Jane Lees

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

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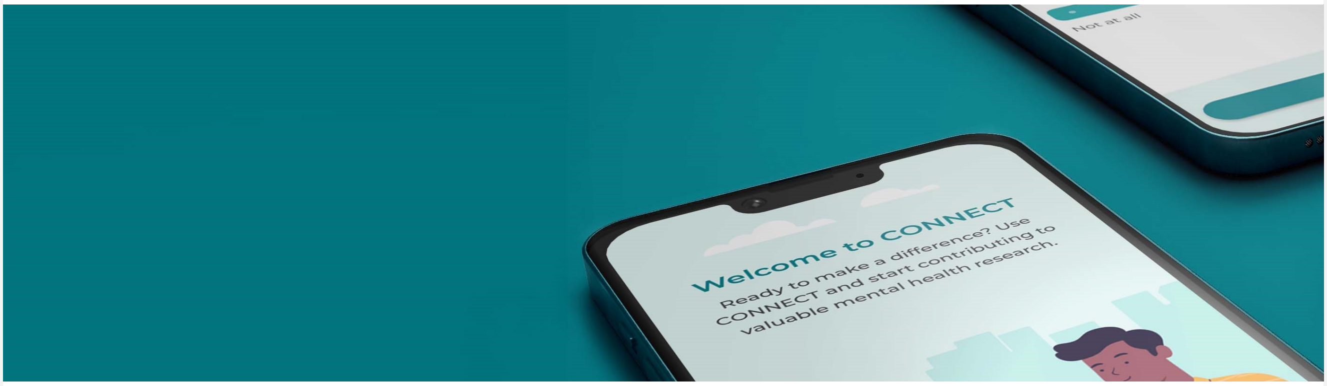
Newsletter

June 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

Time is flying and we’re now past the 12-month mark in the CONNECT study. 368 people have consented into the study to date, and 47 participants have already completed it!

Our research teams are working hard to recruit participants into the study across all six sites – Manchester, Cardiff, Glasgow, Edinburgh, King's College London, and Sussex – and collect all the data. We are looking to recruit many more participants and would like to hear from anyone who is interested in taking part.

Our data and stats team have been working hard and have developed data transfer software to move data to local data storage facilities. They have also released an iOS data burst feature, allowing us to collect high frequency data from participants over a 3-day period. Two feature processing workshops have been held to identify which derived features from the raw data are required, and they have initiated a systematic review of behavioural features from passive sensing.

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. The first, looking at '*Mental health professionals' perspectives on digital remote monitoring in services for people with psychosis*' has been published (https://doi.org/10.1093/schbul/sbaf043 [connectdigitalstudy.us17.list-manage.com]), whilst the second, exploring the views of people with psychosis on using passive sensing to predict psychosis relapse is under review.

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. Below, Annie, Michael and Lois share their accounts of our latest PPI Learning Session - Evaluating the Impact of Lived Experience Involvement.

Introduction written by Annie Walsh, Public Involvement in Research Manager at the McPin Foundation

As part of the program of patient and public involvement (PPI) work on the CONNECT Study, McPin run biannual PPI learning sessions with the aim to increase knowledge and understanding of PPI for researchers to implement in their own work and future studies. We recently held our third PPI learning session, the focus of which was, “Evaluating PPI Impact”.

This is becoming increasingly important to evidence the role of PPI in research, demonstrate to people with lived experience the value of their input, and encourage more transparent reporting of PPI activities for knowledge exchange of best practice and exploring any unintended consequences. However, there are many variables that can shape PPI impact, including research domain, research type and contextual and process factors, such that meaningful, impactful PPI may look different across different studies. As such, it can be difficult to work out the best way to capture the PPI impact journey and breadth and depth of some of the impacts. During the PPI learning session, we covered these nuances of evaluating PPI impact, provided an overview of some of the frameworks and tools that have been developed to help, and held an interactive activity to start putting these learnings into practice.

