Participant Information Sheet

PROJECT TITLE: Getting used to wheelchairs as an adult: what helps?

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2023-290

PRINCIPAL INVESTIGATOR: Associate Professor Stacie Attrill

STUDENT RESEARCHER: Kimberly Charlton

STUDENT’S DEGREE: Doctor of Philosophy (PhD)

Dear Participant,

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

What is the project about?

Manual wheelchair training is important for the safety, independence and community participation of manual wheelchair users. Having good training can reduce health service use and reduce reliance on carer partners. However, many wheelchair users receive insufficient training or training that is not appropriate to their needs. This research project seeks to understand the experiences and perceptions of people introduced to wheelchair use as an adult or older adult due to chronic or progressive conditions.

The research also explores healthcare professionals’ experiences and perceptions of wheelchair training for adults/older adults with chronic and progressive conditions.

This knowledge will help enhance understanding of what training approaches exist, who they work for and why so that recommendations and guidelines can be developed for people providing wheelchair training to ensure wheelchair training is delivered and centred around users’ needs.

Who is undertaking the project?

This project is being conducted by Kimberly Charlton. This research will form the basis for the degree of Doctor of Philosophy at the University of Adelaide under the supervision of Associate Professor Stacie Attrill, Dr Carolyn Murray and Dr Natasha Layton

Why am I being invited to participate?

You are being invited because you can provide perspectives on manual wheelchair training. The project specifically aims to recruit participants who are any of the following:

* A manual wheelchair user who commenced wheelchair use as an adult or older adult. Wheelchair users with a spinal cord injury who do not have any other underlying conditions/ whose primary disability is a spinal cord injury are not included in this research.
* A caregiver or care partner of a manual wheelchair user who commenced wheelchair use as an adult or older adult
* Working with, or have been involved with providing manual wheelchair training to adults or older adults living with progressive or chronic conditions

What am I being invited to do?

Take part in an interview with our researcher. The interview will ask about your experiences and perceptions of wheelchair training, including how you received or delivered wheelchair training/how wheelchair training was provided, what it included, your perspectives of barriers and enablers of wheelchair training. If you are a wheelchair users or carer of a wheelchair user, you will also be asked to inform us of the reason for wheelchair use, age, gender, frequency of wheelchair use and duration of wheelchair use. If you are a wheelchair trainer you will be asked to inform us of your professional background and training, years of experience with wheelchair training, the setting training has been delivered and the user group that you have worked with.

The interview can be online (via Zoom or Microsoft Teams), in person or via the telephone. Interviews will take 30-60 minutes and will be video recorded and transcribed (if interviews are online) or voice recorded (if interviews are in person or via telephone).

How much time will my involvement in the project take?

Your involvement in this project will include one 30-60 minute interview.

Are there any risks associated with participating in this project?

There is no foreseeable risk that is anticipated from participation in this research, however some participants may have an emotional response to questions posed and it will require 30- 60 minutes of their time. If participants to become distressed or overwhelmed during the interview they will be referred to Lifeline for support.

What are the potential benefits of the research project?

The research may support increased understanding of what wheelchair training works best. This knowledge will inform service providers and health professionals. The research will improve evidence about wheelchair training provision. As a gesture of appreciation and reimbursement for inconvenience and expenses a $30 voucher is available for participating in this research

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at anytime before or during the interview or immediately post interview. There will be no adverse effects if you do not participate in the project.

**What will happen to my information?**

*Confidentiality and privacy:* Your personal information and responses to the interview questions will be de-identified. However, while all efforts will be made to remove any information that might identify you, as the sample size is small, complete anonymity cannot be guaranteed. However, the utmost care will be taken to ensure that no personally identifying details are revealed.

*Storage:* Your interview response and personal details will be stored on a secure server space approved by the University of Adelaide’s IT Department. This information will be kept for a minimum of 5 years post publication and will be accessible to members of the project team only.

*Publishing:* The information that you provide may be reported on and publicised in journal publications, thesis report and conference presentations. All information will be de identified.

*Sharing:* Participants can access to ongoing publications, which can be found in relevant journals

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 any questions about this project please contact a member of the research team.

Primary Contact: Kimberly Charlton: 8313 3660 / Kimberly.charlton@adelaide.edu.au

Secondary contacts: Associate Professor Stacie Attrill: 8313 3518/ Stacie.attrill@adelaide.edu.au

Dr Carolyn Murray: 8302 2485/ Carolyn.murray@unisa.edu.au

Dr Natasha Layton: natasha.layton@monash.edu

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-2023-290). 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

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 wanting to participate in this research, you have the following options:

1. Complete the consent form below. If you are a suitable applicant, you will be asked to provide some details about yourself and then a member of our research team will be in contact with you to book in a time for an interview.
2. Contact the research team via email/phone to express your interest and a member of the research team can get your verbal consent to participate and will then book in a time for an interview.

Please do not hesitate to reach out if you have any questions.

Yours sincerely,

Ms Kimberly Charlton

Associate Professor Stacie Attrill

Dr Carolyn Murray

Dr Natasha Layton

**Human Research Ethics Committee (HREC) – Consent Form**

1. I have read the attached Information Sheet and agree to take part in the following research project:

|  |  |
| --- | --- |
| **Title:** | Getting used to wheelchairs as an adult: what helps? |
| **Ethics Approval Number:** | H-2023-290 |

1. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.
2. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
3. Although I understand the purpose of the research project is to improve the quality of health/medical care, it has also been explained that my involvement may not be of any benefit to me
4. I agree to participate in the activities outlined in the participant information sheet.

1. I agree to be:

Audio recorded ☐ Yes ☐ No

Video recorded ☐ Yes ☐ No

1. I understand my participation is voluntary and that I am free to withdraw my information from the project before, during or immediately after the interview.
2. I understand that if I decide not to take part or withdraws from the project, that this will not affect medical advice in the management of my health, now or in the future.
3. I have been informed that the information gained in the project may be published in a journal article, thesis, conference presentation.
4. I have been informed that while I will not be named in the published materials, it may not be possible to guarantee my anonymity given the nature of the study and/or small number of participants involved.
5. I consent for the use of my data by the same or other researchers for any future research purposes. I understand personal information that may identify me (e.g. name, address, date of birth) will be removed or changed before it is either shared with other researchers or made accessible on a public data repository: Yes [ ]  No [ ]
6. I understand my information will only be disclosed according to the consent provided, except where disclosure is required by law.
7. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: Signature: Date:

Researcher/Witness to complete:

I have described the nature of the research to

 *(print name of participant)*

and in my opinion she/he understood the explanation.

Signature: Position: