

Rehab Choices

INFORMATION FOR PARTICIPANTS

You are invited to take part in a research study that seeks to understand what factors affect decisions to take part in different rehabilitation programs. You are being sent this document, as you requested to receive more information about this study.

What is the research about?

The overarching goal of this research is to ensure people have access to the most appropriate rehabilitation for their needs. To do this, we need to with the factors that support access to different rehabilitation programs and make sure any barriers can be overcome. Hearing your thoughts and experiences will help make this happen.

Currently, very little is known about the factors considered when choosing to get rehab in hospital, in the home or in a community-based program. Some evidence suggests that multiple people can affect these decisions, including doctors, surgeons, family and friends. We would like to know how much these groups influence choices, and what other factors are taken into account. We also want to understand how much awareness there is of other available options.

As part of this research, we will also be talking to health care professionals to understand why and when they refer patients to different forms of rehabilitation. By talking to both patients and health professional, we can work with both groups to ensure appropriate information is provided, and that all rehab programs are accessible for when people need it most.

Information gained in the study will help to identify gaps in knowledge that can be targeted by developing improved communication materials. If there is a need, this may also lead to the development of referral guidelines for patients to support their rehab decisions.

Where is the research being done?

The study is being conducted by the Centre for Rehab Innovations (CRI), University of Newcastle.

Who is funding the study?

The study is financially supported by a research grant from Medibank Health Research Funding and The University of Newcastle, Priority Research Centre for Stroke and Brain Injury. These funding bodies have no role in research design, data analysis or reporting.

Who can participate in the research?

We are inviting anyone 18 years or older who is currently or has previously taken part in a rehabilitation program to be involved in this research. We are seeking 50 people to join in a group discussion (around 6 people per group) over Zoom (a shared audio-video platform), led by members of the research team. To take part, you will need to have access to a computer, tablet or other mobile device that connects to the internet. These sessions will be held in English.

What would you be asked to do if you agree to participate?

If you agree to take part in a group session, we ask you to read and sign the consent form and return to us by email or SMS. We will then ask for some general details about yourself and the condition for which you had or are having rehab before the session starts. We will then send you details and an invitation to join one of the Zoom sessions.

Before the session, we will send you a *Chat-in-a-Box*. This is a package with some treats to enjoy during the session, as well as some resources to be used during the session. This includes some pages with the discussion topics. We ask that you please take some time before the session starts (about 30 minutes) to look through the materials and jot down some of your experiences to share during the discussion.

During the group session, a research team member will guide the discussion. They will first invite the group to share their experiences of what type of rehabilitation they are taking part in (e.g. in-patient, out-patient, at home or community-based rehab). The group will then be asked to think about how they found out about the rehab program, what other options (if any) they looked into, who (if anyone) they talked to about this decision, and any other factors that helped determine which rehabilitation program to join.

While these discussions will be kept confidential, the video sessions will be audio recorded and transcribed by Zoom ([privacy policy](#)). This is so we can collate each group's responses and analyse the scripts. We will email you a copy of the transcript to review. If you would like any of your comments removed before analysis, please let us know within two (2) weeks of the email being sent. This script will then be de-identified for analysis, which means no names or identifying information will be included.

What options do you have?

Participation in this study is entirely voluntary. You do not have to take part. If you choose to be involved, you can still withdraw at any time without having to give a reason – simply leave the Zoom call whenever you like. We will still send you the transcript up to that point for review of your comments. Please let us know if you would not like these included in the analysis. Whatever your decision, please be assured that it will not affect your treatment or relationship with the staff who are caring for you.

What are the risks and benefits of participating?

Risks - There are minimal risks associated with participation in this study. However, for some people, recalling memories involving a serious health issue can cause distress. The focus group will be run by experienced facilitators, who will explain the scope of the focus group to you and the entire group before starting. You do not need to take part in any part of the discussion which makes you feel uncomfortable. You can also choose to leave the discussion group at any time without consequence. We will include all your responses up to that point in the analysis unless you instruct us otherwise.

Taking steps to cope with stressful situations is important. If you are experiencing high levels of stress, talk to your GP or a Counsellor. You can also get support by calling Lifeline on 13 11 14 (free call) or chat to a professional online at <https://online.beyondblue.org.au/#/chat/start>.

Benefits - Your involvement in this study will help us improve access to rehabilitation services in the future. The outcomes may not have any immediate direct benefits to you.

Will the study cost you anything?

Your participation will not cost you anything except your time. Unfortunately, we are unable to pay you for your involvement.

Study Results

If you choose, we can send you a copy of the study report at the completion of the study.

How will your privacy be protected?

All the information collected from you for the study will be treated confidentially. Access to any identifiable data will be restricted to members of the research team, named below, unless you have consented otherwise; or disclosure is required by law in order for us to comply with our regulatory obligations.

For the focus groups discussions, all participants will be asked to maintain confidentiality of the group discussion, and not divulge specific content to outside parties.

The overall results of this study may be presented at a conference or in a scientific publication, but individual participants will not be individually named or identifiable. Research data and transcripts will be stored confidentially on password protected university computers for a minimum period of 5 years from completion of research and managed/stored in accordance with the University's Research Data and Materials Management Guideline (<https://policies.newcastle.edu.au/document/view-current.php?id=72>) or any successor Guideline, and applicable University of Newcastle policy provisions (as amended from time to time).

Further Information

When you have read this information, a member of the research team will discuss it with you further and answer any questions you may have. If you would like to take part, please sign the consent form and return to us by email or SMS. We will then arrange a group session time with you. If you would like to know more at any stage, please feel free to contact Nicki Hodyl or Gill Mason using the details below.

Thank you for considering this invitation to participate in the research study. This information statement is for you to keep.



A/Professor Nicki Hodyl

Research team and contact details

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Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2020-0324. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research & Innovation Services, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au.