

Jane Lees

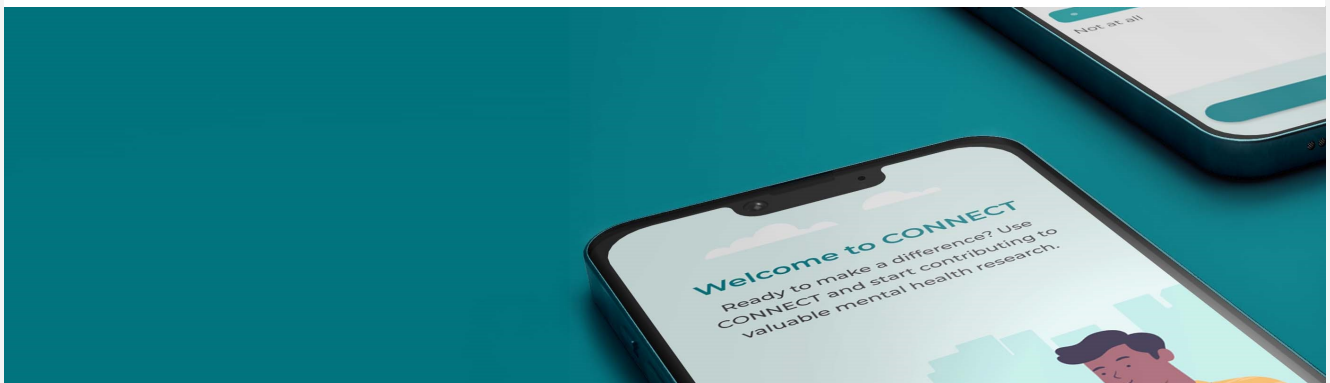
From: The CONNECT Study <connectdigitalstudy@manchester.ac.uk>
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Newsletter

February 2025

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Welcome to the CONNECT Study newsletter

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 by collecting data from people using a smartphone and wearable device. 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.

Study Update

It's hard to believe, but we've now hit the 12-month mark in the CONNECT study! Over the past year, we've made great progress, and we're excited to share some updates with you.

Our data and stats team have been working hard. They are now co-located in the same building and are busy working on the methods to extract features from the passive sensing data we are collecting in the study. They are also preparing a summary that can be shared with participants at the end of the study period so our participants can see all the amazing data they have contributed to the study over time.

A highlight this past month was our in-person event, which brought together all our study sites. It was fantastic to connect, share experiences, and reflect on our work so far. Be sure to check out our PPI member's blog for a great perspective on the event!

We are also pleased to share that we've submitted two papers from the qualitative phase of our work for publication—an exciting step in getting our findings out into the world.

Finally, we want to say a huge **thank you** and **goodbye** to Dr Pauline Whelan, who has played a key role in developing the CONNECT digital platform. While we'll miss her, we're thrilled that she's moving on to work with a University of Manchester spin-out company, and we wish her all the best in this next chapter.

Stay tuned for more updates, and thank you for being part of the CONNECT journey!

We are collaborating with [The McPin Foundation \[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com) to ensure people with lived experience of psychosis are at the heart of the CONNECT study. Below, Kane, one of the CONNECT Lived Experience Advisory panel, shares his account of the in-person event.

Since the event's announcement in late 2024, I have been excited to meet everyone from the CONNECT study, especially the other Lived Experience Advisory Panel (LEAP) members. It was like we were all old friends meeting for our annual get-together.

The event was held in Manchester at the Core Technology Facility (CTF), approximately a 10-minute taxi journey or a 25-minute walk from Manchester Piccadilly station. Transportation and accommodation were covered for LEAP members, allowing 8 of us to attend the event.

Upon arrival, I was greeted by Alex and Annie, from the McPin Foundation, and who coordinate the LEAP. They helped me check in and find the conference room. This was my first time meeting them in person, and they were just as friendly as they were in the online meetings we had throughout the study.

Refreshments and lunch were catered for by the venue, with friendly staff on hand. The conference room itself was spacious and clean.

