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CESP: Cognitive and Emotional Symptoms in Psychosis

Information for Participants

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Introduction

You are invited to take part in a research study on psychosis. We will look at how connections in the brain affect people's emotion and thinking. This study is happening at the Hunter Medical Research Institute (HMRI), by researchers from the University of Newcastle.

What is the research about?

People with psychosis can have difficulties with getting motivated, expressing their emotions, or engaging socially with other people. These changes can make it hard to keep in touch with friends and family, continue working, or participate in enjoyable activities and hobbies. This research study tries to understand which connections inside the brain may be contributing to these problems.

Who is conducting the research?

The study is being conducted by:

Dr Jayson Jeganathan, as part of the requirements for a Doctor of Philosophy degree at the University of Newcastle under the supervision of Professor Michael Breakspear

Mr Nikitas Koussis, Doctor of Philosophy student, University of Newcastle

Dr Megan Campbell, Post-doctoral fellow, University of Newcastle

Renate Thienel, Research manager, University of Newcastle

Professor Michael Breakspear, University of Newcastle

The study is being supported by a research grant from charitable donors.

Who can participate in the research?

We will be comparing how connections in the brain are different between people with psychosis, and people without any mental health condition. Therefore, we are seeking some people aged 16-50 who do not have a history of any mental health condition. We are also recruiting participants with a history of psychosis.

As this study involves MRI brain scanning, it would not be suitable for people with claustrophobia, metal implants, pregnant women, or previous neurosurgery or traumatic brain injury.

What choice do you have?

Participation in this study is voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without giving a reason. We will not be disclosing your participation or non-participation to anyone else in the health service.

What would you be asked to do if you agree to participate?

The research session happens at HMRI, and should take 3-4 hours. During the research session, the research team will collect basic demographic information. You will complete a brief IQ test.

After this, you will do some tasks which involve

- Watching a short movie clip
- Making posed happy or frowning faces
- Rating the emotion in pictures of faces
- Solving problems quickly

During these tasks, we will record your heartrate, eye movements, and webcam video of your face. These recordings allow us to look at emotion-related changes in heartrate and facial expressions.

After this, you would have an MRI scan of the brain. A safety questionnaire needs to be filled out to ensure you are fine to have a scan. The scan will take about 1 hour. During the scan, you will do some of the same tasks that you completed earlier.

What are the risks and benefits of participating?

Risks

If you don't have any metallic objects in your body, and you're not pregnant, then there will be no health risks from MRI scanning. The space inside the scanner is quite small, so people who get anxious in enclosed spaces might feel anxious or distressed. The MRI radiographer will help you to fill out a questionnaire to ensure it is safe for you to have the scan.

What if an abnormality is found on my scan?

The MRI scan being done is designed to answer research questions, not examine you medically. This MRI scan is not a substitute for one a doctor would order. It may not show problems that would be picked up by a clinically performed MRI scan. All our scans will be

reported by a doctor who is trained in the reading of MRI scans, a radiologist. If the radiologist thinks that there may be an abnormality in your MRI scan, we will contact you and will help you get medical follow-up for the problem. If you have a primary care doctor or GP, we can contact your doctor, with your permission, and help him or her get the right follow-up for you. All information generated in this study will become part of a hospital record routinely.

Benefits

While this will not be of direct benefit to you, we intend that this research study furthers medical knowledge and may improve treatment of psychosis in the future. Your contribution to this research is greatly appreciated.

Will the study cost you anything?

Participation in this study will not cost you anything, nor will you be paid. However, you will be compensated with lunch for the day, and a Coles voucher.

How will your privacy be protected?

All the personal information collected from you for the study will be treated confidentially, and only the researchers named above will have access to it. Information usage will comply with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002. Study results may be presented at a conference or in a scientific publication, but individual participants will not be identified.

Any information you provide will have your name replaced by a participant code number, and will be securely stored within a restricted access office. Only the researchers listed on this sheet will have access to your information. The code numbers and identifying information will be kept entirely separately from your assessment and imaging data. It is technically possible to identify people from their MRI scan because their face is included in the scan. However, we will remove that part of the image in the first step of data processing, and the original image will be stored on secure password-protected servers. Facial video recordings will be stored separately from the other data, and your name will not be attached to this recording.

Data will be retained securely for a minimum period of 5 years from completion of the research and managed in accordance with the University's Research Data and Materials Management Guideline (see <https://policies.newcastle.edu.au/document/view-current.php?id=72>) or any successor Guideline, and applicable University of Newcastle policy provisions (as amended from time to time).

If you were to give specific details (eg date, place, perpetrator) about an illegal activity during the interview, the researcher may be obliged to report the information to the appropriate authority. If you were to disclose information that puts yourself or others at a significant risk of harm, the researcher may be obliged to report the information to the appropriate authority.

If you withdraw your consent during the research project, the study staff will not collect additional personal information from you, although information already collected will be retained to ensure that the results of the research project can be measured properly, and to comply with law.

How is this information used?

We intend to publish the results of this research in a scientific journal, and it will be in a thesis to be submitted for Dr Jeganathan's degree. In any publication, information will be provided in such a way that you cannot be identified. We will also ask for your specific consent for the pre-processed de-identified (anonymous) brain imaging data to be included in future research and shared via open science platforms such as <https://openneuro.org/> to contribute to further research. This is optional. If you would like to participate, please tick the relevant box in the consent form.

If you would like a summary of the study results, please provide an email address, and we will email it to you once the research study is done.

Further Information

When you have read this information, Dr Jayson Jeganathan will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact us on [insert research phone] or participate-
sng@newcastle.edu.au

This information statement is for you to keep. If you would like to participate, please complete the attached Consent Form.

If you are consenting on behalf of a child or young person under 18 years of age, please discuss the project with them before making a decision. Where a parent/guardian consents to their child or young person participating, the final decision will rest with the child / young person.

Thank you for considering this invitation.

Dr Jayson Jeganathan and Professor Michael Breakspear
School of Psychology
The University of Newcastle

Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 202/ETH00531.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or if an independent person is preferred, to Dr Nicole Gerrand, Manager Research Ethics and Governance, Hunter New England Local Health District, Level 3, POD, HMRI, Lot 1 Kookaburra Circuit, New Lambton NSW 2305, telephone (02) 49214950, email HNELHD-HREC@health.nsw.gov.au