

## STUDY PROTOCOL

# Title: Tele-Wheelchair and Seating Assessment Stakeholder Consultation: A Mixed Methods Study

**Short Title: Tele-wheelchair assessment**

**Principal Investigator: Dr Fiona Graham**

**Investigation Site: University of Otago Christchurch**

**Version 27/03/2019**

## The Protocol

### *Project Overview*

#### **Rationale**

Well-designed and carefully fitted wheelchairs are often an essential first step towards inclusion and participation in society for people with disabilities. Complex wheelchair assessment requires the skills of highly specialised assessors. Access to these specialists can be delayed and require considerable travel—either by the wheelchair user or assessor. Even for urban living wheelchair users, travel to specialist assessment services can negatively impact on health, cause fatigue and impose considerable stress on support systems. Tele-wheelchair assessment (via video conference) is currently in ad hoc use in NZ to improve access to specialist assessment. However, there is currently no policy or infrastructure to support wider use of telehealth wheelchair assessment and no existing information on which to robustly plan for such a service.

#### **Objectives**

1. What are the socio-technical design requirements of a tele-wheelchair assessment service in NZ from the perspectives of wheelchair users with NMC, their family and carer, specialist and non-specialist assessors, managers, funders and policy developers?
2. What are the culturally specific perspectives and needs of Māori wheelchair users with NMC, of a tele-wheelchair assessment service?

#### **Methods**

The proposed study is an explanatory (two phase) mixed methods consultation with key stakeholders exploring their perspectives on the value of a tele-health complex-wheelchair assessment service. A two-phase mixed methods study design is proposed involving electronic survey (Phase One) and video-conference interview/focus group (Phase Two) data collection with all stakeholder groups.

#### **Population**

Stakeholders are wheelchair users with neuro-muscular conditions, their carers and significant others, wheelchair assessors and technicians, and wheelchair service managers, and funders.

#### **Timeframe**

Data collection (phase one survey) is anticipated to commence in April/May 2019 (subsequent to ethical approval). Interviews and focus groups are intended to commence August 2019. Publications and reports are anticipated to be completed by Dec 2019.

#### **Expected Outcomes**

Findings will inform a subsequent co-design of a tele-health wheelchair assessment service for those with complex wheelchair needs in a subsequent study and inform policy

development of such a service with particular attention to the needs of Māori. Three publications and two conference presentations are anticipated from this study.

### *Background / justification for project*

Wheelchairs are one of the most commonly used and highly valued assistive devices for people who require them for personal mobility [1]. Well-designed and carefully fitted wheelchairs are often an essential first step towards inclusion and participation in society for people with disabilities [2]. Wheelchairs can rapidly enable a person to achieve their mobility goals, maintain employment [3], alleviate pain [4], and avoid other secondary health consequences (e.g., pressure areas) of ill-fitting wheelchairs. For people with neuro-muscular health conditions (NMC), which are often progressive and affect multiple body functions, wheelchair assessment is often complex, requiring the skills of highly specialised wheelchair assessors. Access to these specialists can be delayed and require considerable travel - either by the wheelchair user or assessor especially for wheelchair users living outside of large metropolitan areas.

The proposed study is a mixed methods consultation with key stakeholders exploring their perspectives on the value of a tele-health complex-wheelchair assessment service. Stakeholders are wheelchair users with NMC, their carers and significant others, wheelchair assessors and technicians, and wheelchair service managers, and funders. Findings will inform a subsequent co-design of a tele-health wheelchair assessment service for those with complex wheelchair needs in a subsequent study. Assessment of wheelchair need is broadly defined as ‘complex’ when multiple, tailored wheelchair components are required. Complex wheelchair assessments are almost exclusively undertaken for people with NMC (excluding accident related injury; Sally Wallace, specialist assessor, Enable New Zealand [NZ], personal communication, 02 August, 2018).

