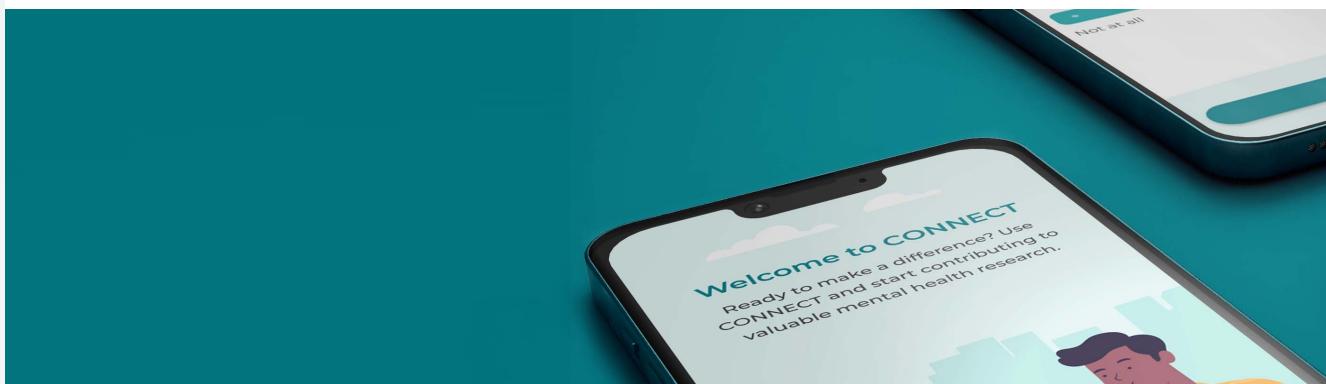


From: The CONNECT Study <connectdigitalstudy@manchester.ac.uk>
Sent: 23 December 2025 11:54
To: Jane Lees
Subject: CONNECT Digital Study December Newsletter



Newsletter

December 2025



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



The CONNECT cohort study has been up and running for 18 months and we've hit the halfway mark with 551 people consented into the study and 225 have finished their 12 months participation.

Our research teams have completed nearly 1400 assessment visits, set up over 900 devices, and they're still working hard to recruit more participants into the study across all ten NHS locations

Manchester: Greater Manchester Mental Health NHS Foundation Trust, and Pennine Care NHS Foundation Trust

Cardiff: Aneurin Bevan University Health Board, Avon & Wiltshire Mental Health Partnership NHS Trust, Cardiff & Vale University Health Board, and Cwm Taf Morgannwg University Health Board

Edinburgh: NHS Lothian

Glasgow: NHS Greater Glasgow & Clyde

King's College London: South London & Maudsley NHS Foundation Trust

Sussex: Sussex Partnership NHS Foundation trust

We are looking to recruit many more participants and would like to hear from anyone who is interested in taking part. Please contact jane.lees@manchester.ac.uk, let her know what your nearest site is, and she will put you in touch with the local research team.

Alongside recruitment and carrying out assessments, our research teams have also been looking at Equality, Diversity and Inclusion (EDI), comparing NHS data to the demographic characteristics of our participants which will help inform and guide recruitment going forwards. To find out more, look at the [feature](#) by Sarah later in our newsletter.

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] to ensure people with lived experience of psychosis are at the heart of the CONNECT study.

Putting Together a Symposium for the IEPA in Berlin

Alex Kenny, CONNECT LEAP Coordinator

We started thinking about the IEPA15 as early as August 2024. This was the 15th International Conference on Prevention and Early Intervention in Mental Health, which took place in Berlin, Germany from 8th to 10th September in 2025.

With a large portfolio of research and involvement work in prevention and early intervention in mental health at McPin, we thought the IEPA15 was a good opportunity to showcase best practice examples, including the CONNECT study. We also wanted lived experience advisory panel representation at the conference.

We heard exciting news that our symposium abstract had been accepted in February 2025! We looked forward to the experience of attending a large international event later in the year.

We put together a symposium co-chaired by our Research Director and Cofounder at the McPin Foundation, Vanessa Pinfold and Senior Public Involvement and Research Manager, Annie Walsh. At the IEPA, symposia sessions are a ninety minute, chaired symposium with four presentations of fifteen minutes, each with a five-minute discussion. We presented about the CONNECT study, with a CONNECT lived experience advisory panel member present, as well as three other studies. We also shared our An Ode to Peer Research film ([link here \[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com)), a brilliant piece of McPin work.

