

# Research Project Information Sheet

## Technology Enabled Homes for People with Spinal Cord Injury or Traumatic Brain Injury

### Research Team Contact Details

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### Project Description

The purpose of this research project is to gain a deeper understanding of the electronic technologies that are used in the home by people with spinal cord injury (SCI) and traumatic brain injury (TBI). This will include gathering examples of electronic technology use, as well as understanding barriers, meaning and value of electronic technology in your home. This project has been approved by the UniSC Human Research Ethics Committee, project number A242174.

You are invited to participate in this research project if you are:

- Aged 18 years or older living in Australia
- Have a SCI and/or TBI and have experience using electronic technology around the home to support activities of daily living.
- Or you are the guardian or person authorised by law responding on behalf of a person with SCI and/or TBI who has experience of using technologies in the home to support activities of daily living

There are **two parts** to our study: Part A is an online survey and interview followed by Part B a round table discussion workshop called a World Cafe. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following research participant information carefully. Please contact us if anything is unclear or you need more information.

### Funding

The National Injury Insurance Scheme QLD (NIISQ) Agency provided funding to the University of the Sunshine Coast to conduct research that aims to improve the health and quality of life outcomes for NIISQ participants. NIISQ will not have access to any of your individual data and participating will not impact any services or funding that you may receive from NIISQ or any other funding body.

## Advisory Panel

For this project we have formed an advisory panel of individuals to provide insight and guidance. Members of the advisory panel have expertise and experience with assistive and mainstream technology and the associated supports required. The panel is voluntary and act under a Terms of Reference. Three members of the research team are on the panel (Dr Verdonck, Ms Fowler and Dr Craven), additional members of the panel are:

Renee Hebson (NIISQ representative), Carmel Larkin (lived experience TBI), Alison Barber (lived experience SCI, parent of a person with a TBI, and Queensland Disability Network QDN), JJ Hitchens (lived experience SCI, NIISQ participant), Stephen Martin (NIISQ smart tech provider), David Harraway (occupational therapist, assistive tech consultant, online communities champion).

## Participation

If you agree to participate in this research project, you will be asked to participate in two parts. Part A includes a brief survey followed by an interview. Part B is participation at a World Café session.

Part A will require you to complete a brief online questionnaire followed by an interview with a member of the research team. The interview may be done in-person or online at a mutually convenient time, and, with your permission, the interview will be audio-recorded. The online questions will take approximately 15 minutes, and the interview will take approximately 1.5 hours. You can either meet with the researcher one time or choose to complete the interview at intervals that suit you. You will be asked questions about the nature of your disability and the types of electronic technology you use in the home. During the interview you will further describe the technology you use in your own home. Interviews will be digitally audio-recorded and transcribed (typed out).

Part B will require you to attend a roundtable discussion called a World Café with approximately 25 other attendees, who will be divided into smaller groups of 5-6 per group. They will all be people with SCI and/or TBI who have experience using electronic technologies in their own homes. Some participants may have a guardian attending with them. All participants, including guardians, will be asked to keep Round Table discussion confidential. The Round Table discussion will be facilitated by the Chief Investigator, Dr Michele Verdonck, and supported by the other members of the research team (listed above).

The Round Table discussion will take place in 2025 after we have analysed the interviews. This will be hosted in person at the University of the Sunshine Coast (UniSC) as well as online via zoom.

Topics to be discussed include:

- What are the key principles for successful electronic technology use for people with SCI and TBI?
- What do funders need to know about using electronic technologies?
- How can different types of electronic technology support people with SCI and TBI in their homes?
- What are the best enablers for best use of electric technologies?
- What can be done better to support the maximising of technology use in the home for people with SCI and TBI?

Discussions will be digitally audio-recorded and transcribed (typed out). Data will also be collected by research team members taking of notes during the roundtable, participants can write or doodle their thoughts on butcher's paper, and an online Padlet (private digital discussion board) will be optional for participants to use.

Your participation is voluntary. Your participation, or not, will not affect your relationship with UniSC or NIISQ. If you decide to take part and later change your mind, you are free to withdraw at any time/up to the point at which data is aggregated and analysed as appropriate to the project. Data collected online cannot be deleted once it has been de-identified. All other data can be deleted by chief investigator prior to de-identification. Please contact the Chief Investigator Michele Verdonck (details listed above) to discuss withdrawal.

## Consent

You will be asked to provide written consent via an online survey question. Consent to participate will be confirmed before progressing to the survey. Consent is for your data and information to be collected, stored, and used in analysis and publications in a non-identifiable format. You will be asked to consent to the use of your data and information for this project and future related research. Individuals with TBI may have some level of cognitive impairment and may require a communication partner. In this case, consent will be sought from their guardian or person authorised by law. All communication partners/guardians in attendance at the World Café will be required to complete written consent forms to facilitate confidentiality for all participants.

You will be asked to choose a pseudonym (false name) for research purposes. This name will be used when referring to you in academic research papers sharing the findings of this project. This allows you to find your own information without identifying you to others.

## **Risks and Benefits**

There are minimal risks associated with your participation, which may include the risk of privacy breaches, and inconvenience and indirect costs of time and travel to attend. All data will be stored on a firewall-protected university database, and your personal information is treated confidentially. Due to the nature of the project/the industry/the case study, it may be possible for your identity to be inferred. Where this may be possible, please let the research team know if you wish to review transcripts/direct quotes/publications etc.

Sometimes thinking about the questions discussed during the interview might create uncomfortable or distressing feelings. You are not required to answer any questions you don't want to, and you may discontinue or pause your participation at any time, if required. If you need to talk to someone you may wish to contact family or friends/your General Practitioner/Lifeline (131114)/Beyond Blue (1300 224 636).

The benefits of participating in this research include informing the future use of technologies in the home for persons with SCI and TBI and will include learning from others as well as sharing your own experience to assist others. This research will help us compile principles which lead to successful electronic home technology use for people with SCI and TBI. You will be invited to contribute to the development of these principles as part of the project at a later stage. Due to the potential inconvenience and indirect costs of time to participate in the questionnaire and interview, you will be offered a small honorarium of \$75 for time.

Due to the potential inconvenience and indirect costs of time and travel to attend the World Café, you will be offered a small honorarium of \$75 for attending the World Café discussion. This is to compensate you for your time to mitigate some of these personal costs. You will also receive light refreshments if you attend the round table discussion event on campus. Please let the chief investigator (listed above), know if you would not like to receive the honorarium.

## **Privacy, Confidentiality and Results**

Any data collected as a part of this research project will be stored securely as per UniSC's Research Data Management Procedures. All comments and responses will be treated confidentially unless required by law.

The research team will be able to identify if you choose to participate. Members of the advisory panel who are not researchers listed above will not have access to any of your data or personal information. They will only have access to our findings. The results of this research project may be presented at external or internal conferences or meetings, or by publication. If you would like a summary of findings of this research project, please contact the Chief Investigator (listed above).

## **Concerns or Complaints**

If you have any concerns or complaints about the way this research project is being conducted, you can raise them with the Chief Investigator (listed above). If you prefer an independent person, you may contact the Chair of the UniSC Human Research Ethics Committee: (c/- Office of Research, University of the Sunshine Coast, Maroochydore DC 4558; telephone (07) 5430 2823; email [humanethics@usc.edu.au](mailto:humanethics@usc.edu.au)).

**Please save the information above if you choose to participate.**