Complex wheelchair assessment are undertaken by occupational- or physio-therapists, with advanced clinical training. Assessments involve interviewing wheelchair users about their goals and needs, accurate measurement of their body position, evaluation of the home environment and use of product knowledge to optimise seating and wheelchair configurations [5-7]. Equipment costs range from \$15,000 to \$65,000 per wheelchair/seating system, at a cost of \$20 million annually (personal communication, Madeleine Sands, Contract Relationship Manger, Equipment Modifications Services, Ministry of Health, 10 May 2017). Typically, specialist assessors travel to the wheelchair user’s home with a technician and local therapist or the wheelchair users travels to a specialist clinic. Given the progressive nature of many NMCs, assessment in the home environment, in the presence of significant others is preferred, but can result in delayed assessment. Travel to specialist clinics is prohibitive for many people with NMC given the associated fatigue, volume of health appointments often required and expense of travel. A tele-health wheelchair assessment may provide a more timely service, particularly for follow-up or monitoring. For these reasons, strong support for this project has been indicated by Enable NZ and Seating to Go (who almost exclusively provide the complex wheelchair assessment to the NMC community) and from the Burwood Academy of Independent Living Consumer Advisory Group (see supporting documents).

Tele-health wheelchair assessment involves the use of technology (e.g., video-conferencing) to connect a wheelchair-user (and local support person or non-specialist therapist) with a specialist assessor based at a different geographic location. Bespoke and software-as-service systems have been proposed in the literature [8]. Existing technology relevant to wheelchair assessment varies considerably in cost, functionality, bandwidth and device requirements, data privacy and security functions. In NZ, ad hoc use of technologies have been used with success including the use of

personal Smartphones, Dropbox and Skype when a tele-health assessment has been negotiated between wheelchair users, and specialist and non-specialist assessors (Sally Wallace, specialist assessor, Enable NZ, personal communication, 02/08/18). However, there is currently no policy or infrastructure to support wider use of telehealth wheelchair assessment and no existing information on which to robustly plan for such a service.

Our recent scoping review on the perceptions and use of tele-health wheelchair assessment, and evidence of its effectiveness identified limited, low quality studies to date [8]. Findings from non-randomised case-controlled studies indicate that tele-health assessment of wheelchairs can be cost-effective with clinical outcomes equivalent to in-person assessment by trained assessors when well-planned [9, 10]. Satisfaction with tele-health assessment is generally high for wheelchair users [11]. Most significantly, tele-health assessment facilitated any access to services for wheelchair users when travel to assessment services isn't possible [12]. However very limited information on wheelchair user health condition was given, with none specifically reporting services designed for people with NMC and complex wheelchair needs.

Specialist and local (non-specialist) assessors reported mixed opinions however. While time efficiencies and some educational advantages were reported, some therapists are hesitant to adopt tele-health wheelchair assessment, citing concerns about clinical errors [13, 14]. The perspectives of service managers, funders, digital or legal specialists have not been reported despite these roles representing significant stakeholder interests in a tele-health wheelchair service. Our recent scoping review of telehealth wheelchair services (under review) indicates a need for early engagement with stakeholders if the aims of this tele-health service are to be achieved.

Specific exploration of the perspective of Māori (as a distinct stakeholder group) on a tele-health wheelchair service warrants attention. Constructs such as health, disability and participation in society, are critical to a successful match of wheelchair-users with wheelchair technology solutions [15], and are known to vary in meaning between cultures [16-18]. A wheelchair user's assistive technology (including wheelchair) needs are embedded in culturally situated values and experiences [19]. To this end, we propose specifically recruiting Māori wheelchair users to this study (aiming for 13% of wheelchair users to match representation of Māori among with disability) and undertaking a subgroup analysis of the views of Māori on tele-health wheelchair assessment.

Tele-health assessment of wheelchair needs has the potential to save considerable health dollars through avoided wheelchair users and specialist assessor travel time; avoided hospital admissions from secondary complications of ill-fitting equipment and minimising disruption to employment for wheelchair-users. However designing a safe and effective tele-health wheelchair assessment service requires rigorous stakeholder consultation. This needs to happen in order to design intervention protocols that are appropriate to the NZ digital and healthcare context. Large, well-funded digital health technology initiatives elsewhere have spectacularly failed to realise proposed benefits due to flaws in the concept, product design, implementation, embedding and timing of delivery [20]. In contrast, implementation of mobile technology in community allied health services in NZ, to address specific problems of efficiency, security and accessibility of health information, has been shown to improve patient and clinician interactions, workflows and health information management [21]. In relation to this study, the wheelchair-users with NMC may have unanticipated needs in engaging in tele-health wheelchair assessments [22] related to fatigue, grief and progressive changes in health affecting participation in work and family roles.