The McPin Foundation involve people with relevant lived experience in mental health research – as lived experience advisory panel members, peer researchers and programme leaders. At the symposium we explored how we do this through four early intervention in psychosis case studies, based on current research. It's not just about what we do, but how we do it.

The experience was something new. We prepared and presented as a team which was empowering and confidence building. There was also the social element of getting to know each other during the process, and the logistics of travelling to Berlin.

Our talks showcased how lived experience involvement varies by project and is embedded at different stages. We reflected on the importance of exploring impact on the research and people involved, to unpick how meaningful involvement might be achieved.

The involvement of people with lived experience of psychosis has been embedded within the CONNECT Study, through its lived experience advisory panel and is led and co-ordinated by two people with lived experience themselves.

We shared the lived experience advisory panel model of lived experience involvement, details of study team training sessions and study local site work.

Embedding meaningful lived experience involvement within the CONNECT study has laid the foundations for impact, which we hope will contribute to successful implementation in mental health services and psychosis relapse prevention.

During the McPin symposium I was happy to see CONNECT Chief Investigator Professor Sandra Bucci in the audience.

After we had spoken there was the chance for the audience to ask questions. Lots of people approached us once our symposium was finished. The conference was an opportunity to network with existing contacts as well as forge new connections. There was also the opportunity to attend many other talks. This included one which looked at linking first episode psychosis and risk of metabolic disorder, which our own Annie Walsh presented from a lived experience perspective.

The McPin team attended the evening conference social at the Zig Zag Jazz Club where the conference organisers led an improvised jazz session. It was an interesting and unique experience in the heart of Berlin.

It was interesting to reflect on the experience of attending an international conference on early intervention in psychosis, take part presenting as part of a team and attend other talks.

One Flew Over the Clinician's Nest - Zach Howarth, CONNECT LEAP member.
It was nice attending the conference, I felt like I was a part of the research community. I found the talks on psychosis as inflammation and possibly a physical reaction to trauma interesting. It got me thinking about the term illness when used to describe psychosis is misleading as it suggests infection. I think damage would be a better term.

One thing I found difficult at times was listening to lots of talks about psychosis which got me reflecting on my own journey with brain, damage, psychosis and epilepsy to this point. I felt both grateful and guilty. Grateful that I'd got to a point in my recovery where I can use my experience to inform and develop research that helps those going through similar struggles, but I felt guilt reflecting on all the people I've met over the years still struggling or lost to the world due to mental health issues and broken mental health systems.

I didn't do much sightseeing but explored the local area, the campus and visited the Reichstag. I found Germany very accommodating and friendly. Britain could learn a lot from its public transport system which is very efficient.

I was nervous about speaking at the conference, but the McPin team were lovely and still let me join the panel for a question-and-answer session at the end. It was peculiar being amongst clinicians and academics in this setting and allowed me the opportunity to see the world through their eyes. It felt more human than the clinical and academic settings we work within, and the experience felt more relatable. A lot of people looked tired and pressured, stressing about normal things like lunch queues.

As a patient it's easy to see doctors and clinicians as infallible and the experience reminded me, we're all going through the same struggles to a greater or lesser degree. One difference though is that listening to presentations about something you're living can be emotionally draining. A lot of people studying in this field can study and talk about these things then walk away from it. To lived experience researchers this isn't just work or a job. It's life.

What is Psychosis? - Annie Walsh, Senior CONNECT Manager

Similarly to Zach, the CONNECT LEAP member, the conference very much took me on a personal and professional journey around the concept of psychosis. With a diagnosis of major depression with psychotic experiences, I can sometimes feel like an imposter working in lived experience involvement on psychosis studies – is my lived experience “good enough”? However, with the conference theme focused on breaking boundaries, particularly those around diagnosis, there was increased discourse around psychotic experiences, and a fantastic seminar on, “What is psychosis?”. From this seminar, I took away the key learning to avoid Westernising lived experience involvement in a similar way to how mental health care has been Westernised. And I have been dedicating time to reflect on how we can integrate this learning into lived experience involvement best practice.

