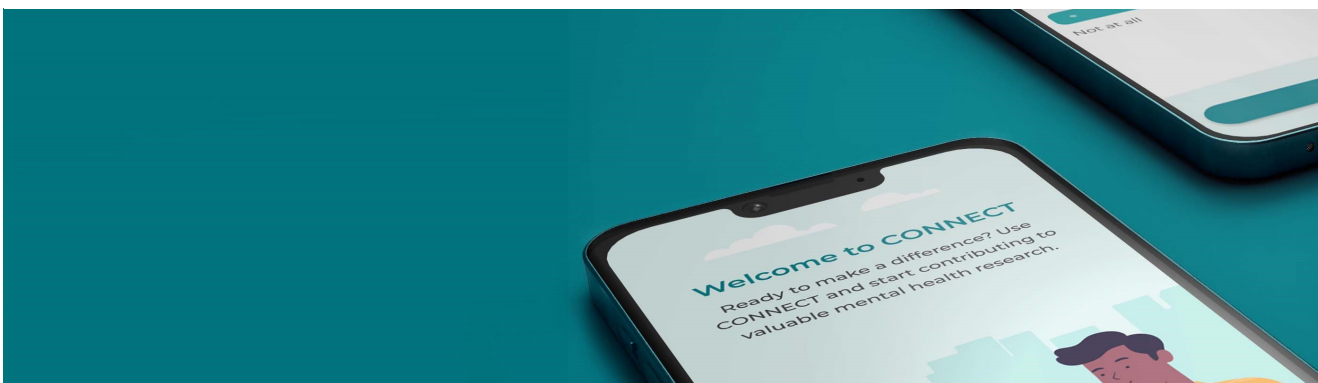

From: The CONNECT Study [REDACTED]
Sent: 25 April 2024 10:49
To: [REDACTED]
Subject: CONNECT Digital Study



Newsletter

April 2024



Welcome to the second newsletter for the CONNECT Study

CONNECT launched on March 11th 2024 with a successful online event attended by over 120 people. A distinguished line up of speakers included Miranda Wolpert MBE, Director of Mental Health at Wellcome. You can watch the recording below and also read an account of the event by expert by experience, Dan Elton.

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. 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.



[\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com)

We are collaborating with The McPin Foundation

[\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com) to ensure people with lived experience of psychosis are at the heart of the CONNECT study. Below, expert by experience and member of the CONNECT Lived Experience Advisory panel Dan Elton shares his account of the launch event.

The CONNECT Study [\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com) Launch marks a significant event in the push to improve outcomes in psychosis, and the start of referrals for people wanting to participate in this research. The launch began with a talk by Professor Sandra Bucci [\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com) the lead or 'Chief Investigator' for the study. She outlined how smartphones and wearable, digital technology (e.g. Fitbits and Apple Watches) will collect data and that the aim of the study is to be able to detect in advance if people's mental health might be getting worse.

The Wellcome Trust [\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com) has funded the CONNECT Study and it is very encouraging to hear that input from people with experience of mental health issues will be embedded throughout its development. Professor Miranda Wolpert MBE [\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com) Director of Mental Health, The Wellcome Trust also described how Wellcome is committed to both improving interventions in anxiety, depression and psychosis and to better understanding these conditions. This approach for psychosis-related research has targeted pharmacological (e.g. KarXT by KARUNA [\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com)) and non-pharmacological interventions (e.g. AVATAR [\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com) as well as CONNECT).

In terms of Patient and Public Involvement, or PPI, for the study, Alex Kenny Senior Public Involvement in Research Officer at McPin [\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com), delivered an informative and thorough presentation. PPI can give a voice to marginalised

Meet the CONNECT Glasgow site



One of the Scottish recruitment sites for CONNECT is NHS Greater Glasgow and Clyde. Glasgow has a rich history, vibrant culture and friendly people. From its beginnings as a rural settlement to its development as a popular trade, industrial and ship building city, the story of Glasgow can be seen through our heritage sights and many public museums. Glasgow was the first city in the world to give Nelson Mandela Freedom of the City in 1981.

We are proud of our historic Duke of Wellington statue and his traffic cone hat. A 2013 petition garnered over 10,000 signatures successfully opposed Glasgow City Council's plan to remove it – it is, after all, Banksy's "favourite work of art in the UK". Glasgow is world renowned for its music scene, boasting as the UK's first UNESCO city of music. From its "wee" venues to outdoor parks and sold-out arenas, from traditional folk (come see our Celtic Connections music festival) to electronic, indie to pop – there is something for everyone in each corner of the city. We don't always have sunny weather, but we have a belter music scene!

communities, and in this study is ensuring research is guided by people with lived experience of mental health issues to keep it relevant. The CONNECT Lived Experience Advisory Panel (or LEAP for short) alongside a wider Involvement Network advises on PPI and consists of members from each of the 6 university sites across England, Scotland and Wales.