This study is theoretically grounded in the New Socio-Technical model for Health Information Technology (NST-HIT) which specifically addresses the socio-technical challenges involved in

design, development, implementation, use, and evaluation of NST-HIT within complex adaptive healthcare systems [23]. This study will address the eight dimensions of this model (people, clinical content, workflow and communication, human-computer interface, organisational policies, procedures and culture, external rules and regulations, hardware and software, systems measurements and monitoring) explicitly in both phases of data collection. Specifically, the research aims are:

## Objectives

1. What are the socio-technical design requirements of a tele-wheelchair assessment service in NZ from the perspectives of wheelchair users with NMC, specialist and non-specialist assessors, managers, funders and policy developers?
2. What are the culturally specific perspectives and needs of Māori wheelchair users with NMC, of a tele-wheelchair assessment service?

## Methodology

A sequential explanatory two-phase mixed methods design [28] is planned involving survey (Phase One) and interview/focus group (Phase Two) data collection. An explanatory design is proposed as the phase two interview/focus group findings will be used to explain phase one survey findings. Mixed methods are helpful when multiple perspectives and data types better inform the research question than a single approach [28]. The survey will facilitate participation by a wide range of stakeholders [29], and the interviews/focus groups will facilitate in-depth exploration of perspectives [30]. Integration of survey and interview data will enable broad stakeholder engagement and perspective sharing, with elucidation of contextual factors that influence stakeholder perspectives and needs in the design of a tele-health wheelchair service.

### Phase One: Survey

A survey (using REDCap™ secure data capture software, posted-paper format and telephone format) will provide broad information about stakeholders' perceptions of tele-wheelchair assessment in the areas targeted in the survey questions.

### **Phase one Inclusion/Exclusion criteria**

Participants will be included if they have been involved in complex wheelchair assessment within the past six months as either wheelchair-users with NMC (as per the Muscular Dystrophy Association NZ definition); specialist or non-specialist (i.e., local to wheelchair-user) assessors including technicians and service managers. Wheelchair-users will be aged >18 years, have NMC and self-report a wheelchair as their main means of mobility inside the home (as an indicator of 'complexity'). We excluded children because we felt that children and their families would have a distinctive set of needs.

1. The service user in paediatrics is not just the wheelchair users (while recognising good practice at any level involves relevant loved ones)
2. The recruitment strategy would be more complex (outside of budget) for children given the multiple agencies often involved.
3. Rapid changes in children wheelchair needs = greater level of complexity. While this might also occur for those with rapid degenerative conditions, who do meet study criteria as adults, we wanted to take a tiered approach to understanding stakeholder needs and views (given anxiety already reported elsewhere from health professionals about telehealth).

## Recruitment

Recruitment will occur by multi-channel purposive and snowball sampling given the disparate nature of stakeholder networks. Wheelchair users will be recruited via wheelchair user networks including the New Zealand Neuromuscular Dystrophy Registry, NZORD (rare disorders) and Motor Neuron Disease New Zealand. Assessors will be recruited via clinical networks (e.g., professional associations), equipment provision agencies (such as Enable New Zealand, AccessAble, ACC and DHB specialist wheelchair assessment services (e.g., Burwood Spinal Unit seating service). Service managers, funders and information security stakeholders, (e.g., Chief Information Officers of DHB's) will be identified via information on organisations websites and phone calls to the organisation and personally emailed an invitation to the survey. Each organisation will be asked if study invitations could be distributed through their Māori liaison service/staff/processes (e.g., kanohi-ki-te-kanohi) in addition to other communication systems (e.g., newsletters, email or social media, notice boards). A hyperlink to an online (REDCap) version of the survey will be included in all electronic distribution of the study invitation. Wheelchair user invitations will include the ability to request a posted paper version of the survey or survey completion via telephone with the research assistant. The research team will be contactable by email or phone. Two subsequent reminders will be emailed to all stakeholder groups to pass on to stakeholders through their networks.

