

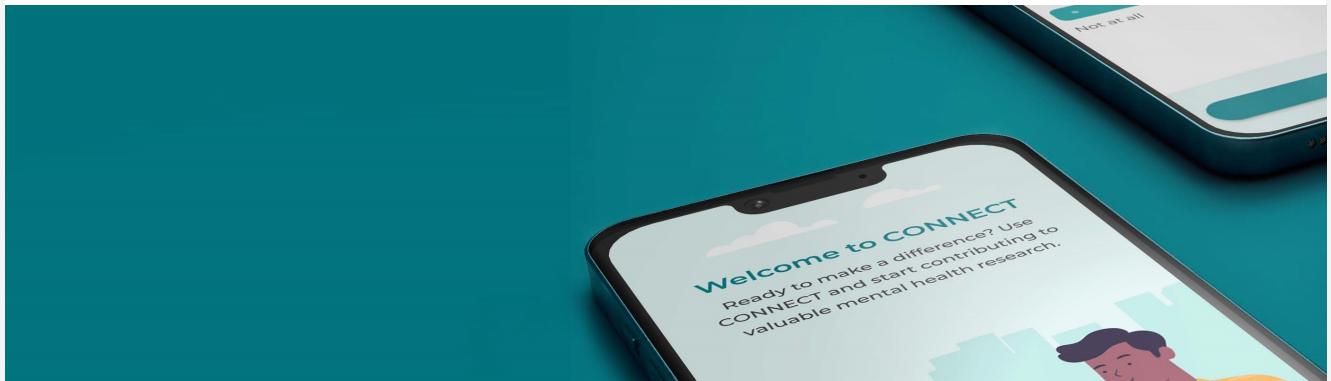
**From:** The CONNECT Study <connectdigitalstudy@manchester.ac.uk>  
**Sent:** 01 November 2024 14:19  
**To:** ConnectDigitalStudy  
**Subject:** CONNECT Digital Study October Newsletter



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## Newsletter

October 2024



### 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.

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As reported in our July newsletter, we are  
collaborating with [The McPin Foundation](#)  
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Meet the CONNECT  
KCL site

people with lived experience of psychosis are at the heart of the CONNECT study. Following the qualitative analysis training, Alie and Tor-Ivar, two members of the CONNECT Lived Experience Advisory panel, were invited to take part in further training about qualitative coding with the opportunity for them to carry out some coding analysis work.

*What made you express an interest in taking part in subsequent stages of the qualitative work?*

**Tor-Ivar:**

Mainly, this was due to my interest in helping others, but also because I need some kind of income that would be somewhat more stable. The research was to me obviously relevant to improving the methods for treatment, and that alone was to me enough to make me want to apply for it.

*How did you feel about being accepted to take part?*

**Tor-Ivar:**

I didn't expect it, so it made me incredibly happy. It also made me hope and believe that yes, I can make a positive change in the world, I do have skills that are useful to others, and that my desire to fight when I had to, was worth it.

*How did you find attending the coding training?*

**Alie:**

The coding training was comprehensive, we were required to engage in the conversation of the training for coding. This has helped me to build on the foundation set during the stage for the thematic analysis training, helping to

The CONNECT team is dedicated to exploring how technology can predict relapses in psychosis and improve outcomes for service users in the South London and Maudsley area.

### **Our Leadership**

Professor Dame Til Wykes and Dr Matteo Cella lead the team. Til is a professor of Clinical Psychology and Rehabilitation who has contributed significantly to understanding the effectiveness of psychological treatments and the role of digital tools in supporting individuals with mental health challenges. Matteo is a reader in Clinical Psychology, with research focusing on how technology can improve treatment and support for individuals with mental health challenges. Their experience and expertise in mental health research

demystify the coding process. I have especially enjoyed the interactive elements, including the successive meetings we have held as a follow up to assess the initial practise of coding which gave us a chance to practice coding in real time and receive feedback.