Below are reflections from two researchers who attended the recent PPI learning session:

Reflection written by Michael Fowler, Research Assistant at King’s College London

Good decision-making dictates that people affected by decisions should be involved in how they are reached. Patient and Public Involvement (PPI) is therefore crucial to any patient-focused psychology study, but particularly so in one as large and hopefully impactful as CONNECT.

Our learning session on understanding the impact of PPI fell in my third week as a research assistant at the King’s College London site. In addition to increasing my understanding of PPI’s role in shaping CONNECT, the session provided some useful guidance as to how I can keep PPI in mind as I begin my work on the study.

In particular, one key message was the importance of continuously reflecting on PPI – in other words, that it must be an ongoing process, rather than a one-off box-ticking exercise.
During the session, PPI was framed as a link between CONNECT and wider society. Central aims of the study are to ensure a smooth experience for the real-world people we recruit and

fine-tune how wearables and phone technology can be most palatable for those who have experienced psychosis.

This is why a Lived Experience Advisory Panel was consulted while preparing CONNECT’s guidelines. The panel provided recommendations on day-to-day tasks for research assistants such as myself. For example, they suggested there should be no set limit on the number of follow-up check-ins with participants and these should instead be approached on a case-by-case basis.

Having been implemented in our study protocol, this recommendation represents one example of a chance for continuous reflection. Hypothetically, we as research assistants could observe over time that a set limit on follow-ups in fact would be a helpful guideline. In that case it would be important to discuss our thoughts not only as a research team, but also with patients and members of the public, including those who initially made the suggestion. By doing so, we can ensure that we as researchers continually focus on what is best for participants. Just as our CONNECT research team holds regular scoring meetings to prevent “rater drift” and ensure we remain aligned in our assessments, continuously reflecting on PPI’s impact can help us remain aligned with participants.

Maintaining this real-world link also ensures our work remains appropriate for those from a range of ethnic, cultural and socio-economic backgrounds, as well as for neurodivergent people and those facing mental health challenges.

The learning session usefully outlined some qualitative frameworks for understanding PPI impact, such as the Public Involvement in Research Impact Toolkit (PIRIT). The framework records metrics such as PPI’s intended impact, what its contribution turned out to be and why it matters. Crucially, PIRIT is co-completed by researchers, patients and members of the public throughout the course of a study, allowing it to capture qualitative detail and encourage continuous reflection.

As I settle into working on the CONNECT study, I am grateful for the chance to participate in PPI-focused learning sessions such as this one and intend to use it as motivation to continuously prioritise patients’ perspectives in my role.

Reflection written by Lois Parri, Research Assistant at King’s College London

Having been part of the CONNECT study since its earliest days, it’s easy for me to get caught up in the daily rhythm of assessments, visits, and various forms. In a study of this scale, there’s always something to do. The machine runs so smoothly that it can be easy to forget how much thoughtful planning, driven by lived experience, has gone into shaping the study’s design in the first place, which is ironic, because it is that same involvement that helps it to run so smoothly; allowing us to forget and focus on the task at hand.

Attending the recent Patient and Public Involvement (PPI) learning session on evaluating impact was a timely reminder of the foundations from which we work. The session, led by our brilliant PPI advisors, unpacked not only what “impact” looks like in PPI, but also how we might meaningfully capture it. It was a great opportunity to pause and reflect on how many of the procedures I carry out without a second thought - what we ask participants, how we provide support, our assessment schedules - stem directly from recommendations made by people with lived experience of psychosis.

As the session highlighted, impact in PPI can be tricky to pin down. It’s often subtle and deeply embedded. But that’s what makes it so powerful - because the better the involvement, the more naturally it becomes part of how we do things.

One of the key takeaways from the session was the value of continuing to reflect on PPI throughout the life of a study. It shouldn’t be relegated to a pre-launch checklist or a token slide in a presentation. Resources, like the Public Involvement in Research Toolkit (PIRIT) and recently released National Institute for Health and Care in Research guidelines, offer a way to evaluate impact collaboratively and iteratively, capturing the full picture of how PPI shapes research in real time.

