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Newsletter

September 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



It's amazing to think the CONNECT cohort study has been up and running for nearly 18 months. 440 people have consented into the study, with KCL hitting the milestone of recruiting 100 participants! Manchester isn't far behind on 97.

Our research teams have completed over 1000 assessment visits and have set up 725 devices, and they're still working hard to recruit even more participants into the study across all six sites – Manchester, Cardiff, Glasgow, Edinburgh, King's College London, and Sussex. 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'll put you in touch with the local research team.

In the wider CONNECT team, we've been busy writing up our findings so far. Two papers from the qualitative phase of our work have been published - 'Mental health professionals' perspectives on digital remote monitoring in services for people with psychosis' (doi:10.1093/schbul/sbaf043 [connectdigitalstudy.us17.list-manage.com]) and Using passive sensing to predict psychosis relapse: an in-depth qualitative study exploring perspectives of people with psychosis (doi:10.1093/schbul/sbaf126 [connectdigitalstudy.us17.list-manage.com]). A third paper from the qualitative work which is exploring the views of people with psychosis on algorithm-based relapse prediction, as well as a paper from the pilot study evaluating the different wearables, will be submitted soon.

We are collaborating with <u>The McPin Foundation</u> [connectdigitalstudy.us17.list-manage.com] to ensure people with lived experience of psychosis are at the heart of the CONNECT study. Below, we reflect on Mentoring for Growth: Fostering Skills and Connections in Research.

At the University of Edinburgh, we are exploring innovative ways to integrate Patient and Public Involvement (PPI) into research, moving beyond traditional consultation towards genuine collaboration. One of our most exciting initiatives is bidirectional mentoring, a programme designed to support professional development, confidence-building, and knowledge exchange between researchers and experts by experience.

Bidirectional mentoring flips the conventional mentor-mentee relationship on its head: both participants act as mentors and mentees, sharing their expertise, perspectives, and experiences. This creates a unique space where knowledge flows in both directions, fostering mutual learning and growth. By recognising the value of lived experience alongside academic and clinical expertise, we are building amore inclusive and holistic approach to research.

In practice, the programme pairs research assistants with local representatives from the McPin Foundation Lived Experience Advisory Panel (LEAP), meeting every two months for hour-long sessions. During these meetings, participants engage in practical skill development, including employment coaching, networking, and SMART goal planning, a structured approach to setting goals that are specific, measurable, achievable, relevant, and time bound. Beyond these technical skills, sessions provide opportunities for resource sharing, exploring university initiatives, and understanding the multiple roles researchers, clinicians, and experts by experience occupy.

The programme also nurtures professional confidence. Mentees can gain experience in public speaking, workshop facilitation, seminar organisation, and building connections in the third sector. Mentors offer guidance, active listening, and non-judgmental support, sharing their own experiences of employment and navigating professional environments.

A central aim of bidirectional mentoring is to deepen understanding of perspectives that have historically been underrepresented in research. By fostering open, human-to-human connections, we aim to close the divide between academic research and the community. Researchers gain insights into NHS services from a service-user perspective, while experts by experience expand their networks within academic settings.

These structured, reflective sessions exemplify how collaborative mentoring can enhance skills, confidence, and professional networks for all involved. Ultimately, bidirectional mentoring is not just about exchanging knowledge, it is about creating a culture of mutual respect, learning, and empowerment. Through this initiative, we are proud to champion a more inclusive, insightful, and connected research community.

Read more from Edinburgh LEAP member Margaret who took part in a bidirectional mentoring session with CONNECT researcher Veronika.

Bidirectional mentoring is something I had not heard of before starting. I had heard of mentoring, although not had it before. But bidirectional mentoring was completely new to me. I think this added to the excitement I felt before starting. Also, the interest in where doing this could take me as a mentor/mentee and my colleague too. And I wasn't wrong. Even just starting the process as so far been very interesting.

From this experience I hope to gain by learning from my mentor's journey, by developing skills I have but also learning new perspectives and ideas that my mentor has. I hope to share my knowledge to help my mentee develop and learn in a way she wants and about things that will help her moving forward.