***Describe the process of doing the coding task. What did you do step by step?***

**Alie:**

Familiarization: I began by thoroughly reading through the data information to understand the content and context to notice similar opinions, concerns and phrases.

Initial coding: I then started coding the data by tagging relevant segments with preliminary codes that aligned with recurring ideas.

Refining codes: After completing the first round of coding, I reviewed the codes to ensure consistency and adjusted them where necessary.

Final review: Lastly, I revisited the entire dataset to check for any missed codes, ensuring that the analysis was comprehensive.

***What did you find difficult?***

**Tor-Ivar:**

The main difficulty to begin with, was to simply get started. Dørstokkmila – the threshold mile in Norwegian – can be very long indeed. Once I did get going, however, I found a good flow and was able to work through it efficiently. It was challenging to begin with to find good words to code with, and I also felt I should try to stick to fewer rather than more

and digital innovation guide our work in the CONNECT study.

**Our Team**

Our study coordinator, Dr. Uzma Zahid, is a King's research fellow with a background in psychiatric neuroimaging and experience in psychosis research. Uzma manages recruitment, liaises with clinical teams, and oversees project operations at King's.

Our research assistants, Lois Parri and Lucy Miller, support recruitment, data collection, and participant engagement. Both have experience in psychosis research and aim to pursue academic and clinical careers. They help ensure data integrity and participant care.

**Acknowledgments**

While this introduction highlights the CONNECT team, our work would not

code words. Eventually, I found a good rhythm and felt it was easy-going and self-evident what to do.

The first two texts I coded were very different from one another. One included lots of small, verbal cues, the other was a more edited text, removing most of the ooo-s and um-s. It took much longer to work through the first of the two texts, as it was much slower, more staccato to read.

### ***What did you find easy?***

**Alie:**

The guidance from the training has made it easier to segment the data into meaningful parts, every element of the conversation from the participants is important. The precise elements of the responses helped make the coding more manageable. Once I got into a rhythm, I could concentrate on identifying the more obvious in the coding patterns that came naturally.

### ***How did you feel afterwards?***

**Alie:**

This was the first time I have been given the opportunity to perform coding for a qualitative study utilising thematic analysis. I have felt accomplished, it sort of built a foundation that I can grasp confidently in my qualitative research skills. The process and understanding, while intuitively challenging, was intellectually stimulating, and it felt good to contribute to the research in such a meaningful way.

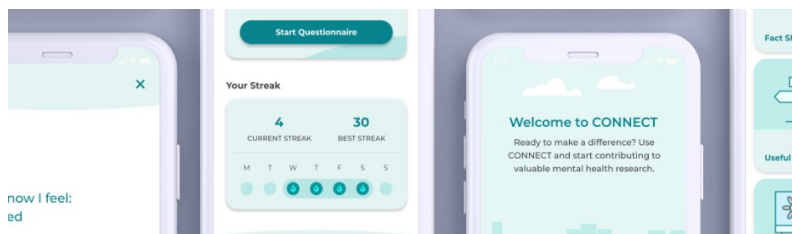
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be possible without the support of our clinical teams, who recognise the benefits of this research and play a pivotal role in our recruitment and facilitate their clients' participation. We are continuously grateful for their collaboration.

### **Our Mission**

Together, we aspire to create an environment that prioritises access to research while advancing our understanding of digital tools to predict psychosis relapse, all while ensuring that our research has a real-world impact.





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## Study Update

CONNECT started in November 2022 and will design and test a digital data capture platform in people who experience psychosis. People who experience psychosis can encounter changes in things like their sleep pattern and getting out and about just before they experience a relapse. In the CONNECT study, we are building on previous research to see how changes in behaviours and patterns might relate to someone's mental health getting worse. In the future, it might be possible to tell in advance when someone's mental health might be getting worse by looking at these changes and offer extra support at the time it is needed.

