Department of Psychology

Faculty of Medicine, Health, and Human Sciences

MACQUARIE UNIVERSITY NSW 2109

INFORMATION SHEET

HREC Project Number: **12138**
Research Project Title: Deconstructing Post-Concussion Syndrome: Is it a Neurological Condition?

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You are invited to take part in this research study because you have post-concussion syndrome (i.e., persistent post-concussion symptoms) or chronic pain. The aim of the research project is to better understand the factors that contribute to post-concussion syndrome.

This participant Information Sheet will tell you about the research project, and what is involved. Knowing what is involved will help you decide whether you want to participate. Please read this information carefully. If you have any questions about the study or what will happen to you in the study, please ask a member of the study team.

1. What is the purpose of this research?

The primary goal of this study is to better understand why some individuals continue to experience symptoms of concussion for months to years after their initial injury. We will do this by examining the presence and progression of these post-concussive symptoms in patients with post-concussion syndrome and chronic pain. By comparing these conditions, and by tracking how these symptoms change and evolve over time, this study will assist clinicians in finding more suitable treatment and management strategies that can more effectively target the underlying causes of this condition.

2. What does participation in this research involve?

You will first be required to complete a short 10–15-minute screener questionnaire to determine if you are eligible to participate in this study. Health records will be retrieved for patients attending Dr. Rowena Mobbs at Macquarie Health Neurology and Harbour Neurology to verify diagnoses of post-concussion syndrome. If you are eligible, you will then be sent a second online survey with additional questions. This survey will take approximately 30-to-40 minutes to complete. After you have completed the second survey, you will be contacted to schedule a psychological assessment. This assessment will examine your thinking skills, such as your attention, memory, and problem-solving ability. This assessment can be completed in person at the Australian Hearing Hub, University Avenue, Macquarie University NSW 2109, or online through zoom if you are unable to come in for the assessment. It may also be possible to conduct the assessment at the clinic where you were recruited from; however, this option is only available at specific clinics. This assessment will take approximately 90 to 120 minutes to complete.

You will then be followed up at 4- and 8-months to track the progression of your symptoms. (Note: this follow-up phase is optional for chronic pain participants. If you have chronic pain, you will be given the option to participate in the follow-up phase upon completing the initial psychological assessment). This follow-up will involve filling out a short 20-minute survey. Your thinking skills will also be reassessed in person or online through zoom at the 8-month follow-up. This assessment will take approximately 90 to 120 minutes to complete.

3. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. If you do decide to take part, you will be sent a screener questionnaire which will contain a Participant Information and Consent Form to sign. Your decision to take part or not, or to take part and then withdraw, will not affect the services you are currently receiving at your respective clinic (i.e., Macquarie Health Neurology, Harbour Neurology, the Sydney Concussion Centre, MQ Health Physiotherapy Clinic, MQ Health Pain Neuromodulation Clinic, MQ Health General Practice Clinic, the Royal North Shore Hospital Concussion Clinic, the Macquarie University Chiropractic Teaching Clinics (Summer Hill, Eastwood, and Macquarie Park), or any other clinic you are currently attending).

4. What are the possible benefits of taking part?

All participants that enter the study and complete the initial series of psychological tests will be entered into a draw to win one of ten $100 vouchers. Additionally, all participants that complete the repeat psychological assessment at the 8-month follow-up will be entered into a separate draw for one of six $500 vouchers. Following the completion of the study, you will also be provided with a summary report covering the overall findings from the project upon your request.

5. What are the possible risks and disadvantages of taking part?

You may be asked some questions or encounter certain tasks that you find confronting or stressful. If you experience discomfort from any part of this study, please let the researcher know. Small breaks can be provided and if necessary, you can withdraw from participating at any point. Support can also be found by calling Lifeline Australia on 13 11 14, or at the Beyond Blue website (https://www.beyondblue.org.au/) or by calling their helpline: 1300 224 636

6. What if I withdraw from this research project?

If you decide to participate in this study, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw.

7. What will happen to information about me?

By consenting to participate in this study, you agree to the research team collecting and using your medical history and personal information for the research project. Any identifying information or personal details gathered during the study will remain confidential, except as required by law. At the start of the study, you will be allocated a code, and all your data will be labelled with this code rather than your name. De-identified copies of your data may be made available to scientific researchers outside the research team. Such cases include whether other scientists wish to check the integrity of published results or where the Chief Investigator and/or collaborators wish to undertake additional analysis.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums and will be used by the PhD candidate to compose their thesis. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

A summary of the results of the data can be made available to you on request by emailing a member of the research team named at the end of this document. You also have the right to request that any information with which you disagree be corrected.

8. Complaints

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics

Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

9. Who is organising and funding the research?

The study is being conducted by Keefe Ip to meet the requirement for a Doctor of Philosophy Master of Clinical Neuropsychology degree (combined degree), under the supervision of Prof. Richard Stevenson, A/Prof. Jennifer Batchelor, Dr. Rowena Mobbs, Dr. Vincent Oxenham, Dr. Susanne Meares, and A/Prof. Rosemary Giuriato at Macquarie University. The project will be funded by the Macquarie University School of Psychological Science's Higher Degree Research Grant scheme.

10. Who has reviewed the research project?

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee.

11. Further information and who to contact

If you are interested in participating in the study, would like more information about the project, or need to speak to a member of the research team in an emergency, please contact:

Co-investigator: Keefe Ip, Email: keefe.ip@hdr.mq.edu.au