Before doing the bidirectional mentoring, as I have said, the only feeling was that of excitement. I felt positive about beginning these sessions and just ready to learn and teach from our work and life experiences.

I learnt a lot from even just the first session. We began our sessions with introductions. We knew each other from working together but wanted to learn more about where our lives had taken us and how we got to the point of working where we are now.

I found providing mentoring a positive experience. It made me feel good being able to share tips and ideas on things that have helped me and allowed me to share my experiences. Receiving mentoring was helpful and I look forward to the process going forward.

I wasn't expecting to learn so much about where I want my career to take me and how to develop this in just the first session. I had ideas but chatting them through helped me and I feel I'm developing them already. Which is exciting. I look forward to learning and teaching more. And who knows where it could take us both in our journeys! Watch this space...

Meet the team: The people behind the Edinburgh site

Research often brings to mind publications, conferences, and data. Yet behind every study site are people whose identities, histories, and passions shape how they show up in the world. Today, I want to take you behind the scenes of our Edinburgh site, to introduce not just colleagues, but the people.

The five of us have each arrived in this city by different routes. None of us are truly local, yet here we are, drawn to Edinburgh, sometimes loving its rugged beauty, sometimes bracing against its unforgiving winds. We work in the shadow of great minds like Charles Darwin, Adam Smith and Arthur Conan Doyle, and alongside the legacy of the *Edinburgh Seven*, the first women ever to matriculate at a UK university. What I personally love about Edinburgh the most, are the city's hidden nooks and crannies you could spend a lifetime exploring and still have not explored at all.

Our team reflects that same richness.

Matthias, our Principal Investigator and Head of School, is a consultant clinical psychologist from Germany. Beyond his impressive academic achievements, he works clinically with children and adolescents affected by complex trauma and early psychosis. He's also an avid cyclist, and the keeper of a thriving sourdough starter, details you might never guess unless you got to know him (or read this newsletter).

Jen, our Research Coordinator, began her academic journey in Ireland studying chemistry. Then she wandered across New Zealand and Australia for a decade and eventually circled back to Edinburgh. This summer, she wowed audiences as sea captain Antonio, performing Shakespeare's Twelfth Night. Soon, she will begin her journey on the Doctorate in Clinical Psychology, and we already know her shoes will be very hard to fill.



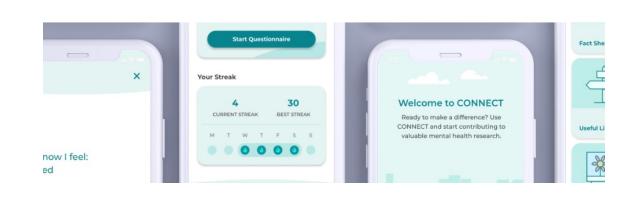
(Prof Matthias Schwannauer, Alisa Mandrigin, Samah Naseem, Veronika Kassova, Jen Ward)

One of our Research Assistants is Alisa, a former philosophy researcher, originally from London. She chose a new path in mental health, moving from clinical support worker to Assistant Psychologist, and now to CONNECT researcher. Alisa has a love of travel, ballet (both watching and dancing), and is caring for two pet rats. She will soon be joining Jen on the DClin, and the team will miss her dearly.

Samah, with Pakistani roots and a Milton Keynes upbringing, is both researcher and activist, passionately giving voice to marginalised people through her cultural awareness and her work in Gendered Based Violence. On top of this, she is pursuing a master's in pluralistic counselling, builds intricate Lego creations, and writes poetry. Samah always has a witty, encouraging word for anyone who needs it.

And then there's me - Veronika. I grew up in a small Slovak town called Nove Zamky ("New Castles") and, as part of the Hungarian minority, learned early how history shapes identity. My path was far from straightforward: HR, business, politics, and psychology; living in Indonesia, working as a digital nomad, and finally finding my calling in mental health care as an Assistant Psychologist and CONNECT researcher. Thanks to my Scout days, I still love hiking, and I've fallen for Pilates. Shout out to anyone else navigating life with a stubborn back!

