Jane Lees

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

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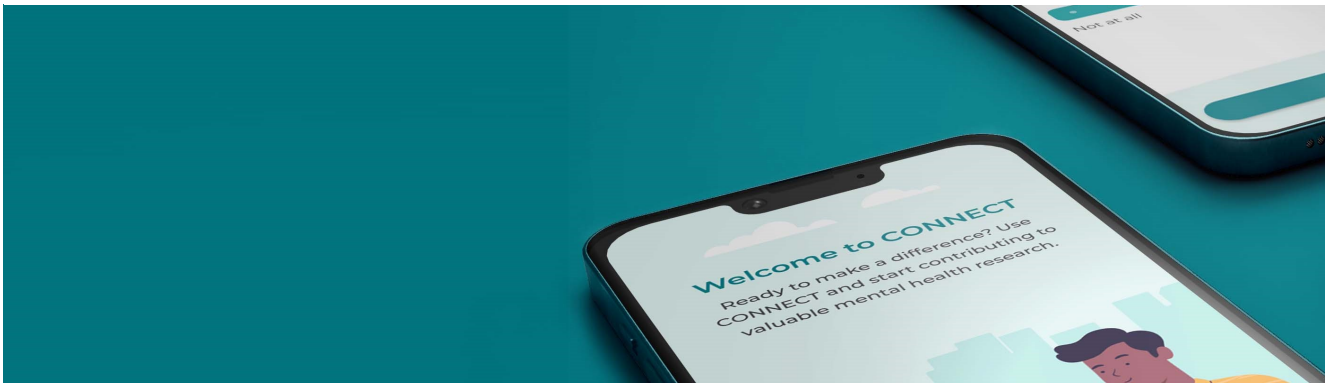
[connectdigitalstudy.us17.list-manage.com]



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.

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, a member of the CONNECT Lived Experience

Meet the CONNECT Manchester site

Advisory panel shares their account of the qualitative analysis session that was held recently.

The Lived Experience Advisory Panel (or LEAP) for the CONNECT Study [connectdigitalstudy.us17.list-manage.com] met online on 3rd June 2024 for a training session in Qualitative Analysis. The training was mainly delivered by Tanya Mackay and Abi Burgess, Head of Research and Involvement, and Research and Training Manager from McPin respectively, with the aim of preparing the LEAP to carry out Thematic Analysis on interviews with people with psychosis.

Personally, I had done some of this kind of work before on other studies, but I was still very interested in refreshing my knowledge on the process, and as I discovered later, the CONNECT Study was going to take its own particular approach in carrying it out. Before the meeting we were emailed some slides from a previous meeting (presented by Hannah Ball and Sandra Bucci) which outlined a three study structure: ***Study 1*** consisted of the previously conducted interviews with people with psychosis and clinicians, ***Study 2*** was to look at developing a theory to explain what affects the implementation of digital remote monitoring in mental health services for people with psychosis and ***Study 3*** would consist of semi-structured (with a flexible schedule of questions) exit interviews with people who took part in the cohort (specifically targeted group) study.

To give some background, this qualitative work is being done because digital health innovations are difficult to integrate into services with many attempts failing. To integrate a digital remote monitoring system like CONNECT in mental health services, the factors that will likely affect its implementation need to be understood as early as possible. It also needs to be understood better how the digital system works, whom it works for, and in what contexts. This understanding will help develop strategies which can support the implementation of digital remote monitoring

Manchester has many nicknames that describe some of its characteristics. Cottonopolis, as the first industrial city which generated so much wealth for some and so many adversities for many that it provided the grounds for fundamental criticism of capitalism by Friedrich Engel, who visited the city at the time. Rainchester, as a place that is often so soggy that pubs and music venues are thriving. Perhaps it was farfetched when a Mancunian band formerly fittingly known as The Rain renamed itself in the 90s to Oasis. Manchester is definitely a great, exciting, and diverse place to live.

