

Plain Language Statement

Medicine, Dentistry and Health Sciences
Department of Physiotherapy



Project: Designing a telehealth physical stroke rehabilitation program for people with moderate to severe stroke using an integrated knowledge translation approach

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Introduction

Thank you for your interest in this research project. The following pages will provide you with information about the project, so you can decide if you want to take part in this research.

Please take time to read this information carefully. Please ask **questions** about anything you don't understand or want to know more about.

Your participation is **voluntary**. If you don't want to take part, you don't have to. If you are participating, you can **withdraw** at any time.

What is this research about?

Telehealth is the delivery of healthcare through technology where clinicians and patients are located separately. It includes ordinary phone calls and video calls, where health professionals and patients can see and hear each other live. Telehealth is being used more in stroke rehabilitation. Traditional stroke rehabilitation for people who **require help from another person to attend to their daily needs (for example walking, toileting and dressing)** involves physical assistance from therapists and special equipment. The aim of this research is to design a package to support:

- Clinicians to provide stroke physical rehabilitation via telehealth,
- Stroke survivors and carers to participate in physical rehabilitation via telehealth.

We will use a **knowledge translation approach** to design this package. This approach brings together stroke survivors, carers, clinicians, researchers and others involved in stroke rehabilitation.

It is important this package:

- meets the needs of stroke survivors, carers and clinicians,
- can support people to participate in safe and effective rehabilitation,
- is something that people will actually use.

What will I be asked to do?

If you agree to participate in this study, you will be asked to sign the Participant Consent Form.

You will be asked to complete a brief questionnaire (either at the beginning of the workshop or before the workshop). The questionnaire will ask for information such as:

- age
- amount of time since your stroke
- current abilities
- occupation (if applicable)
- experience with telehealth
- confidence using the internet

The questionnaire will take less than 5 minutes to complete.

You will then be asked to join **1 or 2 workshops** that will run for no longer than **2 hours**. The workshop will involve:

- people who have had a stroke,
- carers,
- health professionals,
- researchers,
- other members of the community involved in stroke rehabilitation.

The group will be supported to discuss their **knowledge, opinions and experience** to create a package to guide telehealth stroke rehabilitation.

You can join the teleconference system for the workshop via an internet link or telephone call. There will be a chance to familiarise yourself with the teleconferencing system before the workshop. This is likely to take a maximum of 15 minutes and is optional.

Regular breaks will be provided during the workshop. The workshop will be audio video recorded so that the researchers can review the information discussed. The researchers will also take notes during the workshop.

You will be provided with a summary of the discussion after the workshop. You will have the opportunity to give the researchers feedback if you think something is not clear or was missed.

All notes, questionnaires and audio video recordings are confidential and will only be accessed by members of the research team.

What are the possible benefits?

This research is unlikely to be of direct benefit to you. We hope this research will help improve access to stroke rehabilitation when face to face care is difficult to provide.

This could be:

- due to being rural or remote from the health service,
- during times of physical distancing restrictions such as COVID-19,
- when traveling to the rehabilitation centre is difficult.

You will not be paid for your participation in this study.

What are the possible risks?

We understand when participating in this research there is a chance that you may become upset while remembering or talking about your experiences. Our experienced research team will provide you with support if this occurs. If you **do not want** to talk about a topic you do not have to. You can **leave the workshop immediately** if you wish.

If you feel distressed as a result of the study you will be encouraged to contact:

- the Principal Investigator,
- Your GP,
AND/OR
- Beyond Blue (available 24 hours a day) on 1300 224 636.

You can put your involvement **on hold**, or **withdraw** from the study at any point if you feel distressed.

You may experience fatigue from participating in the workshop. Please let our research team know if this is an issue for you. We will provide supports to assist you manage fatigue.

Do I have to take part?

No. Participation is completely voluntary. You are able to withdraw at any time. If you choose to withdraw, any information you have previously shared will **be included** in the results as we cannot separate it from other participants' discussions in the workshop. If you withdraw we will not ask you for any follow-up data. Your decision to participate will not impact on your care in any way.

Will I hear about the results of this project?

All participants will be provided with a summary of the project. You can also have a copy of the resources developed.

The study results may be presented at conferences or in a scientific publication. In any publication or presentation information will be presented so that **you cannot be identified**, unless you have given the researchers written consent to be identified.

What will happen to information about me?

All the information collected from you for the study will be treated confidentially. Only the researchers named above will have access to it

Your personal information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. All data including questionnaires, audio video recordings and the notes from the workshops will be kept by the University of Melbourne. Data will be stored on a password-protected file or in a secure filing cabinet. It will only be accessed by the researchers named on this document.

All data will be held for 5 years after the last report is published. After this time, the data will be destroyed to ensure confidentiality is maintained. You have the right to access information about you collected and stored by the researchers. Please contact one of the researchers named below if you would like to access your information.

Who is funding this project?

This project has been funded by the Melbourne Disability Institute (\$19,308).

Where can I get further information?

If you would like more information about the project, please contact the research contact person Ms Cassie McDonald.

Tel: 0460 004 629 or Email: cassie.mcdonald@unimelb.edu.au

Who can I contact if I have any concerns about the project?

If you have any concerns about the project you can contact the responsible researcher Associate Professor Cathy Said.

Tel: 0423170253 or Email: csaid@unimelb.edu.au

Alternatively, this research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Research Ethics and Integrity, University of Melbourne, VIC 3010.

Tel: +61 3 8344 2073 or Email: HumanEthics-complaints@unimelb.edu.au.

All complaints will be treated confidentially. In any correspondence please provide the:

- name of the research team,
OR
- the name of the research project,
OR
- the ethics ID number of the research project: 2057050.1.