**Data collection:** Survey questions will begin with self-defined selection of stakeholder role in wheelchair assessment. The REDCap version will use skip-logic functions take the participant to the questions within the survey relevant to their role. Questions will be configured to address the dimensions of the NST-HIT model [23], with answers provided on Likert scales. The NST-HIT incorporates technical, clinical, human, organisational and external influences on health technology implementation. Open ended questions will be used to allow participants to explain their numerical responses. Interest in participating in phase 2.

Wheelchair users will be asked to complete a functional assessment of wheelchair mobility, the Quebec User Equipment Satisfaction with assistive Technology measure (QUEST) [31] in order to contextualise their satisfaction with current wheelchair assessment services. The QUEST will be embedded in the survey. The QUEST has 12-items and will provide objective indication of wheelchair user satisfaction with equipment. The QUEST will be built into the REDCap data capture and added to the postal paper survey.

A pilot of the survey, including cognitive interviewing on interpretation of survey questions will be undertaken prior to data collection. Pilot participants will be approached in-person via Advisory group and research team connections. Attempts will be made to obtain a representative sample of all stakeholder groups aiming for a sample of 8 to 10 participants. Electronic, paper and phone versions of the survey will be piloted. Total time for survey completion is anticipated to be between 10 to 30 minutes (including demographic questions) depending on the extent of reflection of responders and any impacts of disability on response time. Response time will be included in the pilot data collection.

#### Data collection from people with communication impairments

All practicable attempts will be made to recruit and enable participation of wheelchair users with impairments that affect their capacity to complete the survey. All invitations to the study will emphasise the importance of supporting wheelchair users to decide if they wish to participate in the study. Wheelchair users and their carers will be advised to use the communication system they would normally use (e.g., carer acting as reader/writer, augmentive communication device). Information on how to obtain paper copies of the survey or to request a phone delivery of survey questions will be provided on all participant information sheets. Electronic and paper copies of surveys will be in large font, with generous spacing between words and sections as per aphasia

friendly guidelines. A reminder will also be provided that all views documented are those of the person named as the participant on the survey, and that a separate survey should be completed to express the views of any person (e.g., carer) assisting with survey responses.

Participant demographic information gathered for all stakeholders roles will be age-range, gender and ethnicity. In addition the following role specific demographics will be collected: **Wheelchair-users and Carers:** source of NMC diagnosis, general health, household composition and employment status, District Health Board, travel time to nearest major hospital, satisfaction with current services (using the QUEST); **Assessors:** professional qualification, specialist wheelchair training (i.e., level of Enable NZ accreditation), number of complex wheelchair assessment undertaken per month and employer, geographic location. **Funders and Managers:** employer, role.

**Data Analysis:** Quantitative findings will be analysed descriptively using means, medians, frequencies and percentages in order to provide an overview of views related to tele-health wheelchair assessment. Graphs and tables will be used to illustrate key findings. Qualitative (free text) responses will be analysed thematically [30] and used to develop the interview/focus group schedule to be used in phase two. Given the highly exploratory nature of this study no sampling frame will be identified and no a priori sample size is targeted however 100 to 150 responses are anticipated and we feel would provide adequate stakeholder representation (no data is currently available on the number of complex wheelchair users in New Zealand. The sample size target is based on the combined clinical perspective of named investigators. A breadth of views from stakeholders from a wide variety of roles and contexts are sought in order to understand the perceptions of tele-wheelchair assessment hence a single, unifying set of themes may not occur, with themes related to specific stakeholder groups.

## Phase Two

The second phase of this study uses interviews and focus groups within a pragmatic qualitative approach [30] to explore contextually specific considerations in design of a wheelchair service.

### **Recruitment:**

Inclusion/ exclusion criteria for phase two is the same as for phase one with the addition of Information Technology (IT) specialists within the health sector, legal advisors within the health sector, funders directly involved in wheelchair and seating services. Participants will be purposively selected from Phase One participants who have indicated they are interested in participating in Phase two. IT specialists, legal advisors and funders will be approached through DHB channels. Phase two participants will be selected to represent a broad mix of stakeholder roles, levels of enthusiasm about tele-health assessment and levels of satisfaction with current services. Wheelchair-users who are Māori (n=3, 13%), rural, as well as new and experienced wheelchair users will be specifically sought.