Despite the great music scene, Manchester is also a place of stark inequality with some of the most deprived areas of the country next to some of the

systems in mental health services. To recap, the CONNECT Study is looking at digital remote monitoring of active (input deliberately by user) and passive (e.g. heart rate and movement) data via smartphones and digital wearable devices like Fitbits or Apple Watches.

Since Study 1 interviews had already been conducted, to contextualise the source of the transcripts we would be working from, some vignettes were shown to exemplify the topic guide used to explore people with psychosis' views on digital remote monitoring and its implementation in mental healthcare. Our qualitative training then consisted of learning how to identify features (or codes) from transcripts of the interviews and being able to arrange these into themes (recurring and important topics). We would be adopting the Braun and Clarke [connectdigitalstudy.us17.list-manage.com] method of Thematic Analysis to do this, an accessible yet still rigorous approach, which has 6 steps. The method runs as follows:

1. Becoming familiar with the content of the transcripts by reading and re-reading and then noting down ideas,
2. Systematically generating initial codes,
3. Collating initial codes into themes,
4. Reviewing themes for a good fit with the codes and then mapping out themes,
5. Refining the process through repeated analysis of the transcripts, then defining themes,
6. Selecting vivid and compelling examples from the data, relating these back to the analysis, to the research question and literature, and writing them up in a report.

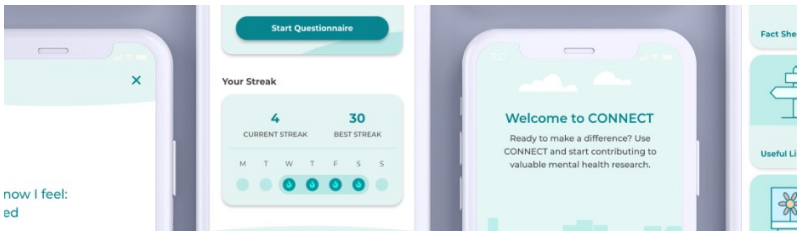
At this stage, the LEAP would be focusing on the first two steps. The transcripts have already been produced, so after familiarisation, we would be asked to use various techniques to organise the data according to individual preference e.g. using coloured pens, sticky notes or text editing programs. We were advised that there is no right or wrong way about doing the coding and to note down whatever seems important.

wealthiest. The local community is served by two NHS Trusts: Greater Manchester Mental Health NHS Foundation Trust and Pennine Care NHS Foundation Trust, and like everywhere in the country, the demand for mental health service is so high that the required mental health care cannot always be provided as needed.

In Manchester, we recruited our first participants for CONNECT in March 2024 and we have all learned a lot in the weeks since then. By now, we all feel comfortable explaining the study to potential participants and to service providers. We have found ways to enthuse service providers for the study and to help busy services identify potential participants on their caseload. Moreover, we feel much more confident now with all the administrative work involved in the study. The two research assistants, Anuoluwapo Oluwatayo and Elizabeth Barlow, and the research coordinator, Dr Fritz Handerer, agree that the

I felt the pace and content of the training was very good and we were encouraged to ask questions whenever we needed any further clarification. I took away a better understanding of Thematic Analysis as a whole and also now realised that the CONNECT Team would be using the 6-step approach developed by Braun and Clarke [connectdigitalstudy.us17.list-manage.com]. I also felt that I should do some extra research myself into the process and looked online and at some YouTube videos e.g. here. [connectdigitalstudy.us17.list-manage.com]

I understood that there would be additional training and involvement sessions in future on this topic with work offered on analysing interview transcripts, contributing to the development of themes/codes and sense-checking the coding framework. The aim is to explain what affects the implementation of digital remote monitoring systems in mental health services for people with psychosis and contribute to a theory to explain how digital remote monitoring for psychosis operates and for whom and in what situations it does and does not work. In Study 3, there will be opportunities for LEAP members to support exit interviews including planning of the study design, developing/reviewing the topic guide, as well as the possibility to co-facilitate interviews and implement thematic analysis again. As previously mentioned, this training will help the LEAP to aid in the effective implementation of CONNECT into services and it is hoped this will enable more people with psychosis to access timely, evidence-based support for their mental health.



best part about working on the CONNECT study is meeting so many different people when completing assessments and to hear people's story. We have been particularly glad to see widespread interest in CONNECT across Manchester. Many service users were happy to get involved and we have already had participants joining the study following recommendations from other participants in the study.

