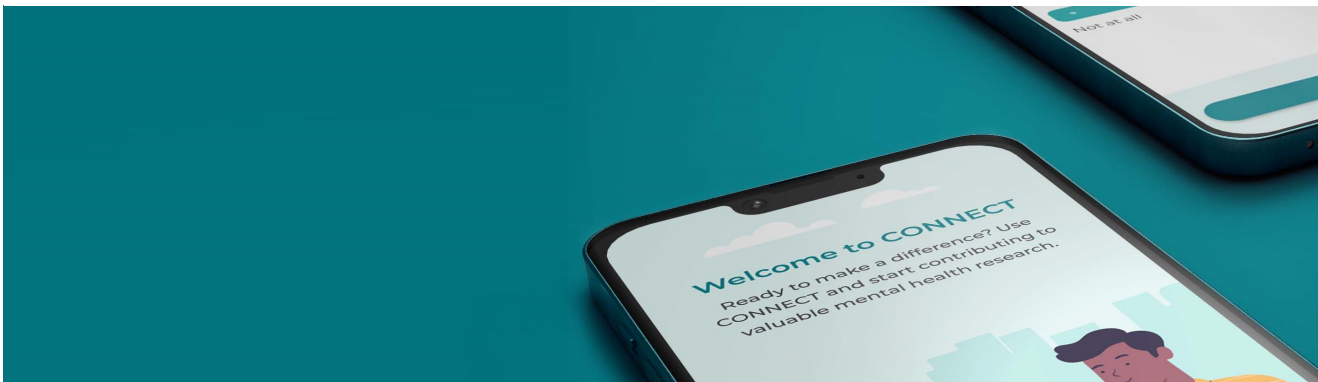


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**Sent:** 13 December 2023 12:11  
**To:** [REDACTED]  
**Subject:** CONNECT Digital Study



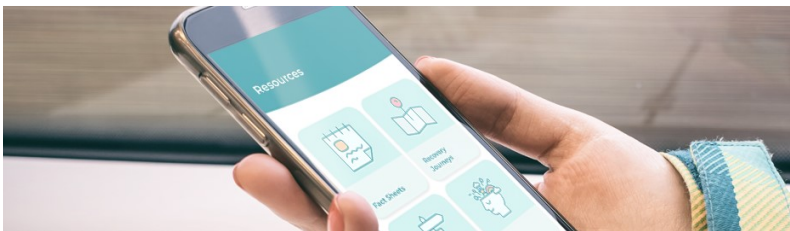
## Newsletter

December 2023



### Welcome to the first newsletter for the CONNECT Digital Study

CONNECT is a ground breaking Wellcome Trust funded study across six UK universities. The aim of the study is to develop and validate a personalised risk prediction algorithm for psychosis relapse. In the future, we hope to be able to use the digital data capture platform we develop in this study to help service users in a timely manner.



Meet the Chief Investigator  
of the CONNECT Study:  
Sandra Bucci

We are collaborating with [The McPin Foundation](#)  
[\[connectdigitalstudy.us17.list-manage.com\]](mailto:connectdigitalstudy.us17.list-manage.com) to ensure people with

lived experience of psychosis are at the heart of the CONNECT study. Below, three people with psychosis share their experience of relapse and how they think the CONNECT study might help.

*“The thought that I might have a relapse in the future fills me with fear” says Alison, an expert by experience for CONNECT. “But even with this constant fear, a relapse takes me by surprise. How could this happen again? What did I do wrong?”*

Relapse also has a huge impact for Alison. *“A relapse of psychosis is a major disruption to my life” she says. “And it not only affects me but all the people I care about. It is disturbing and so confusing. My mind is over processing thoughts in a manic state. I experience ideas, feelings, and experiences but not in a rational way. I cannot process or learn from any of it. There’s also a breakdown in relationships, financial loss and the inability to work. I have become my own worst enemy. One day I wanted to die taking all the steps and methods necessary. I was fighting for my life, physically and mentally.”*

Alison believes the CONNECT app could play an important role in preventing relapse. She also thinks it could be empowering. *“An app can help with future planning. If the app makes me feel confident and secure, I am free to learn about my condition.”*