Looking back, it’s clear that the thoughtfulness of the CONNECT PPI process has helped create a study that’s not just operationally effective but also participant-centred. Our lived experience panel didn’t just help shape the study - they built the scaffolding that allows us to focus on delivering a good experience to participants day-to-day. My time on the project is coming to an end soon, but the sheer amount and dedication to PPI in CONNECT's development has left a lasting impression and is something I'll take forward with me.

For me, this session was a helpful nudge to pause, zoom out, and recognise the invisible work that continues to shape what we do – a reminder that the best research is collaborative at every level.

Fanning the Flame: Cardiff's Dragon-Spirited Research Journey

A Warm *Croeso* from the Cardiff Research Site

Dear Colleagues,

I'm Dr. Sandapa Punchihewa, Research Manager at the Cardiff site, and I'm delighted to bring you the latest updates from our vibrant research team here in the heart of Wales. Our work continues to be inspired by the spirit of the Welsh dragon (Y Ddraig Goch)—a symbol of strength, resilience and identity. Guided by these values, our team thrives through collaboration, compassion, and connection.

Meet the Team Behind the Flame
At the helm of our research in Cardiff are Professor James Walter, Director of the Centre for Neuropsychiatric Genetics and Genomics, and Dr. Kimberly Kendall, Clinical Psychiatry Fellow. Their leadership blends scientific excellence with a strong vision for inclusive, participant-focused research that continues to set national standards.

Driving the day-to-day success of our work are our outstanding Research Assistants, Eden Cronin and Jordan Harrington. Through their hard work, compassion and unwavering commitment to quality, they ensure that every participant experience is handled with care, respect and professionalism. Their work plays a key role in progressing our research through meaningful interactions with each participant.

We also work closely with Stephen Ash, a member of our Lived Experience Advisory Panel (LEAP). Stephen's contributions ensure that the voices and experiences of participants stay central to our work.

Our recruitment spans three major University Health Boards, allowing us to engage with diverse communities across both urban centres and rural areas:

Cardiff & Vale UHB

Local PI: Norman Young, Nurse Consultant, EI Team

Based in the heart of the capital, Norman brings deep clinical expertise and a steadfast commitment to early intervention. His leadership ensures robust engagement with participants from one of Wales’s most dynamic and diverse urban populations (~500,000).

Aneurin Bevan UHB

Local PI: Dr. Gemma Williams, Consultant Psychiatrist, EI Team

Dr. Williams is known for her holistic and inclusive approach to care. Serving a large and varied population (~650,000), her team covers a mix of urban, suburban and semi-rural areas, bringing mental health research to the forefront of local communities.

Cwm Taf Morgannwg UHB

Local PI: Laura Howe, Lead, EI Team

Laura is a dedicated advocate for mental health services in some of Wales’s most rural and historically underrepresented areas. Her passionate leadership helps bridge geographical barriers and ensures voices from the valleys are part of this pioneering work.

These partnerships are crucial in ensuring our research is inclusive, far-reaching and reflective of the people we aim to serve.

A Visit from Professor Sandra Bucci

Last month, we had the privilege of welcoming Professor Sandra Bucci, Chief Investigator of the CONNECT study. Her site visit fostered enriching discussions around recruitment progress and strategic development. Professor Bucci also delivered a compelling presentation as part of the Division of Psychological Medicine and Clinical Neurosciences (DPMCN) Seminar Series:

"Digital Horizons: Transforming Care of People Who Experience Severe Mental Health Problems".

Her talk offered an inspiring look at how digital tools have the potential to revolutionise mental health care delivery.

(Prof James Walter, Dr Gemma Williams, Norman Young, Eden Cronin, Dr Sandapa Punchihewa, Jordan Herrington, Dr Kimberly Kendall, Prof Sandra Bucci)

Research with Heart

Wales offers more than data - it offers heart. From winding coastal roads and majestic castles to the warm, cariadus (affectionate) nature of our communities, every site visit reminds us of the meaningful connections we are building.

