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Participant Information Sheet

Title TeleWheelchair and Seating Assessment Stakeholder

Consultation: A survey and interview Study

Principal Investigator

Dr. Fiona Graham

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You are invited to take part in a study, exploring your views on the value of a tele-health complex-wheelchair assessment service. Your views will help researchers decide if a tele-health wheelchair assessment could work in NZ.

Your participation is this study is voluntary (your choice). If you do not wish to participate, you don't have to. You don't have to provide any reason for your decision. If you do want to take part now, but change your mind later, you can withdraw from the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to indicate your consent.

Matching the right wheelchair for the wheelchair user requires an assessment by specialised assessors. These assessments can require considerable travel-either by the wheelchair user or assessor. Travel and delay in specialist assessment services can cause fatigue and stress on support people. Tele-wheelchair assessment (via video conference) is currently used sometimes in NZ to improve access to specialist assessment. However, we do not really know the best way to design these services or if they would work nation –wide.

Who are we asking to participate?

We are inviting wheelchair users aged >18 years with neuro-muscular conditions, their family, paid carers who have been involved in a wheelchair assessment in the last 24 months. We are also seeking participation by wheelchair assessors and technicians, and wheelchair service mangers, and funders, IT and legal specialist.

What will my participation in the study involve?

If you agree to participate, in phase one of study, you will be asked to complete survey. You may complete the survey electronically, on paper or over phone. It will take around one hour to complete this survey. Participants will be offered to participate in interview or focus group discussion with other participants by phone or video conference. The group interviews will run for an hour and will be recorded for data collection by research team.

What information will be collected and how will it be used?

The survey will explore a range of things that are relevant to the use of a telehealth service for wheelchair assessment. The interviews and focus group will help us get better understanding of factors that influence participant's views. The information gathered as part of this study will be completely confidential. It will be available only to the study members of the research team. Study findings will be presented to consumer and professional groups in written and oral formats. No identifying information will be shard.

What are the possible benefits and risks of this study?

The benefit of this study is to understand if a telehealth service for wheelchair assessment could work in NZ. And, if it could work, what is required for it to work well. We do not expect any harm to you by participating in this study

Who pays for the study?

This project has been supported by a grant from the Neuromuscular Research Fund. There will be no additional costs to participants. The Wheelchair users who complete survey will go in the draw for one of five \$200 grocery vouchers. All wheelchair users who complete interviews will be provided a \$50 grocery voucher as well.

What are my rights?

Participation in this study is voluntary. You may decline to take or you may withdraw from the study at any time without any disadvantage.

You may have a copy of any information collected about you during this study.

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Who do I contact for more information or if I have concerns?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Dr. Fiona Graham

Lead Investigator

Email: Fi.graham@otago.ac.nz

Jasjot Maggo

Research Assistant

Phone: 0221856729

Email: Jasjot.maggo@otago.ac.nz

For Maori health support please contact:

Bernadette Jones (RGON)

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This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

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