A member of the Lived Experience Advisory Panel, Katherine, experiences what has been termed the fear of relapse. *“I regularly think about how much I do not want to be hospitalised again”, she says. “I fear medical professionals knocking on my door announcing that I am having a relapse and taking me to hospital based on their own poor observation skills and very little other evidence. This is something that has happened to me before.”*

Katherine takes her medication as prescribed, and she worries that she might experience a relapse and be sectioned if she changes her medication. *“Without my medication I could become very unwell in a matter of days and my fear is that things could become out of control and my life could be disrupted yet again. If my medication is changed while I am having a relapse in hospital I am locked up with no freedom or autonomy. I am stripped of my human rights and there is no optimal solution for my treatment or care. At this stage it feels like nothing could make me better. Recovery from relapse is slow and takes far too long. An app that helps prevent relapse getting to this stage could make a big difference.”*

Expert by experience, Sally, says that she finds worrying about relapse counterproductive and benefits from psychological treatments. *“Worrying about something such as relapse is inevitably counterproductive. Time and practice help. And the times I have relapsed, CBT [Cognitive Behaviour Therapy] for psychosis has proved a very handy tool.”* Sally hopes the CONNECT app will help to reduce fear of relapse. She also believes it will



### **What made you want to work in digital mental health research?**

I was noticing the long waiting times for service users to be seen in clinics and wondered how we could bring about efficiencies.

Digital technology was booming at the time and I started to think about how we could leverage technology to improve quality of care and delivery of services. That was how my programme of digital mental health research was born.

### **How did the CONNECT study come about?**

We had run some studies looking at how we can deliver psychological interventions to service users in the flow of their daily life.

A big limitation was that we were not able to personalise the intervention strategies because of limitations to the technology and our methods.

CONNECT will allow us to develop more personalised insights to service users about changes in their mental health.

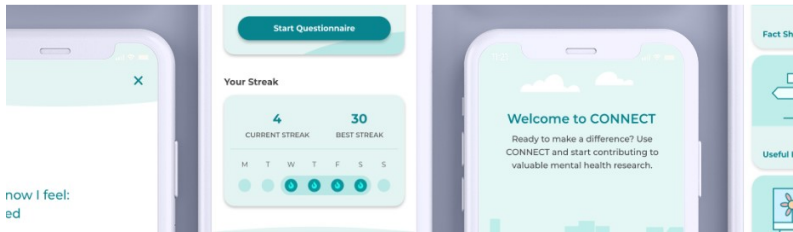
### **What are the biggest challenges that you anticipate for the CONNECT study?**

Reaching our sample size and making sure that we keep people using the system over the 12-month period.

### **What are you most excited about for the CONNECT study?**

be valuable in capturing personal indicators of relapse and will support to people be better prepared for and potentially prevent relapse in the future.

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## Study Update

CONNECT started in November 2022, and will design and test a “digital remote monitoring” (DRM) platform. This digital platform will allow people to use their smartphone and/or wearable device to keep track of how they’ve been feeling day-to-day.

Phase 1 of the project involved interviews with service users and staff to understand their views on using a smartphone or wearable device (e.g. Fitbit or smartwatch) to manage mental health, including any barriers to using a DRM system for psychosis, ethical issues and the use of machine learning methods and algorithms in mental healthcare. We have completed 50 staff interviews and 58 service user interviews to date.

Service users’ views of using mobile apps to collect data on their mental health were positive, and most reported they would feel comfortable answering questions about their symptoms and mood via an app. Interviewees acknowledged the usefulness of collecting passive data to identify symptomatic patterns which might support the future prediction of psychosis relapse – this was seen as an important milestone.

Findings from these interviews, as well as feedback from PPI groups, have been used to inform the design of the CONNECT digital data capture platform, app and study procedures which will be used in phase 2. Phase 2 is an observational cohort study. People who experience psychosis can encounter changes in things like their sleep pattern, activity levels and socialisation pattern just before they experience a relapse. We will invite service users to use a smartphone and a wearable device (e.g. Fitbit, Apple watch or Samsung Galaxy watch) to collect information about, for example, their sleep pattern, activity levels, phone usage and social behaviours to see whether changes in this information might relate to people’s mental health getting worse. Recruitment for this phase is due to start in the new year.

I am most excited about the potential to develop actionable and personalised insights for service users about their mental health and to bring efficiencies into service delivery.

**What is the one change you most want to see happen from the CONNECT study?**

That the work becomes embedded into routine clinical service delivery.

