

PARTICIPANT INFORMATION SHEET FOR CLINIC MANAGERS
Exploring how clinicians delivering community-based rehabilitation exercise programs
assess individuals with neurological conditions.
UTS HREC APPROVAL NUMBER: ETH23-8554

WHO IS DOING THE RESEARCH?

My name is *Dr Camila Quel De Oliveira*, and I am an academic in the Discipline of Physiotherapy at the University of Technology Sydney (UTS). I will be conducting this research with my colleagues in the Graduate School of Health at UTS (*Laura Stendell, Dr Peter Stubbs, Dr Erin Turbitt and Prof Arianne Verhagen*) and The University of Sydney (*Dr Mohit Arora*). We also have a person with lived experience in spinal cord injury (*Ms Rachael Presdee*) who attends community-based rehabilitation exercise programs, informing the design and conduct of the study.

WHAT IS THIS RESEARCH ABOUT?

Continuous rehabilitation and access to exercise programs after discharge from acute or subacute hospital rehabilitation is crucial for prolonged function and health after a neurological condition. However, many people are ineligible for further rehabilitation or are discharged to outpatient rehabilitation with few options. Community-based therapy programs allow patients to continue to achieve functional and health benefits from exercise and are easier to access than some outpatient programs. As patients quickly lose therapeutic support, this is a potential avenue to continue to work towards achieving their goals.

However, there seems to be a lack of understanding by government-led funding organisations on the requirement of exercise and therapy following a neurological condition, resulting in reduced resources being allocated to patients after discharge from rehabilitation hospitals. This could be related to the limited evidence exploring the patient engaging in community-based programs. To appropriately assess the impact of community services, an evidence-based approach is required. For that, data is required on patient outcomes during these programs.

Hence, this study aims to identify how clinicians who deliver community-based rehabilitation exercise programs assess people with neurological conditions from the clinicians' perspectives. As a first step to increase the reach of these programs and to allow participants access to funding, we need to ensure that data are consistently collected to facilitate accurate clinical reporting. This aim will support the development of a 1) core set of outcome measures for community-based clinicians; and 2) a registry of client data to inform the effects of community rehabilitation.

FUNDING

Funding for this project has been received from the University of Technology Sydney, Graduate School of Health Seed Grant.

WHY HAVE I BEEN ASKED?

You have been invited to participate in this study because you are a clinic manager or leader working with people with neurological conditions at a community-based rehabilitation or exercise centre. Your service has been identified on the NDIS registry or via Google search, and your contact details were obtained from the website/social media of your service.

IF I SAY YES, WHAT WILL IT INVOLVE?

If you decide to participate, you will be asked to:

Answer an online survey via REDCap

A link will be provided to complete an online survey that will take approximately 25 minutes. In this anonymous survey, you will be asked to provide a few details about the service you are working at (e.g., location, services provided, number of clinicians and their level of experience) and how assessments are being implemented at your clinic (e.g., list of assessments used, how assessment procedures are standardised across clinicians and the frequency of assessments).

AND/ OR

Join a Focus Group Discussion

You will be asked to join a group discussion with other 5 to 8 clinic managers or leaders with **Camila** (moderator) and **Esminio** (assistant moderator). You will be asked to provide:

- Your perspectives on performing an assessment of people with neurological conditions.
- Type of assessments you usually perform.
- Preferences when performing assessment.
- Your decision-making process in choosing the outcome and tools to measure client outcomes.
- Any barriers when assessing clients with neurological conditions.

The focus group discussion will be held via Zoom and video recorded. You will need to have access to the internet to join using mobile devices, computers or tablets.

To help us with scheduling, you will be asked to provide your availability via an online calendar tool (Doodle). Once there is a consensus on a date/time, and enough participants in a group has achieved, we will advise you about the date, time and the Zoom link.

The duration per focus group discussion depends on the depth and complexity of the answers. The focus group discussion may take up to 1.5 hours. Breaks will be provided if the moderator thinks the group discussion will take more than an hour.

If you accept to participate in the study, you can decide if you will join the survey and the focus group or just one of them.

ARE THERE ANY RISKS/INCONVENIENCE?

We are not expecting any serious risks in joining the study and hope your participation will be a positive experience. But we acknowledge that sharing opinions and ideas may be uncomfortable, embarrassing and mentally and emotionally tiring. If this occurs, you may take a break by clicking the “Save and Continue later” button when answering the online survey or leave the focus group discussion anytime. Don't feel obligated to finish answering the survey or the discussion. Our team can offer support and refer you to a counselling service if needed. You may also consider contacting the following services if you feel distressed:

- UTS Counselling service: +6129514 1177
- Mental health support (Department of Health) phone: 1800 595 212
- Lifeline: 13 11 14
- Beyond Blue: 1399 22 46 36
- Local GPs and other health professionals or counsellors

When completing the online survey and/or providing your perspectives during the focus group discussion, **REMEMBER THAT THERE IS NO CORRECT OR WRONG ANSWER!** Positive and negative responses are welcome as this will help us understand gaps in care for people with neurological conditions. For the group discussion, as this will be video recorded, you can turn off your camera throughout the session. You can also change your displayed name on Zoom. For the online survey, if you decide to take a break, you may do so by clicking “Save and Return Later”. But please remember to copy/write down the **RETURN CODE** displayed after clicking “Save and Return Later”. You will need this code to return and resume answering the online survey.

We understand that we will take some of your time in joining this study. We, the researchers, would want to let you know that we appreciate your time and effort. If there is anything that we can do for your convenience, please let us know.

DO I GET PAID FOR PARTICIPATION?

No. There will be no monetary compensation for joining the study.

DO I HAVE TO SAY YES?

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part.

WHAT WILL HAPPEN IF I SAY NO?

If you decide not to participate, it will not affect your relationship with the researchers or the University of Technology Sydney. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Dr Camila Quel De Oliveira, the lead researcher, at Camila.QuelDeOliveira@uts.edu.au or Mr Esminio Rivera at 0407584635 or Esminioii.Rivera@uts.edu.au.

If you withdraw from the study, all the information you provided us will be erased/destroyed. However, it may not be possible to withdraw your data from the study results if we already had your identifying details removed.

If you decide to leave the research project, we will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results.

CONFIDENTIALITY

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. Only the research team will have access to your data, which will be stored in a secured location. We may need to send your recordings to an external transcription service provider to have the focus group discussion transcribed. If this has to occur, all personal identifying information will be removed and the video recordings will be converted to audio recordings.

The information we collected from you will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

We would like to store your information for future use in research projects that are an extension of this research project. In all instances, your information will be treated confidentially.

We plan to *publish* the results in a journal article and conference presentation. In any publication or presentation, information will be provided in such a way that you cannot be identified.

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research that you think we can help you with, please feel free to contact Dr Camila Quel De Oliveira, the lead researcher, at Camila.queldeoliveira@uts.edu.au or Mr Esminio Rivera, Research Assistant, at 0407584635 or Esminioii.Rivera@alumni.uts.edu.au

You will be given a copy of this form to keep.

NOTE:

This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC]. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au, and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.