**Data collection:** Interviews and focus groups will be undertaken using video-conference or telephone in order to maximise accessibility to participate. Interviews will be undertaken by a research assistant (RA) FG and RG with wheelchair users, their carers and their significant others, managers, funders and technical specialists. The RA will undertake specific training with FG and BJ to ensure interview quality, particularly with Māori. Assessors' views will be explored through video-conference focus groups with the aim to garner deeper levels of reflection through encouragement of the social development of ideas between participants during group discussion [32, 33]. Interviews and focus groups will follow a semi-structured interview schedule covering the dimensions of the NST-HIT and developed in conjunction with the study Advisory group. Focus groups for assessors will be restricted to less than eight participants to optimise group member contribution.

### Data collection from people with communication impairments

All practicable attempts will be made to recruit and enable participation of wheelchair users with impairments that affect their capacity to take part in interviews. Interview format only will be offered in respect for the heterogeneity of the wheelchair user group and the potentially sensitive information shared about their healthcare experiences. Participants will be encouraged to have a support person present if they wish and using participants preferred communication strategy (e.g., via an augmentative communication device or through the use of a carer as a communication partner). Interviewers will speak slowly and allow extra time to answer questions. In person interviews will not be possible due to budgetary constraints. This is a recognised limitation of the study.

We estimate inviting 30 people to take part in interviews (~20 wheelchair users, 6-8 managers and 2-4 information technology/privacy specialists nominated by their organisations as having expertise in telehealth applications) and 48 in focus groups (6 groups x 8 assessors [specialist and non-specialist] each).

**Data Analysis:** Phase two data will be digitally recorded, transcribed verbatim and analysed using inductive thematic analysis [30] with all data uploaded to NVivo 12 (QSR International Pty Ltd, 2018). Interviews with Māori will be analysed separately. The NST-HIT model will not be imposed during data analysis. Similarities and differences within and between stakeholder groups will be specifically examined and coded related to the research questions. Drawing from a kaupapa Māori perspective we will build a reflexivity process in to data collection and analysis for all participants. This will include going back to participants and ensuring we have represented their voices correctly (i.e., member checking). This is an essential part of our kaupapa. In the first instance we will provide a digital or hardcopy of draft themes to all participants (via email or post) and invite feedback either in writing or via individual video conference or telephone (including for those in focus groups). Permission to do this will be negotiated at the end of interviews and via private chat functions for focus group participants. An alternative option for interview participants, if the participant does not wish to review formal themes, if the participant is willing, we will summarise the key messages at the end of the interview and check we have those right then send a draft of the main themes for comment. The guiding principle of these steps is to ensure that the views of participants are accurately represented.

Peer coding will be undertaken by named investigators (FG, PB, BJ) with 30% of raw data double coded. Preliminary themes will be discussed as they emerge with all NIs. Brief summaries of interview and focus group transcripts will be offered to all participants. Member checking with consumer participants of initial themes that emerged from individual interviews will occur as described above, however, no formal member checking of resultant themes will be undertaken given that a wide range of perspectives are anticipated across all stakeholder groups and that no participants will be privy to the views expressed by all other participants. All participants who indicated they would like to be kept informed of the study development will be provided brief summaries of findings and notified of publications and presentations ensuing from this study, as well as subsequent research and implementation plans.

Results across both phases will be synthesised and presented as a coherent representation of the current perceptions and priorities of key stakeholders to tele-health wheelchair assessment in NZ. Synthesised findings will provide robust information upon which to decide if, and how tele-health assessment of wheelchair for complex cases could be successfully progressed in NZ.

Responsiveness to stakeholder perceptions of the pre-requisites to, and key components of this service will be instrumental in a successful trial of a tele-health service in a future HRC feasibility study. Findings will contribute to the sparse international literature on this emerging area, a robust

exploration of contemporary stakeholder views and considerations in tele-health wheelchair service design. The study will also enable development of a steering group with cross-sector expertise (including wheelchair users and tangata whenua) to guide co-design of a future study examining the effectiveness of a tele-health wheelchair service, in the NZ health delivery context consistent with the strategic direction of the Health Research Council [34].

