In Recovery conference 2019)
- Produced a clear and inclusive **leaflet** to explain what we do
- Facilitated **one in-person café** in Bognor
- Set up a specific **Young Person PPI café work stream** (led and facilitated by Abi Thompson)

The Original Plan



The original plan was to run **4 in-person cafés and 4 virtual cafés**. The in-person cafes would be held in community venues in locations across Sussex in sites where we were hoping to connect with more diverse populations.

We had held just one of these, in Bognor Regis, when the first lockdown was announced.

Heads On, our funder, agreed that we could change our plans and make all our cafés virtual for the time being.

Covid-19: Adapting to Change

- Created and co-facilitated regular **'Chat & Connect' Sessions** within 2 weeks of first lockdown
- Rapidly saw genuine PPI community being developed as people started to support each other in new changed circumstance – during the lockdown these sessions were as much about peer support as about research involvement
- Discussions of **new research** ideas/studies (e.g. in dementia)
- Discussions led to the **creation of new virtual cafes** (Parents with Anxiety)
- **Co-facilitated** by service users and R&D involvement office staff
- **Evaluated regularly** (and as part of Masters thesis)
- We were thinking about the future and how we would adapt post-lockdown from the outset.
- ✓ Set up and co-facilitated **specific virtual cafes** :
 - Dementia
 - Young Persons Youth Café
 - Parenting with Anxiety
 - Long term physical and mental health

Covid 19: The Young Persons Café

- 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.
- Currently has over 100 young people signed up.
- Has collaborated with the CAMHS Participation Teams in East Sussex and West Sussex, University of Sussex researchers, the ChYPS Clinical Academic Group (CAG) and the ChYPS participation team for ARC KSS.
- Offers an opportunity for young people to discuss research questions, explore resources and **use their unique experience to guide researchers** who are carrying out research centred around children and young people.

What We've Learned and Achieved

- Starting to build a network of service users and carers which **cuts across research themes and cross pollinates ideas** – want this to feed back meaningfully into health research – and we think this **promotes a more holistic approach to mental health research**
- Succeeding in **connecting with so-called "hard to reach" groups** where people have failed time & again before. Benefitted from working virtually, from not hesitating but trusting in each other and our team.
- Believe that the way our PPI operates in R&D is **an exemplar of how to operate on a wider scale**. Not only in other research organisations, but also setting a template for clinical services e.g. around consent for operation of virtual/online appointments.
- Have **gained significant numbers of new people involved in PPI in research**, especially young people.
- Evaluations have shown that **virtual cafés have played an important role in peer support during the pandemic** when other mental health support services have been perceived to be largely inaccessible. This is something we hoped that the cafés would provide alongside their research involvement function.
- Have realised that there's **no channel for SUs and carers to feed important questions and recommendations into the research process** – this is something that needs to be developed and promoted so that research genuinely serves the interests of the public.

We have also learned a lot about good practice for running virtual cafes:

- At least 2 co-facilitators, have a pre-meeting to work out how café will run (inc. safeguarding role)
- Allow time and establish a procedure in advance for technical difficulties
- Some members need support to get on-line
- Establish group rules at the beginning of each session
- Mute people if you need to – be in control
- It takes a lot of time for people to say hello & feel comfortable so you simply don't have as much time for business as you would in a face-to-face meeting & need to allow for this

What next?

- Relaunching the physical cafes
- Promoting the PPI Cafe model while at the same time protecting it from outside demands
- Developing new themed cafes as needs are identified, e.g neurodiversity
- Mixed model of virtual and physical cafes
- More regular and specific virtual cafes?