To start the day, Sandra Bucci read an incredibly inspiring poem about the CONNECT study. This was an excellent introduction to the event and created a welcoming atmosphere. Sandra and Jane put exceptional effort into organising the event and bringing everyone together.

The stats team opened with findings from the CONNECT pilot study comparing the different wearable devices provided to participants. What impressed me the most was the sheer scope of the project itself – the CONNECT study aims to recruit approximately 1,100 participants to develop a robust psychosis prediction model.

It was easy to understand the stats and data team. Although there was some jargon and scientific language used during the presentations, I was glad the teams made the information accessible. As someone with a limited background in statistics and data, I appreciated how they conveyed information, as I could understand most of the content.

A memorable moment during the event was Annie's talk on PPI. Learning just how deeply embedded the LEAP's contributions are in every aspect of CONNECT inspired me. Annie detailed a few points of what we have contributed towards the study, with a few of them as follows:

- Co-designing the app interface
- Providing feedback on participant materials
- Fun facts and quotes to enhance engagement

- Suggesting features like progress bars, weekly streaks, and dark mode settings

As Annie spoke, I felt more like part of the team as she explained how impactful the LEAP's work is.

Nearing the end of the event, representatives of each study site presented a success story from the study. It was nice to hear day to day stories from the different site Research Assistants. Each one showcased the kindness and patience staff have towards participants. Knowing that participants are being treated respectfully reassured me about how Research Assistants conduct the study. Everyone I have met within the McPin Foundation has been exceptionally friendly while remaining professional, so I didn't have many worries regarding the treatment of participants.

Dr Emily Eisner presented findings from interviews with 58 service users about their views on digital remote monitoring. This was a good way to see that the perspectives of service users were considered.

Throughout the event, I gained invaluable knowledge from various teams of data scientists, statisticians and clinical staff. It was great to see such different groups of people brought together across the different teams. The variety of talks helped me understand the ongoing study from multiple perspectives. Questions were encouraged during the presentations and no questions were considered silly. This made everyone feel comfortable and further helped me digest the information provided.

Having a background in cyber security made me cautious of the safety and privacy of the application itself. However, during a talk, it was stated that penetration tests have been conducted and will be continued in the future. I was pleased to know that the safety of users was at the forefront of the development process.

Once the event had concluded, we were all invited to a complimentary meal at Kro Bar, which was only a 10-minute walk from the venue. Upon arrival, everyone was offered a 3-course meal and a free drink token.

The meal was a perfect end to the evening, allowing everyone to interact and talk to each other in a less formal setting. I networked with other LEAP members and discovered a lot of useful information regarding PPI.

As I prepared to go home, I felt hopeful for the future of this study and its potential to make real change.



Meet the CONNECT Sussex site

"Sussex by the sea!" sung from Bognor Regis to Hastings as the unofficial anthem of the county that can be heard on the terraces at Brighton and Hove Albion FC and during the world-famous Sussex bonfire celebrations.

The 75-mile-long geographical footprint of Sussex covers a wide variety of areas, from coastal ports such as Shoreham, to market towns and villages such as Arundel, Horsham and Lewes scattered further inland. Brighton provides a focal point for the county joining together East

and West Sussex, offering a renowned music and arts scene, with the legendary big beats of Fatboy slim consistently heard and the man himself often spotted browsing one of the many unique independent shops in the lanes.

Brighton is also home to the highest proportion of its population being members of the LGBTQ community in England and Wales, and plays host every August to Brighton pride, which is frequently recognised as the most popular pride event in the UK (if not the world!). The South Downs national park provides great access to green space, climbing the magnificent Devil's Dyke rewards you with stunning panoramas of the rolling hills of Sussex.

This variety across the county brings with it different sets of challenges. Global warming and the threat of increased adverse weather events and rising sea levels puts the coastal communities in Sussex at particular risk. The rural nature of many of our communities also means barriers to accessing services and an older age structure compared to the South East of England also presents a challenge when considering the provision of services. As with many other parts of the UK, disparity of wealth is also evident in Sussex with the richest neighbourhood having more than double the net household income of the poorest neighbourhood.