The LEAP has met to discuss important subjects related to the study like ethics, the study protocol, co-design of the CONNECT App and communications. Consent Forms, the Patient Information Sheet, leaflets and posters have been worked on and we gave feedback on user-friendliness, keeping participants interested and motivated in the study and again, reaching diverse communities. One stand out session consisted of giving advice about the App design, going into detail about the text, colours, recommending a zoom function and a 'Dark Mode' option for accessibility. The LEAP also suggested a progress image and a slowly-revealed 'puzzle graphic' was created!

The LEAP has good inclusivity and offers opportunities, training and development to all, while accessibility makes sure members' needs are catered for, enabling them to contribute. The process is a collective, collaborative endeavour with its diversity reflecting a variety of backgrounds, so that different groups in society are represented. This gives meaning in life. Confidence within the team is increased and there is potential for personal as well as professional growth. Lighter moments have consisted of providing 'fun facts and quotes'. A 'we said we did' document was reassuringly provided by the design team and documents of varying complexity were shared with people who were interested, outlining the technology used behind the scenes in the study. The LEAP have also recommended that participants are suitably reimbursed, general thankyou's given at regular intervals and any study-related questions answered.

The last presentation was given by Richard Dobson, Professor of Informatics, [\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com) who holds a joint appointment at University College London and King's College London. He focused on CogStack [\[connectdigitalstudy.us17.list-manage.com\]](https://connectdigitalstudy.us17.list-manage.com), which uses Artificial Intelligence to reveal important data logged in people's health records to support decision making in healthcare. Critically, CogStack can be employed to search medical records of people who suffer with mental ill health and help improve the general health for this population. Historically, many people from this group of patients may have other health conditions and die earlier and it's also important to note that the economic costs to society are very high too.

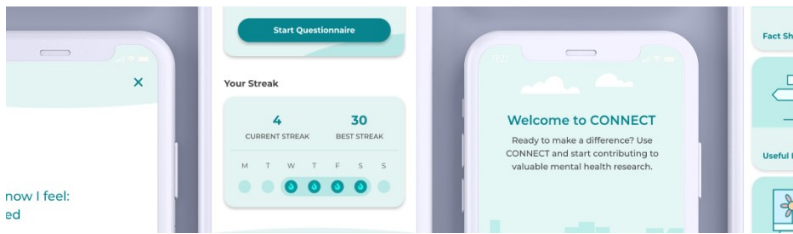
In conclusion, with the present age of Artificial Intelligence, BigData and digital technologies, there are great opportunities for improvements to be made in the treatment of all illnesses, including in mental health. The CONNECT Study is well-placed to deliver in this area for people with psychosis too.

Greater Glasgow and Clyde is the largest NHS board in Scotland serving approximately 1.3 million people.

Unfortunately, Glasgow has the highest concentration of people living in deprivation compared to any other region of the UK. Homelessness applications are at their highest level in a decade, the rate of prescriptions and psychiatric hospitalisations associated with mental health is higher than the national rate and premature mortality rate is higher than other UK cities. Glasgow is disproportionately affected by digital exclusion.

Inclusion of Glasgow as a site in CONNECT is important to ensure an inclusive approach to digital health technology development. As a site, we hope delivering CONNECT in Glasgow will mean increasing service-user's access to and confidence using digital devices. With this in mind, and an ongoing commitment to Equality, Diversity and Inclusion, we will work with our community mental health resource centres and the only early intervention service in Scotland (ESTEEM) as well as a range of third sector organisation across Greater Glasgow to welcome participants to the study.

Our CONNECT team is based in the heart of the west end of Glasgow in the new University of Glasgow Clarice Pears Building. Professor Andrew Gumley is the Principal Investigator, Dr Louise Beattie is Site Co-ordinator, and Research



Study Update

CONNECT started in November 2022, and will design and test a “digital remote monitoring” (DRM) platform. This digital platform will allow people to use their smartphone and/or wearable device to keep track of how they've been feeling day-to-day.

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. This included questions on barriers to using a DRM system for psychosis, ethical issues, and the use of machine learning methods and algorithms in mental healthcare.