**What are you most looking forward to achieving with patient and public involvement in the study?**

Developing insights into things as researchers we either can’t see or don’t anticipate – the PPI input into the programme so far has been fantastic and is one of the most exciting elements of the project.

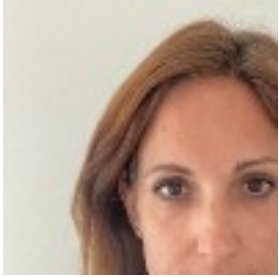
**Tell us a little about how you spend your spare time.**

My spare time is spent with my family, walking the dog, and eating too much pasta!



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[Watch an animation about the study](#)



Ellie Robson [[connectdigitalstudy.us17.list-manage.com](mailto:connectdigitalstudy.us17.list-manage.com)], **Research Coordinator at the CONNECT Sussex site reports from the first CONNECT PPI Learning Session.**

An excellent Patient and Public Involvement (PPI) learning session for the CONNECT Study was delivered on 1 November 2023 and attended by around 20 of the CONNECT research team. The two-hour session was facilitated by Alex Kenny and Annie Walsh from The McPin Foundation to introduce PPI and its role in the CONNECT Study.

McPin is a London based mental health research charity. Many of its staff are people with experience of mental health issues who recruit, and co-ordinate groups of people called Lived Experience Advisory Panels (LEAPs). LEAP members draw on their individual skills and lived experience expertise to collaborate with research teams to help support and shape mental health research. This collaborative approach is a core principle of good PPI and McPin aims to provide a respectful, honest, and supportive environment where LEAP members are given the opportunity to express their ideas and opinions. Contribution occurs throughout all stages of the research process, from consulting and collaborating with funding bodies as well as helping with research design, co-facilitating data collection, reviewing research materials, and advising on dissemination. In this way, vital lived experience perspectives aid the production of relevant and impactful mental health research as well as providing new skills and personal empowerment to the experts involved.

The learning session featured a presentation from a McPin LEAP member, Tor-Ivar Krogsaeter, who gave a brave and honest account of the mental health issues they had faced and how working with McPin and the CONNECT study had been a positive experience, making them feel valued and supported. Tor-Ivar's account was engaging and it was beneficial to see how, as well as being essential to good quality research, PPI can be so important to individuals on a personal level.

*"The biggest surprise was getting paid a decent amount for participating [...it] genuinely made it feel like the project truly appreciated us panel members setting aside the time for the meetings."*

*"I was also very surprised by the follow-up. I would have expected us to be invisible and unknown between the meetings. Actually, getting emails now and then about what happened, and even more so getting the odd personalised email. ('How are you doing? I noticed you weren't able to make the meeting today.')* I was quite vulnerable at the time and being seen like that helped me pull through some really hard times."

The CONNECT study has funding for two LEAP members in each site with an average commitment of 2 hours per month on an ad hoc basis. LEAP members input on various study documents and meet every few months with the study team. Valuable PPI input so far includes the suggestion to include a 'dark mode', zoom function and voice-aloud reader on the CONNECT app for accessibility and recommended adjustments to study documents such as a one-page summary document of the Participant Information Sheet.

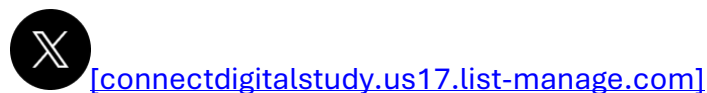
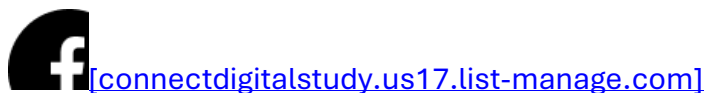
From a local perspective, in Sussex, we intend to invite our LEAP representative to help with troubleshooting any practical and tech issues and to collaborate on our recruitment and Equality Diversity and Inclusion (EDI) strategies. We also hope the LEAP member will participate in role play exercises to help train the researchers in administering study questionnaires. On a personal level, PPI involvement gives me confidence and peace of mind as a researcher that the work I am doing is being steered by vital representation from the people for whom the study is intended.

[Find out more about McPin \[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com)

We are still actively recruiting for LEAP members at the Sussex and Edinburgh sites. Enquiries can be made to alexkenny@mcpin.org

To stay up to date with the CONNECT study, sign up below.

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