



# Participant Information Sheet

**PROJECT TITLE:** Longitudinal outcomes of neurological impairment; guidance and management following traumatic brain injury (LONG-TBI)

**HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER:** H-2023-105

**PRINCIPAL INVESTIGATOR:** A/Prof Lyndsey Collins-Praino

**STUDENT RESEARCHER:** Mr Benjamin Ellul

**STUDENT'S DEGREE:** PhD in Biomedicine

Dear Participant,

You are invited to participate in the research project described below.

## What is the project about?

This research project involves a short REDCap survey for neurologists, neurosurgeons, orthopaedic surgeons, rehabilitation clinicians, psychiatrists, psychologists, occupational therapists, physiotherapists, nurses, and other health professionals who are involved in acute and chronic care of traumatic brain injury patients. It aims to gather information on the current longitudinal management of neurological impairments in TBI patients, as well as to explore the awareness of risk of neurodegenerative disease development following TBI. Through this work, we hope to provide cross-country insights into clinical management, formulate guidelines that can be used by clinicians to provide more effective, long-term clinical management of TBI and raise awareness of the increased risk of neurodegenerative disease development following TBI.

## Who is undertaking the project?

This project is being conducted by A/Prof Lyndsey Collins-Praino, Dr Irina Baetu, Prof Mark Jenkinson, Dr Stephan Lau, Mr Benjamin Ellul (PhD Candidate) and Mr Angus McNamara (PhD Candidate) of the University of Adelaide in Adelaide, Australia.

## Why am I being invited to participate?

You are being invited to participate as we are seeking participants who:

- are board-certified neurologists and/or neuro/orthopaedic surgeons, rehabilitation clinicians, nurses, occupational therapists, physiotherapists, and other health professionals with expertise in the field of TBI management and care;
- have managed/treated TBI patients within the last 5 years;
- are fluent in English

We have obtained your contact details from publicly available email directories listed on hospital/university websites and have deemed your eligibility for our study.

## What am I being invited to do?

You are being invited to complete a one-time short survey online.

## How much time will my involvement in the project take?

The online survey in its entirety will require ~15 minutes to complete



### Are there any risks associated with participating in this project?

There are no anticipated risks in your participation in this project. If you feel the questions make you uncomfortable, you can stop whenever you wish. For any additional support, you can use any of the mental health helplines provided below.

<b>AUSTRALIA</b>	<b>NEW ZEALAND</b>
<ul style="list-style-type: none"> <li>• <b>Healthdirect</b> – 24-hour health advice: 1800 022 222</li> <li>• <b>Mind</b> – mental health support: 1300 286 463</li> <li>• <b>Lifeline Australia:</b> 13 11 14</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Healthline:</b> 0800 611 116</li> <li>• <b>Samaritans:</b> 0800 726 666</li> <li>• <b>Lifeline:</b> 0800 543 354</li> </ul>
<b>CANADA</b>	<b>UNITED STATES</b>
<ul style="list-style-type: none"> <li>• <b>Crisis Text Line</b> (text message service): Text HOME (English) or PARLER (French) to 686868</li> <li>• <b>Crisis Services Hotline:</b> 1 (888) 353 2273</li> <li>• <b>Better Help</b> (online access to professional counsellors): <a href="http://www.betterhelp.com">www.betterhelp.com</a></li> <li>• <b>The Lifeline App:</b> <a href="http://www.thelifelinecanada.ca">www.thelifelinecanada.ca</a></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Mental Health America Hotline:</b> Text MHA to 741741</li> <li>• <b>Crisis Support Services:</b> 1 800 273 8255</li> <li>• <b>National Mental Health Consumer's Self-Help Clearinghouse:</b> 1 800 553 4539</li> </ul>
<b>UNITED KINGDOM</b>	
<ul style="list-style-type: none"> <li>• <b>Mind Infoline:</b> 0300 123 3393</li> <li>• <b>SupportLine:</b> 01708 765200</li> <li>• <b>Samaritans:</b> 116 123</li> <li>• <b>Crisis text line:</b> Text SHOUT to 85258</li> </ul>	

### What are the potential benefits of the research project?

There are no direct personal benefits from participating in this survey. However, the research benefits include the potential development of management guidelines for the longitudinal outcomes of neurological impairment following TBI.

### Can I withdraw from the project?

Participation in this project is completely voluntary. However, since your provided responses to the survey questions will remain completely anonymous, if you complete and submit the survey, it will no longer be possible to withdraw from the research project.

### What will happen to my information?

**Confidentiality and privacy:** Your anonymous survey data will be stored on a password protected computer in the researcher's office. Electronically entered data will be secured and made accessible only to the research staff, according to the Standard Operating Procedures of the University of Adelaide.

**Storage:** Records and materials for the current study will be retained for at least 5 years after the completion of the study.



**Publishing:** Only summaries of findings from all participants will be reported in the future publications and presentations.

**Sharing:** Please note that publication and funding requirements may require submission of data or information to controlled access repositories that meet the international security and safety standards for sharing with researchers globally. Any data shared via such repositories will be non-identifiable.

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

### **Who do I contact if I have questions about the project?**

If you have questions associated with your participation in the project or wish to learn about its results, then you should consult the Principal Investigator:

*A/Prof Lyndsey Collins-Praino, Principal Investigator*

Email: [long\\_tbi@adelaide.edu.au](mailto:long_tbi@adelaide.edu.au)

### **What if I have a complaint or any concerns?**

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2023-105). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research 2007 (Updated 2018). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: [hrec@adelaide.edu.au](mailto:hrec@adelaide.edu.au)

Post: Level 3, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

### **If I want to participate, what do I do?**

If you are willing to participate in the research, please scan the QR code on this information sheet or click on the survey link provided in the email/newsletter and complete the survey. The submission of the survey will be considered as an indication that you understand the above information and consent to participate in the study.

Yours sincerely,

A/Prof Lyndsey Collins-Praino and Mr Benjamin Ellul