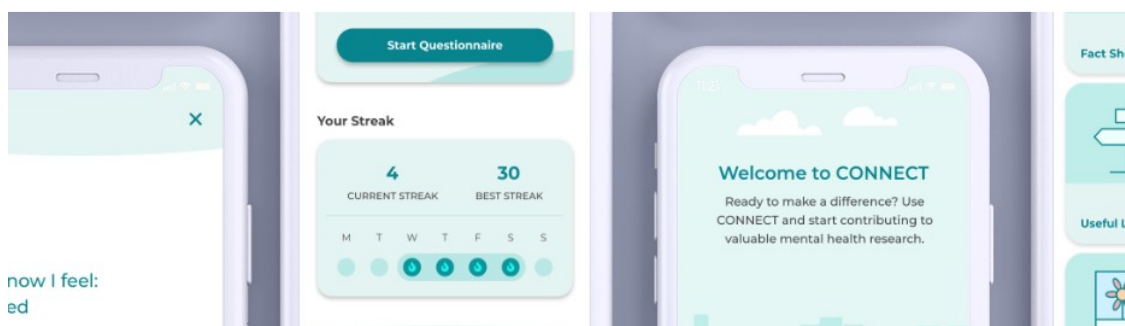


Since welcoming our first participants onto CONNECT in Sussex around Easter time last year, an incredible amount of learning has taken place. Research assistants, Alice Warner and Joe Sherborne, and research co-ordinator Ellie Robson have all been inspired by the interest in

the CONNECT study from service users and hearing their eagerness to contribute to the research. In Sussex we have all enjoyed becoming more adept at completing the research assessments and as the months have passed our confidence has grown more and more. We have worked hard to spread enthusiasm about the study around the variety of secondary care mental health teams across the local NHS trust to try and reach as many service users as we can. As a team we have taken encouragement from some of the clinicians in Sussex that have shown great interest in research and gone the extra mile to support recruitment to the study.

Although there is a way to go with recruitment to the study, we have found it important to recognise the progress we've made and all the good work we've done up until now. A particular highlight here was a joint Christmas and recruitment milestone celebration, enjoying some delicious Indian food with our wonderful site PI Kathy Greenwood.

We look forward to the many milestones ahead and all the learning yet to take place, that will no doubt benefit psychosis populations across Sussex and beyond.



Information Governance Manager, Kate Wicks, explains how the data collected from the CONNECT app and wearables is checked for reliability

The data we collect from CONNECT participants via their phones and wearables is vitally important for the success of the study. The technology we use allows us to collect a huge amount of data from each participant, and the more data we have, the more detailed a picture we can build up of the factors that may predict relapse. What's also true, though, is that we need to be as careful as we can to make sure that the data's integrity and

completeness are as high as possible – that is, that the data we are collecting is reliable. This is where data management comes in.

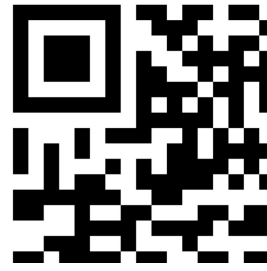
Each week, I check the data portal and data store to see the date of the last recorded data flow for every participant at each site. I check when they last completed a questionnaire; when their phone last connected to the server; and when their wearable (if they have one) last connected. If data hasn't been flowing for a period of at least a week, I contact the site team and ask them if they know why. The site team might already know – for example, some of our participants might be in a situation that means they are unable to use their devices – or they might need to get in contact with the participant to see if everything's ok and arrange any support that's needed. Sometimes it can simply be that a participant has taken a break from answering the questionnaire or using their wearable, or that they need more support to use them. It can also be that the participant is using their phone and wearable as usual, but that for some reason the data isn't reaching our servers. At that point, the central software team can help the site team to work out why this is.

Doing the data check weekly means that we're able to pick up on missing data quickly. If there is a technical issue with the data flow, the quicker we can take action to resolve it the fewer days will go by without data being collected for that participant, and the more complete their data set will be.

If you are part of the study site teams and receive my weekly list of participants to check in on, please know that your hard work is hugely appreciated and absolutely vital to the success of CONNECT. You are the link between the central team and our participants and without your work, data management would be so much harder. Thank you!

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