Meet the team: The data analysis team

The CONNECT data analysis team meets twice a month to discuss issues related to the capture, storage, and analysis of data obtained during the CONNECT study. Discussions range from data collection to data quality and the best strategies for analysing the data. The group is dedicated to ensuring that the study has the best available data and the most appropriate methods for its collection, storage, and analysis.

For example, the team is responsible for developing the CONNECT risk prediction model, including identifying the most promising analytical methods and features derived from smartphone and wearable data to predict relapse in psychosis. The group also regularly brings relevant discussions to other teams and experts within the CONNECT project to ensure alignment among the project's multiple stakeholders.

The team is composed of experts in digital health, mental health, software engineering, machine learning, statistics, and clinical input. Below is a brief introduction to the team:

Glen is a Senior Lecturer in Health Data Science at the University of Manchester. Glen's research centres on improving healthcare through the effective use of clinical prediction models to underpin prevention and early detection of disease. He has broad methodological interest in developing clinical risk prediction models, with particular expertise in multivariate modelling and missing data.

Matthew Sperrin is Professor of Biostatistics and Health Data Science. He has expertise at the intersection of prediction and causal inference, such as in building models that predict under intervention.

Camilla is a research associate at the University of Manchester. Her research background is in the application of a range of machine learning algorithms to healthcare data, with the aim of developing clinical prediction models.

John is Professor of Health Informatics and the Head of the Division of Informatics, Imaging and Data Sciences. He provides technical leadership to the CONNECT programme and chairs the data analysis group meetings.

Ariane is a research associate at the University of Manchester, focusing on transforming wearable and smartphone data into meaningful clinical features and exploring the use of machine learning on continuous digital data for clinical prediction tasks.

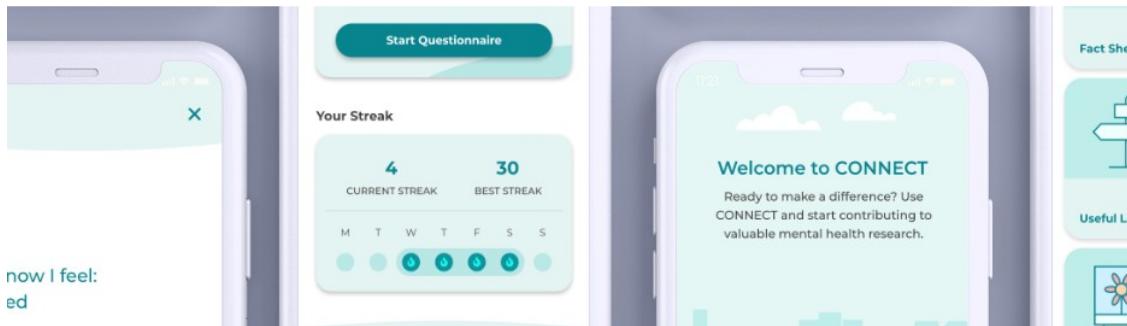
Fendy is a Research Associate in Health Data Science at the University of Manchester. Her research focuses on data analysis and predictive modelling within the CONNECT project, supporting the development of clinical risk prediction tools using digital health data.

Siân is a Lecturer in Health Data Sciences at Manchester, with research interests in incorporating data from digital devices into clinical prediction models. Prior to this Siân was a post-doctoral researcher working on CONNECT and was responsible for writing the analysis plans for the prediction model development and carrying out the pilot study analysis.

Henry is a Software Engineer within the Digital Health Service (DHS) team. His work focuses on the development and support of the CONNECT app, where he has served as one of the primary developers. Prior to joining DHS, he worked as a developer in the sports performance management sector, where his experience naturally translated into developing and supporting digital health applications.



(Dr Sophie Faulkner, Dr Sian Bladon, Dr Camilla Mapstone, Dr Roberto Cahuantzi, Prof John Ainsworth, Mr Henry Gorner, Ms Ariane Morassi Sasso)



Intersectionality in Mental Health Research: Moving Beyond Tick-Box

Diversity

CONNECT Research Assistant Sarah reflects on the information we collect from participants, and how the different categories overlap and add to the diversity of research data.

In mental health research, we often collect demographic information out of necessity; age, gender, ethnicity, sexual orientation. These categories matter, but they only tell part of the story - people do not live single category lives. Their experiences may be shaped by overlapping identities, such as race, gender, socioeconomic background, disability, language, or spirituality.

This is the heart of intersectionality: the idea that a person's identity cannot be understood by looking at one characteristic at a time. For research, this means recruitment and analysis must go deeper than simple demographic boxes.

As I've been preparing the Manchester Equality, Diversity and Inclusion (EDI) report for the CONNECT study, I've seen how tick-box diversity gives us numbers but not always understanding. It tells us who is taking part, but not the full picture of how their identities shape their experiences of research, health, and care. Yet CONNECT is in a strong position to take the conversation further, because EDI has been built into the study from the very beginning.

What CONNECT Has Already Achieved

It is still unusual for research studies to develop a full EDI plan from the outset. CONNECT did, making it a standout example of proactive and thoughtful inclusion. The plan outlines not only barriers to participation, but also the actions needed to address them.

Accessible and inclusive communication

CONNECT has taken multiple steps to make study materials more accessible and culturally appropriate. Participant-facing documents have been reviewed by a diverse lived experience advisory panel (LEAP), ensuring they are clear, sensitive, and avoid jargon. The study also uses a wide set of communication tools, including animations and videos, to reach people with different learning needs and preferences. These materials are co-produced and checked by people with lived experience, making them more relatable and trustworthy.

Reducing burden and making participation flexible

We have made deliberate efforts to reduce the number of forms and assessments, and researchers are trained to offer breaks and help participants complete them when needed. Home visits, phone appointments, and remote assessments are all available, ensuring accessibility for people with mobility issues, caring responsibilities, or transport barriers. Travel costs can be reimbursed for participants and carers, and appointment times are adjusted around individual needs.

Cultural sensitivity and personalised support

CONNECT emphasises adapting to participants' cultural and religious needs. During assessment visits, researchers are encouraged to ask what support a participant may need throughout the study, including around language or specific cultural considerations. Researchers are also encouraged to develop skills in communication, particularly when supporting people with learning differences.

Proactive and targeted recruitment

CONNECT uses multiple recruitment routes such as clinical teams, self-referrals, social media, and community events to ensure people can engage in ways that feel comfortable and safe. The EDI plan highlights using accessible branding and promoting the study across diverse community spaces.

Together, these achievements place CONNECT well ahead of many studies in terms of inclusive design and practice.

The Role of Intersectionality

Despite strong progress, CONNECT's own EDI data like many research studies, shows patterns that cannot be fully explained by single demographic categories alone.

Intersectionality helps us understand why these patterns might emerge. A participant may face overlapping barriers such as language, cultural stigma, socioeconomic disadvantage, or mistrust of healthcare systems. CONNECT's EDI plan anticipates many of these barriers; for example, communication support, culturally appropriate materials, and flexible assessments but intersectionality encourages us to look at how these barriers combine and interact.

Embedding Intersectionality Across the Research Cycle

Intersectionality isn't only about who takes part in research; it shapes the entire research process. CONNECT is already doing many things well, but the intersectional lens invites some further opportunities:

1. Research questions

- Framing research questions to explore how experiences differ at the intersections of identity (e.g., gender × ethnicity × socioeconomic background).
- Anticipating combined barriers (e.g., someone who is both neurodivergent and from a migrant background may experience difficulties differently from someone with either identity alone).

2. Recruitment

- Continuing targeted outreach, not just by demographic group but by intersectional community needs (e.g., older adults from ethnic minority backgrounds, LGBTQ+ participants in areas of deprivation).

3. Data analysis

- Looking at how identities interact to shape engagement, adherence, and outcomes.

4. Dissemination

- Ensuring findings are shared in formats accessible across literacy levels, cultures, languages, and community spaces.

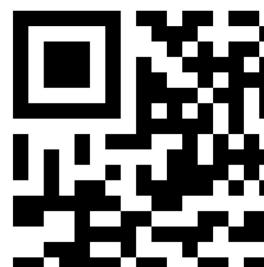
A Call to Action

CONNECT has already achieved an impressive amount in making research more inclusive, thoughtful, and flexible. The EDI plan shows a real commitment to ensuring participants feel valued and supported.

By moving beyond tick-box diversity and embracing the richness of people's layered identities, we can produce research that is not only more ethical, but more accurate, meaningful, and impactful.

To stay up to date with the CONNECT study, sign up by clicking on the link below or scanning the QR code

Sign up to get the CONNECT
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