## Ethics

### Participant safety

It will be important to impress to stakeholders that a wholly tele-wheelchair and assessment service is not yet proposed. Assessors may feel apprehensive about tele-health assessment. On the survey and prior to all interviews/focus group we will explicitly reiterate that this project is not indicative of a move to a tele-health service. Wheelchair users are considered a 'vulnerable population' by the Health and Disability Ethics Committee and as such all steps to avoid any sense of coercion to participate will be taken. All wheelchair users will be invited to have a support person present for interviews. For participants who identify as Māori, the Hui process [43] will provide an overarching structure to interviews, trained by BJ.

### Informed consent

Informed consent for phase one (survey) will occur in the same format as the survey is being completed (electronic, paper or via telephone). In each instance, informed consent will be outlined (as per informed consent page on this ethics application) prior to any survey questions. In the electronic version of the survey informed consent will occur via tick box. On the paper version participants will be asked to sign their consent; for telephone completed surveys, informed consent will occur by verbal reading of the consent page and verbal informed consent, noted down by the reader/writer.

Informed consent will be completed separately for phase two (interviews and focus groups) given that the nature of what is being consented to varies from phase one. Consent forms will be completed using the same system that participants used to complete phase one: electronically via Redcap data capture system, via posted paper consent or via telephone prior to the commencement of the interview. No coercion will be used in order to obtain consent. Consent documentation and participant information sheets (paper, read via phone or electronic) state that participation is voluntary and will not affect the quality of service of the person with a wheelchair.

Some health-consumer participants may have restricted communication or cognitive ability. Their participation in both phases of the study, including the giving of consent will follow their current communication strategy that may include use of an assistive device, verbal only, written only, via a communication partner (typically their carer). There is a risk that these participants may feel coerced to take part in the study. Several strategies are in place to mitigate this risk: (1) the incentive to participate is modest so that only participants interested in the topic will take part; (2) the research assistant will be trained in being communication partners by Graham and Boland who both have extensive clinical experience in this role; (3) carers are also invited to participate in the study thus can voice their views about the study topic in their own survey/ interview.

### Confidentiality

All efforts to maintain the confidentiality of participants will be taken. All steps outlined below will be conveyed to participants on the informed consent sheet and just prior to all data collection, at

which point they are free to withdraw from the study. All data collection- survey and interviews/focus group audio recordings will be described to participants including storage place, time, security and who will have access to the data, and for what purposes. Interviews and focus groups will be audio recorded and transcribed verbatim. A brief (one page) summary of key discussion points during interviews and focus groups will be offered to participants in the week following each meeting via email. No identifying information will be included in the written summaries. For interviewees a brief verbal summary will also be offered at the end of interviews. All data will be stored on the University of Otago Synchplicity secure data storage system at the highest security settings. All named co-investigators will have access to this data for the duration of the study. The only identifying information about participants on surveys will be their contact details in order to receive the incentive for the study or if participants have indicated they would like to be informed of the study findings. Contact details will be removed from the dataset in an unrecoverable way as soon as the incentive has been distributed. Identifying information on interview and focus group recordings will not be transcribed.

There is a risk that some smaller populations of participants (e.g., legal advisors within DHB's, specialist assessors; health consumer sub-populations) will be identifiable from the description of their roles. To mitigate this risk caution will be used in describing the role, employer, health condition or any other identifying features of participants to ensure that there is ambiguity regarding who they may be. All participants will also be able to leave out any specific demographic information which they feel may compromise their privacy. In most instances they will still be able to participate in the study. Participants will be informed that they may amend their personal details if they wish by directly contacting the research team.

Focus group participants may have concerns about the privacy of their views between other focus group members. To mitigate this risk, the membership of focus groups will be shared with all attendees prior to the meeting. Focus groups will commence with an explanation of the privacy and confidentiality processes of this study, including that information shared during focus groups remains private to the focus group members and no names of either attendees or views expressed should be shared outside of the groups.

### **Data storage / protection;**

All electronic survey data and interview/ focus group transcription will be kept on the Synchplicity system until 2024 as per University of Otago policy. Paper surveys and any paper consents will be stored in a locked filing cabinet in a locked room in University of Otago grounds, also for 5 years (until 2024). No identifying information will be shared on any distribution of findings including reports, peer reviewed articles or oral presentations.