Phase 1 of the project ran from November 2022 to January 2024, and involved interviews with 58 service users and 60 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 digital technology, ethical issues, and the use of machine learning methods and algorithms in the context of predicting relapse and mental healthcare. Interviews are in the process of being analysed and written up for dissemination and publication. A content analysis of these interviews has already contributed to the design features of the CONNECT app and study procedures for phase 2 of the programme of work.

Phase 2 uses an observational cohort study design. Our main aim in phase 2 is to collect data of sufficient depth, breadth and resolution using a range of methods to develop and validate a relapse prediction algorithm. People are invited to use a smartphone and a wearable device 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 commenced in March 2024. 184 participants have been recruited across all sites with 114 having completed 3 months in the study, and 23 have reached 6 months. We are looking to recruit many more participants across our study sites and would like to hear from anyone who is interested in taking part.



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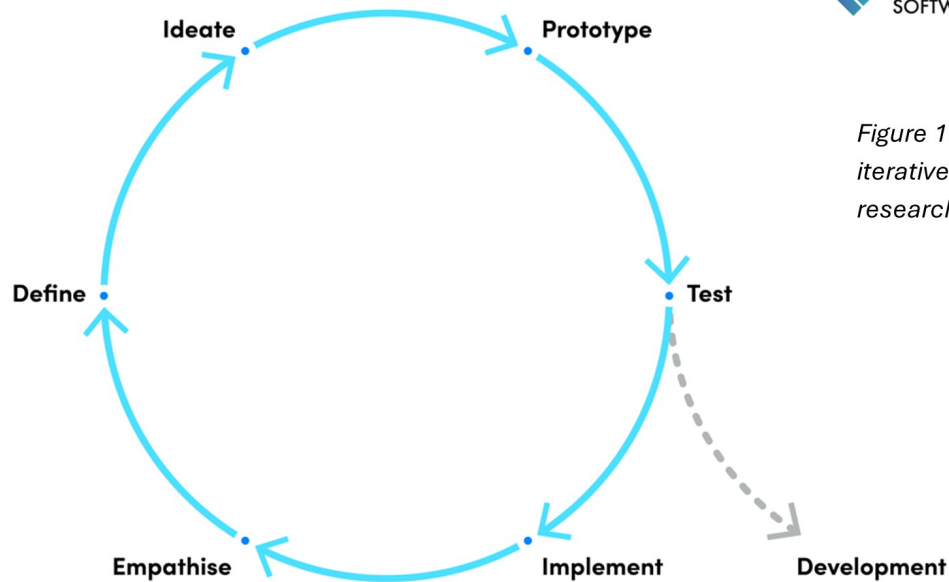
### **Software engineer, Henry Gorner, and software designer, Simon Foster, explain how the CONNECT app was designed**

Designing the mobile app for the CONNECT study was a collaborative process that emphasised the importance of user-centred design. It was developed through a series of co-design workshops with the study team's Lived Experience Advisory Panel (LEAP).

#### **Co-Design**

The design process began with a series of co-design workshops. The goal of these sessions was to ensure the app was intuitive, accessible and met the needs of its users.

In the initial workshops, we focused on understanding the daily challenges individuals face when using technology. Participants shared their experiences, highlighting the importance of an engaging interface design, accessible content, non-intrusive monitoring and the need for privacy and data security. These insights were invaluable in shaping the app.