I have the privilege of working with this remarkable team. Each a researcher, clinician, and above all, a human being with rich experiences. Together, we form a constellation of lives and stories, woven into the research we do in this beautiful city we made our home: Edinburgh.



From Participant to Partner: The Power of Storytelling in Psychosis Research

CONNECT Research Assistant Veronika Kassova reflects on a video created by Ash, a CONNECT study participant with lived experience of psychosis, which you might remember from our last newsletter. The video offers a real and insightful look at what it means to take part in research, and how meaningful involvement can foster connection, confidence, and change.

The other day, I had two very different participant calls that perfectly illustrated the essence of the CONNECT study. One participant asked about the specific machine learning algorithm we were using on the passive data we collect. A few hours later, another asked what did I mean by a "research study" in the first place. It was a striking reminder of the incredible diversity within our participant group, and how important it is to meet each individual exactly where they are. CONNECT is a multi-site cohort study involving a team of multidisciplinary staff and lived experience members, exploring whether it is possible to predict relapse in psychosis using data collected from smartphones and smartwatches. Through a combination of in-person questionnaires, electronic health records, and digital technology we aim to build dynamic, individualised relapse risk models that can forecast clinical relapse within a 7- or 28-day window. The use of digital phenotyping and machine learning gives us a powerful, data-driven way to detect early warning signs, but it's the people behind the data who truly bring this study to life.

One of those people is Ash. Ash, 25, participated at the University of Glasgow site after experiencing psychosis in the past year and a half. As part of her involvement, she created a short video reflecting on what it felt like to be part of the research. It is honest, thoughtful, and deeply human. In it, she talks about her initial anxiety around discussing mental health with strangers, how that changed over time, and the unexpected comfort she found in small moments, like chatting with the research team, finding her voice, and even sharing a joke: "How does a scientist freshen her breath? Experiments." The video premiered at the Scottish CONNECT launch in December 2024.

Ash's video doesn't promote the study - it illuminates it. It offers a glimpse into the participant experience and echoes findings from studies like Jakobson et al. (2023), who highlight how service user involvement helps create safer, more open research environments. Collaborative approaches, they argue, don't just improve participant wellbeing, they strengthen the research itself by encouraging flexibility and deeper dialogue.

This has been well-documented across other studies too. In the Empowering the Participant Voice (EPV) project, Kost et al. (2025) found that one-third of research participants felt unprepared for their role, despite completing formal consent procedures. It's a striking reminder that paperwork doesn't always translate into understanding. Videos like Ash's have the potential to bridge that gap, making participation feel more real, more approachable.

And we know that storytelling works. The Self-Management And Recovery Technology (SMART) research program led by Williams et al. (2018) found that participants with lived experience found peer-led videos not only informative but empowering. These videos fostered a sense of connection and hope—helping people feel less alone.

Ash's contribution also prompted reflection within our own team. As researchers, we're used to thinking about procedures, models, and outcomes. But as Staley et al. (2017) remind us, involving participants meaningfully changes us too. It encourages us to step outside of our own frames of reference and engage with the lived realities behind the data.

Trimmel et al. (2024) describe this as "fostering community growth." Their study on participatory research with individuals with psychosis revealed how collaboration can spark creativity, trust, and new directions. Ash's video aligns with that ethos—it's not just feedback; it's co-creation.

So, what does this mean for the CONNECT study?

It means we are listening. We are rethinking how we introduce and explain research, and how we support participants not just at the beginning, but throughout their involvement. Most of the participants I've spoken to are curious and invested. They care about the future of mental healthcare—not just for themselves, but for others.

So what? Ash's story shows us that participation isn't simply a box to tick. It's an experience that can be confusing, meaningful, even transformative. And it's our responsibility to ensure it's also supportive and empowering.

Now what? We invite you to watch Ash's video. Share it. Use it as a conversation starter. Let it guide how we all think about involvement, communication, and care in mental health research.

Watch Ash's video here: PPI Video CONNECT Study [connectdigitalstudy.us17.list-manage.com]

Together, we can improve how we research psychosis—and how we support the people at the heart of it.

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 Study Newsletter









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