### **Relevant consultation – Māori & Other.**

Bernadette Jones (co-author, Nga Wairiki, Ngāti Apa) on this study has provided valuable guidance on the design and engagement in relation to Māori. Consultation with Ngai tahu through the University of Otago Māori consultation processes has been undertaken. Ethnicity data has been integrated into data collection and subgroup analysis for Māori will occur for survey data (either descriptively if the sample size for Māori is small or using chi square analysis) and for interview/ focus group data. Any additional advice from Ngai tahu will be integrated into the study protocol prior to completing locality authorisations.

Māori consultation will subsequently be undertaken for each locality authorisation according to the requirements of each locality with recommendations integrated into procedures for each site.

In addition to Māori consultation, several groups were consulted on the development of this project prior to grant application. These include consumer groups via the Burwood Academy of Independent Living and professional groups via the Wheelchair and Seating Special Interest Group (occupational therapy) as well as specialist services including Seating to Go and Enable New Zealand. An Advisory Group for this study has already been established and contributed to the develop of the survey and project plan. Advisory group participants include

### *Project Management*

#### **Participating site(s) and persons**

The host site for this study is the University of Otago, Christchurch campus where the PI Dr Graham is based. However all data collection is occurring remotely in order to maximise the opportunity to participate irrespective of geographic location across the country. Dr Graham has the primary responsibility for co-ordination of all activities and project oversight. The research assistant is responsible to Dr Graham. All contributing authors have committed their availability to their designated activities within this project.

#### **Specific Responsibilities**

The specific tasks within the project and the contributor within the research team are:

1. Ethics, locality approval and Māori consultation: Led by FG. Assisted by RA
2. Survey Design: Led by FG. Assisted by RG and PB.
3. Survey Distribution and monitoring: Led by RA. Oversight by FG. Assisted by SW
4. Survey data analysis: WT
5. Interview/ Focus Group planning: Led by FG. Assisted by PB, RA, RG, BJ
6. Interview/ Focus Group data collection: Co-ordinated by FG. Assisted by PB, RA, RG, BJ
7. Interview/ Focus Group data analysis: Led by FG. Assisted by PB and BJ
8. Integrative analysis all findings: FG, PB, RG, BJ, SW, WT (all named investigators)
9. Publication- FG, PB, RG, BJ, SW, WT (all named investigators)
10. Feedback to participants and stakeholders : led by FG assisted by RA

#### **Advisory group**

The following advisory group is currently being assembled for this study.

1. Sally Wallace (OT)- specialist assessor Enable New Zealand
2. Debbie Wilson (OT)- specialist assessor Seating to Go
3. Stephanie Thompson (PT)- specialist assessor CCDHB
4. Dr Johnny Bourke- consumer- Burwood Academy of Independent Living
5. Siobhan Jansen-Student Occupational Therapist (OT)
6. Rita Robinson- Undergraduate Educator Occupational Therapy -- Otago Polytechnic
7. Hemakumar Devan (PT)- health technologies, physiotherapy, technology and culture
8. David Hood- IT specialist, University of Otago

Note. Bernadette Jones is a spouse/carer of a person with complex wheelchair and seating needs and is also tangata whenua thus these stakeholder groups are represented in the authorship team rather than advisory group.

#### **Data ownership;**

All data is owned by Dr Fiona Graham within the University of Otago.

#### **Risk management of project.**

The primary risk for this project is data privacy and security which has been outlined above. Other risks include lack of participants. Extensive recruitment procedures have been described above in so far as budget allows with broad stakeholder representation in the design of this study. Data analysis will be modified to purely descriptive reporting if recruitment is very low, particularly for the phase one survey.

### Timetable

	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb
Ethics Otago													
Localities													
Survey data collection													
Survey analysis													
Phase 2 recruitment													
Interviews/ Focus groups													
Phase 2 analysis													
Analysis Maori													
Data synthesis													
Reports/draft publications													
Submitted publications													

### Resources

This project has been supported by a grant from the Neuromuscular Research Fund (REDS 17894; \$17533). Funding includes research assistants (\$9853) incentive for consumers (grocery voucher; \$1200) and transcribing services (\$6480).

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