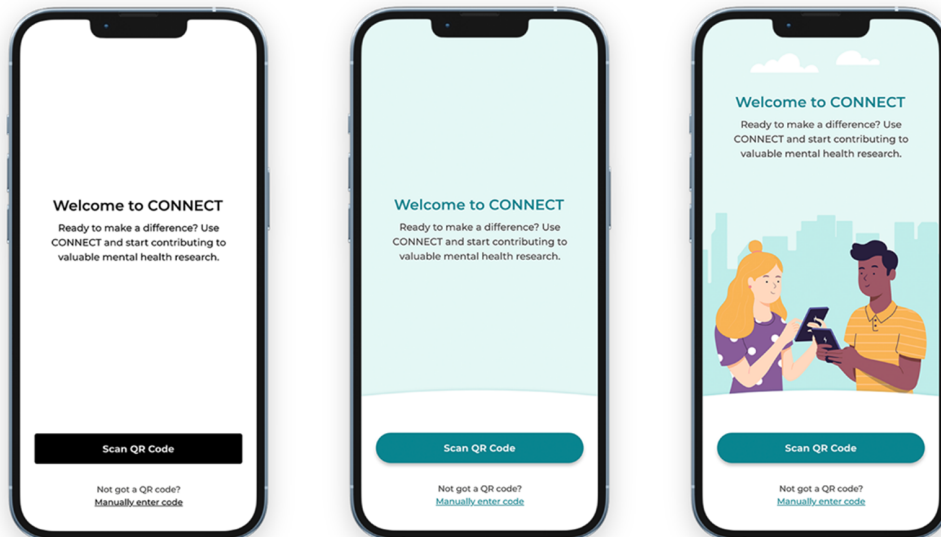
*Figure 1: The iterative user research process*

### **Iterative Development: Rapid Prototyping and Feedback**

Early versions of the app were created using prototyping software and shared with workshop participants for feedback. This iterative process allowed us to refine the app continuously. For instance, participants emphasised the need for an engaging interface, leading to the development of visually appealing design elements and progress-tracking features.

Feedback also highlighted the importance of accessibility in relation to reducing cognitive load. Participants wanted the ability to use the app without having to concentrate for long periods of time. Readability, in particular, was highlighted as an especially important issue to consider. This input guided the integration of features to aid readability. These included support for screen readers and the development of a 'dark mode' for the app.

Figure 2: Evolution of prototype



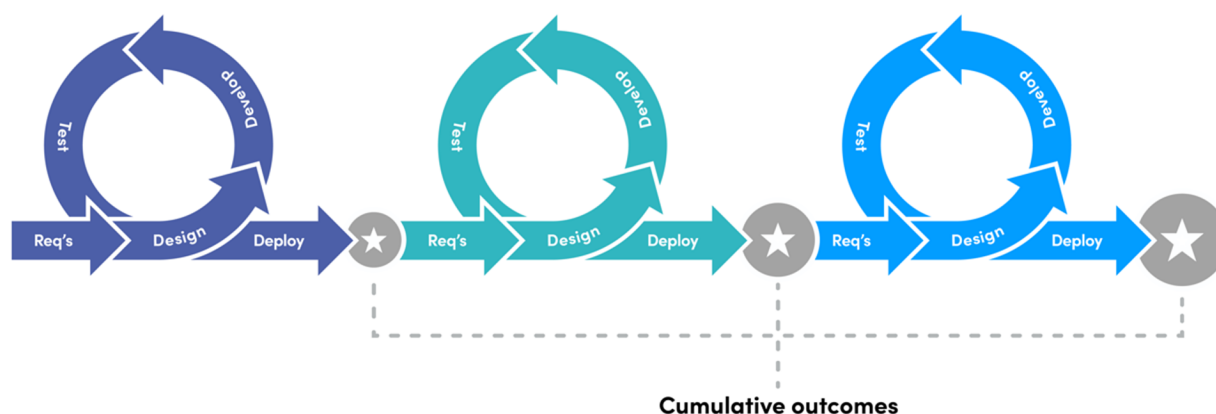
## Privacy and Data Security

So that people could clearly see how data is collected and where it is stored, we created a series of diagrams to explain the 'data journey'. The diagrams were used to explain complex flows of data in a transparent and understandable way.

