

Participant Information Sheet: Lived Experience Group

Research study: *Development of a core set of outcome measures for mobility in moderate to severe traumatic brain injury rehabilitation*

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Hello. Our names are:

- Leanne Hassett, Cathie Sherrington, Gavin Williams, Liam Johnson and Piri Prahatheesan

1. What is this research about?

We are doing research to find out the best ways to measure the way people move around after a traumatic brain injury.

We have asked you to be part of this research because you are a person who has had a traumatic brain injury and so have knowledge and experience that can help us work out which measurements are most important.

You can choose to take part, but you don't have to. This sheet will tell you more about what will happen so you can make up your mind.

If you have any questions, you can ask us or you can talk to someone else who you trust. If you want to you can call us on:

- **Phone (Leanne):** +61 2 9351 9549

2. What will happen if I say yes?

If you decide to take part in this study, this is what will happen:

Part 1: Interview

- Taking part involves answering some questions via video-conferencing. We will ask you to think back on your rehabilitation journey and think about what was measured or what you would have liked to have been measured about the

way you move. For example, walking, climbing stairs, standing up and running.

- This may take up to 30 to 45 minutes. You may also bring a support person with you to the interview if you wish.

Based on what you tell us in the interview, we will then survey health professionals, researchers and staff from rehabilitation funding bodies about the most important outcomes to measure in rehabilitation.

Part 2: Consensus Meeting

- You may also be invited to attend an online meeting with health professionals, researchers and staff who work for rehabilitation funding bodies. We will ask you questions about measures used to assess the way you move. You will then be asked to vote on each measurement tool discussed.
- You will be provided with information before the meeting to read in preparation for this meeting. You will also be able to speak with a member of the research team (Piri) about the process and the goals of the meeting.
- The meeting may take up to four hours with regular breaks, or split into two meetings over separate days. You may bring a support person with you to the meeting if you wish.

When we ask you questions, you can choose if you want to answer. If you don't want to talk about something, that's ok.

We would like to record what you say in the interview and consensus meeting with an audio recorder so we can accurately remember what was said during our discussion.

3. What are the good or bad things about the study?

The study will take up some of your time and you will receive a \$50 gift voucher for each hour of project work completed as a small token of our appreciation.

Your input in this study will help to improve how healthcare professionals measure the way people with a traumatic brain injury

move during rehabilitation and improve how research is conducted. Your participation will also help organisations that fund rehabilitation make informed choices on how funding is provided after a traumatic brain injury.

Once we have finished the study, we will let you know what we have found out.

We understand that some of the topics discussed in the interview might cause distress. If you become distressed during the interview, we will stop the interview immediately.

If you need further support, you can contact the following services:

- Lifeline Australia: 13 11 14 or text 0477 13 11 14
- Beyond Blue: 1300 22 4636 or www.beyondblue.org.au

4. What are my rights?

Anything you share with us is confidential. We will write about the things we learn from you, but we won't include your name or any personal information that could identify you.

If you decide you don't want to be part of the study anymore, that's ok, it won't affect your relationship with our team. If you would like to withdraw any information that you provide to us during the study, please let us know and this information will be removed.

If you have any questions about the study, you can talk to

- Leanne Hassett (email: leanne.hassett@sydney.edu.au) or
- Piri Prahatheesan (email: pirashikah.prahatheesan@sydney.edu.au)

5. What if I am not happy about the study?

If you are not happy with how we are doing the study and want to contact someone else, you can

- **Call** the University on +61 2 8627 8176
- **Email** the manager at human.ethics@sydney.edu.au

This sheet is for you to keep