

“Emotional Functioning after Acquired Brain Injury”

Participant Information

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Thank you for your interest in participating in the “Emotional Functioning after Acquired Brain Injury” study being conducted by researchers from the University of WA (UWA). This information sheet explains what will be involved should you decide to participate. Please read the information carefully before deciding whether to continue.

Why we are doing the study

The purpose of this study is to investigate how differences in a person’s emotional functioning after sustaining a brain injury affects their quality of life, relationships, everyday functioning at work and at home, and participation in the community. We hope this study will improve brain injury rehabilitation by offering strategies to help people with their emotional skills. This study is focused on adults and you must be over the age of 18 years to take part.

What participation in this study will involve

This study involves providing basic demographic information about yourself (i.e., age, gender, years of education) and your brain injury (i.e., when and how it occurred, the part of the head/brain involved), and completing some questionnaires about your emotional functioning, activities of daily living, psychological symptoms and quality of life. Participation in this study will take approximately 30-45 minutes to complete the whole survey.

Nomination of a study partner to complete questionnaires

We are interested in understanding the perspective of a close relative or friend with regards to your emotional functioning and recovery. At the end of the survey, you will be asked to nominate a study partner to complete questionnaires that ask about your recovery, emotional functioning and your ability to undertake activities of daily living such as managing tasks around the

home. This would take about 20 minutes of their time and you will not be able to see each other's responses. The nomination of a study partner is voluntary and is not required for you to participate in this study.

Possible risks and burdens

No significant risks are likely to arise from your involvement in this study. Some of the questionnaires have sensitive questions about your mood and symptoms of depression. A list of national support services will be displayed at the end of the survey, should you require assistance or support.

Possible benefits

We hope that this study will improve the care of future patients undergoing brain injury rehabilitation by offering strategies to help people improve their emotional functioning.

Costs and re-imburement

Participants in this study will have the option to enter a draw to win a \$100 visa debit card. To go into the draw you will be asked to enter your contact information. Your contact information will not be connected to your survey responses or any other study data.

How your privacy and confidentiality will be protected

All of the data collected as part of this study will be assigned a code number (e.g., 001) and will not be connected to any identifying information.* For this reason, once the survey responses have been submitted, we will be unable to remove individual study data from our system. Data collected in this research will be communicated to other researchers studying brain injuries, through published research articles and conference presentations. The data may also be used in research projects completed by students who are learning to do research in this area. Data that are presented will only include very basic information (e.g., age and gender) and no-one would be able to identify who you are from this information.

*If you choose to nominate a study partner (see above), your name and email address will be requested. This information will be temporarily connected to your questionnaire data to enable us to communicate with your nominated study partner. An email will then be generated and sent to your nominated study partner with a link to complete the study partner survey. All information will be kept securely, will only be accessible to a selected member of the research team, and will be deidentified within 14 days of the receipt of all study partner survey responses. Should the study partner not complete the survey, all identifying information will be removed from our systems at the conclusion of the study (approximately June 2023).

Voluntary participation and withdrawal

Participation in this study is completely voluntary. You do not have to participate and, if you decide to take part, are free to withdraw at any time. Data cannot be removed after completion of the survey as we will not be able to identify which responses belong to whom.

Contact for further information

If you have any questions about this study, please contact the UWA student researchers:

Natalie Pepping: natalie.pepping@research.uwa.edu.au

Emily Clements: emily.clements@research.uwa.edu.au

Chloe Stevens: chloe.stevens@research.uwa.edu.au

This project has been granted ethics approval by the University of Western Australia (UWA) Human Research Ethics Committee (HREC). If you have any complaint regarding the manner in which a research project is conducted, this *may be given to the Secretary, Human Research Ethics Committee, Registrar's Office, The University of Western Australia, 35 Stirling Highway, Crawley, WA 6009 (telephone 6488-3703).*