As Research Assistant Eden Cronin shares:

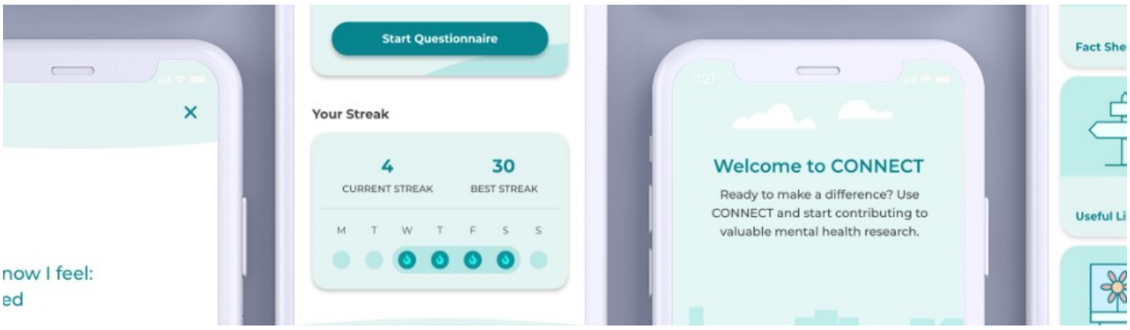
> *"One of my favourite parts of working on CONNECT is the chance to explore new places and meet people across South Wales whom I might never have encountered otherwise. I especially enjoy hearing participant's positive feedback - many say they value being part of the study and speaking with someone outside of their usual care team."*

Diolch yn fawr for your continued support. From the land of dragons, we move forward - together.

Hwyl fawr!

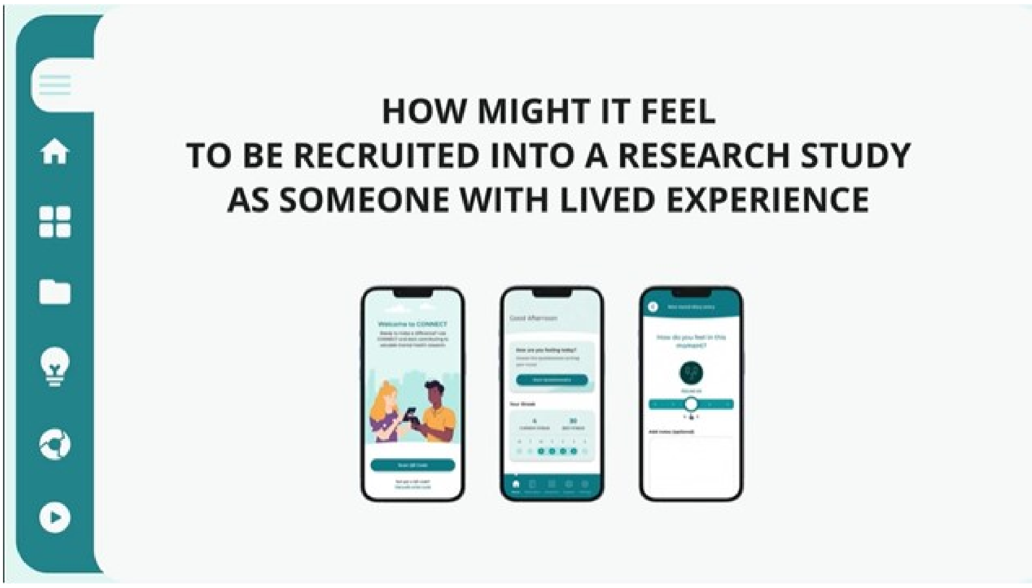
Dr. Sandapa Punchihewa

Research Manager – Cardiff Site



How might it feel to be recruited into a research study as someone with lived experience?

Many people are unsure about taking part in a research study. In our video below Ash talks about their experience of being recruited into, and taking part in, the CONNECT study.



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