Phase 2 is an observational cohort study. People who experience psychosis can encounter changes in things like their sleep pattern, activity levels and socialisation pattern just before they experience a relapse. Recruitment commenced in March 2024, with 13 participants already taking part in the study. Service users 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. This is to see whether changes in this information might relate to their mental health getting worse.



Assistants are Beth McCulloch and Leonie Richardson.





Research Assistants at the CONNECT Manchester site, Anu and Lizzy report on CONNECT's proactive plan for equality, diversity and inclusion

Something that researchers need to pay close attention to is bias. Bias in any study needs to be addressed right from the start, particularly in a study like CONNECT that uses machine learning methods. Machine learning creates an algorithm and this needs to be built from varying backgrounds, experiences and demographics so it is suitable for a wide range of people. In the CONNECT Study, we are proactively paying attention to diversity in research participation by considering issues around Equality Diversity and Inclusion (EDI).

So how have we been prioritising EDI in CONNECT?



We started by compiling a list of barriers to taking part in research that have been commonly reported in studies. We then proposed solutions to these barriers for consideration by the research team. This list of barriers and solutions forms the basis for our EDI plan for the study and will be continuously reviewed. Our EDI plan was made collaboratively across all 6 study sites and takes into account the geographical, socio-economic and population differences between the sites.

As part of running the CONNECT study, we have dedicated time for meeting and discussing EDI issues as well as regularly reviewing our EDI plan. This means we can monitor the diversity of participants proactively and continuously, as we do the research, rather than retrospectively, after the research is finished. This is a real strength of the CONNECT study and it allows us to make changes whilst the research is happening.

As a research team we hope to recruit a diverse group of participants which includes individuals from all walks of life. We think this is important as we want to ensure the findings are reproducible, relevant and address the needs of different communities. We also believe it is important that everyone is provided with the opportunity to take part in research, therefore we want to remove as many barriers to taking part as possible.

So, what were some of the barriers to taking part and what solutions did we find? The first potential barrier was physical distance from a research centre, clinic, or institution. To combat this, we have developed solutions such as offering home visits and remote appointments on the phone and online. We thought about how we can make it as easy as possible for people to join the study, so we decided to only choose appropriate times to offer appointments (e.g., not rush hour), and we will offer payments for travelling for both participants and carers.

We also identified barriers to accessibility and a need to ensure the study is inclusive for people with different educational backgrounds, and neurodivergent people. To address this, we worked closely with a Lived Experience Advisory Panel (LEAP) organised by our partner and The McPin Foundation, a charity who work to put lived experience at the heart of mental health research. The LEAP and Involvement Network were essential in co-creating and reviewing the materials used for participants in the CONNECT study. Features in the CONNECT app such as dark mode and text-to-speech functionality were suggested by the LEAP. We also incorporated similar functionality into the self-report questionnaire which has text-to-speech and text enlarger functions.

We also want to ensure our research is ethnically and culturally inclusive. Our participant materials were reviewed by an ethnically and culturally diverse LEAP and Involvement Network who advised us about whether the

materials were appropriate. The illustrations used in the materials were created and reviewed by the diverse LEAP and include a people from diverse ethnicities.

Finally, because the CONNECT study has a large geographical spread across the UK at the 6 university sites, we wanted to investigate the differences in demographic data in these areas. As a result, each site has complied data on demographic information within their population such as age, gender, sexuality, ethnicity, and disability status. We also collated anonymised NHS mental health service user demographic data looking at the same categories. From this we have been able to compare the demographic trends in the general population to the trends within NHS mental health services for each site in the CONNECT study. We plan to make similar comparisons throughout the study using the anonymised demographic data from our participants. We're doing this because we want to make sure that the group of people who take part in the CONNECT study is as representative of the population as possible and that each site is targeting demographics that are more populous in their region of the UK.

So what will happen now? In this blog we have outlined why we have an EDI plan in the CONNECT study, the work that went into creating the plan, and some specific examples of EDI work we have completed so far. As the study progresses, we plan to keep EDI considerations at the centre of the research by dedicating time to these discussions and reviewing the demographic data collected from our participants as it is being collected. Our hope is that through continuous monitoring of our participants' demographics we can ensure the group of people who take part in the CONNECT study is as inclusive, representative and diverse as possible. We will also have continued involvement from our Lived Experience Advisory Panel and Network. All of this will help us to make sure that the CONNECT app is suitable and accessible for as many people as possible.

To stay up to date with the CONNECT study, sign up below.

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