## Software Development for the CONNECT project

Once the graphical design of the app was finalised by our designer, our software team started working to build the software for the CONNECT study. We systematically transformed the designs into a fully functional app. We employed cutting-edge technology that facilitates simultaneous development for both Android and iOS platforms. This dual-platform approach significantly accelerated our release timeline, allowing us to deliver the app for the project more swiftly than the traditional method of building for each platform independently. Despite our best efforts and planning, it is inevitable that challenges and deviations will arise. To effectively manage these uncertainties, we adopted an Agile development approach. This involved segmenting the app development process into three-week sprints, each focused on achieving specific milestones. At the conclusion of each sprint, we conducted comprehensive testing of the developed features and implemented necessary adjustments based on the feedback received from the project, testing and lived experience teams. This iterative approach not only allowed us to refine and enhance features progressively but also ensured that the application's functionality aligned with real-world user requirements and expectations.

Figure 3: Agile development methodology



### Passive data, challenges and privacy

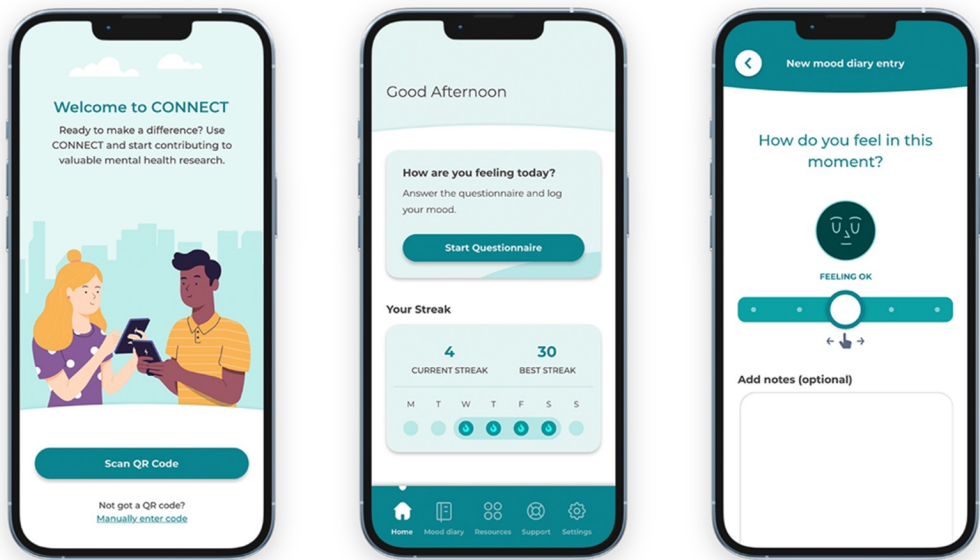
Our most significant challenge was collecting data from various phones and wearable devices. CONNECT supports numerous devices, including Apple watches, Fitbits, and Samsung watches, each requiring individual system integration. Furthermore, we needed to obtain approvals from Apple and Google to access data from these phones and watches; these approvals required completing documentation and responding to technical and research queries.

Given the vast amount of data that the CONNECT project will generate, we needed to ensure efficient data storage and transfer. To address this, we implemented advanced compression techniques to minimise the load on devices. Additionally, we utilised background processing to facilitate seamless data transfer to our servers and allow the app to be used normally while transfer is taking place. This approach ensured that we could handle the extensive data efficiently without compromising device performance or user experience.

Given the nature of the app and its handling of personal information, security was a paramount concern throughout the development process. We implemented stringent measures to ensure that user data remains completely isolated from other aspects of the app. All personal data is transmitted to highly secure vaults, which are protected with multiple layers of security protocols. Access to this sensitive data is restricted to a very limited group of authorised personnel. This robust security framework guarantees the protection of user information and upholds the highest standards of data privacy and security.

Each phase of the development was followed by extensive testing – both automated and manual user testing - to ensure that the app was fit for use. We are delighted that that the CONNECT app is now in live use in the study and we look forward to seeing the results of the research.

Figure 4: Screenshots from the final CONNECT app



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