There are still many months of recruitment ahead of us and in Manchester we decided to break the target number of participants down into more manageable chunks. We reached our first interim target of recruiting 25 participants at our site into the study, and we are celebrating by having an afternoon tea of doughnuts. It will probably rain, but we will sit in an old industrial building, listening to Britpop planning our next milestones.

Study Update

CONNECT started in November 2022 and will design and test a “digital remote monitoring” (DRM) 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 a DRM system, ethical issues, and the use of machine learning methods and algorithms in relapse and mental healthcare. Interviews are in the process of being analysed in collaboration with the McPin Foundation as mentioned above, 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. 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. Recruitment commenced in March 2024, with 101 participants already recruited across all sites. People are invited to use a smartphone and a wearable device (e.g. Fitbit, Apple watch or Samsung Galaxy watch) 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. 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.

Post-doctoral researcher Sian Bladon reports on how CONNECT aims to use the data collected to predict whether an individual has an increased likelihood of experiencing relapse

One of the aims of the CONNECT study is to develop a clinical prediction model that will be able to predict how likely an individual is to experience a relapse within either the next week or month. A prediction model is essentially an algorithm that takes information about an individual and uses this to predict the likelihood of an outcome occurring. In our case, the algorithm will be using the data collected through the CONNECT smartphone app and wearable devices to estimate whether an individual has an increased likelihood of short-term relapse.

As one of the statisticians working on the CONNECT project, my role is to develop this algorithm using the data from participants in the study. We will also be using the data to answer other questions we are interested in:

- *What specific information in the data we are collecting are most useful for predicting relapse? We will be assessing whether the passive data or the active symptom data, or a combination of the two, are the most useful.*
- *Is our model more accurate than other existing models that do not use data from smartphones and wearables to predict the likelihood of relapse; for example, models that use information captured in a person's medical records?*

We have been busy writing a detailed analysis plan specifying how we will develop the prediction algorithm and what methods we will use to answer the other questions we are interested in. When developing a clinical prediction model, there are a number of things you have to consider and best practice guidelines to follow to

ensure the type of model you use is appropriate for the outcome you are interested in and the amount of data you have.

In the CONNECT study, participants are providing a large amount of data over a long period of time. Whilst this is advantageous in some ways it does also mean there are extra challenges for us to consider. Firstly, we will need to decide what specific information we will extract from the data being collected. For example, the wearable devices will give us data about an individual's sleep patterns. There are a number of different measures we could calculate from that data, including the amount of time spent asleep, the amount of time taken to fall asleep, the number of times you have awoken during sleep, etc. Initial stages of the analysis will be to look at all the possibilities for each type of behaviour and assess which have the strongest association with relapse. This will help us decide which measures we will include in the algorithm.

The second thing we need to consider is what type of algorithm we will use. As we are collecting information from participants on a daily basis, the prediction model needs to be able to use as much of this data as possible. We will be exploring statistical models and more complex machine learning models and comparing their accuracy.

As well as writing our analysis plan, we have recently completed a review of previous studies that have collected passive data through smartphones and wearable devices. The focus of our review was to assess how these studies had processed the data they collected, what measures they had calculated from the data around certain behaviours (e.g. sleep or physical activity) and how they had analysed the data. We will use the findings from the review to help inform our own analysis.

Now that the first participants have been recruited to the study and data collection has begun, we are looking ahead to the Autumn when we will have access to the first few months of data. We are all excited to get started with the initial stages of our analysis and look forward to sharing our findings as we progress through the project.
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