

Review of Research Proposal

Funding Body: Neuromuscular Research New Zealand

Proposed project: Tele-health wheelchair and seating assessment: A mixed methods study

Overall Comment:

Thank you for the opportunity to review this project. Telehealth is an understudied health care delivery innovation. This study seeks to provide the foundation for service design that meets the needs of the people it is intended to serve.

The sequential two-phase study design is a well-conceived, with potential to make a significant improvement in the lives of people with neuromuscular conditions who require specialist wheelchairs, dramatically reducing time delays in wheelchair system evaluations, with all the attendant risks that causes. Theoretically grounding the study in the New Socio-technical model for Health Information Technology (NST-HIT) is a sound choice.

I offer some detailed critique below for the consideration of the research group, much of which can be addressed within the study design outlined in their proposal, by greater focus on engagement with Māori, more specific targeting of their recruitment efforts, face-to-face engagement with wheelchair users and significant others in phase two, modification of the budget to enable that, and the addition of further information substantiating the population affected by delays in follow-up assessment due to travel distances and financial constraints.

Significance of the study:

The significance of the study is signalled in monetary terms (\$15,000 to \$65,000 per wheelchair/seating system, at a cost of \$20 million annually) but the size of the population of wheelchair users with NMC, and of them, the proportion for whom attending a clinic or being visited at home is problematic is not estimated. Neither is there any estimate of the frequency of delays causing adverse outcomes – either direct health consequences (pressure areas) or disruption to daily life.

Similarly, there is no estimate of the number of specialist wheelchair assessors involved in travelling uneconomic distances to visit wheelchair users with NMC, or the work hours wasted on travel.


The researchers state that “100 to 150 responses are anticipated” which they feel would provide adequate stakeholder representation”. No basis is given for these estimates. How does it compare with previously reported studies? Is there a minimum below which views would not be taken to be representative?

Rationale for the study:


The claim that “several studies describe early consultation as one of the ‘lessons learned’ from their research” needs supporting citations.


Recruitment:



There is emphasis on participation by a wide range of stakeholders. I suggest targeting wheelchair users, their carers and significant others who would be likely recipients of a telehealth wheelchair assessment, i.e. those who live at a distance from clinics (rural) and not recruiting those local to such services.

“Distance” might be defined in terms of either travel time or travel costs, but surveying people living in the vicinity of a clinic would not seem productive. 


Data gathering:


In phase one, survey questions “will be configured to address the dimensions of the NST-HIT model”, which is congruent with the theoretical foundation of the study, but the process by which the questions will be generated is not clear. There is no indication of trialling the survey before survey implementation. 

Planned data to be gathered from wheelchair-users is the “source of NMC diagnosis, level of functioning, household composition and income range”. I recommend adding “distance from specialist wheelchair seating service” (if they have visited one or know of its location) and “frequency of contact with specialist wheelchair assessors over the previous year”.  This additional information would serve as a check that findings are in fact based on the views of the population who might be the recipients of telehealth wheelchair assessments and the potential frequency of contact with such a service.


In phase two of the study, the intention is that “interviews and focus groups will be undertaken using video-conference or telephone in order to maximise accessibility to participate”. This data collection strategy contains cost  but risks skewing the sample towards wheelchair users and their carers/significant others who are comfortable with and confident in video-conferences or telephone interviews. That would not be a true indicator of the acceptability and accessibility of precisely the mode of communication being studied, as those highly resistant to it would not participate. 

Data analysis:

The 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”. I am unclear whether the data will be analysed as a composite whole or by subgroups, to detect differences in viewpoint and concerns expressed. Given the number of subgroups (wheelchair users, carers/significant others, Māori, assessors, funders/management role), some subgroups would be numerically small.  I note that carers/significant others are not identified as a group to answer the survey, but this seems to be an oversight as they are one of the groups identified for participation in interviews/focus groups in phase two.

There is a statement that “qualitative (free text) responses will be analysed thematically and used to develop the interview/focus group schedule to be used in phase two”. It is not evident whether the qualitative findings from phase 1 would be reported. 

Responsiveness to Māori:

There is a stated intention to consult “with Māori (Ngai Tahu, via University of Otago and all other organisation Māori liaison)”. It is not clear whether the researchers have existing relationships with Ngai Tahu. I understand that the development of research proposals is frequently time-pressured, but consultation prior to designing a study is more respectful. 

Part of the recruitment plan is to ask “if study invitations could be distributed through [the] Māori liaison service/staff/processes (e.g., kanohi-ki-te-kanohi)” of wheelchair user networks including the New Zealand Neuromuscular Dystrophy Registry, NZORD (rare disorders) and Motor Neuron Disease New Zealand. Ideally, participants recruited via these organisations would be 50% Māori, to ensure equal explanatory power of the findings. However, there is no evidence presented that Māori wheelchair users join such organisations, and if they do, how the researchers might seek to build



relationships with Māori liaison service/staff to recruit their support with recruitment of participants for phase one.

None of the research team have identified as Māori and, while the constitution and role of the Advisory group is specified, tangata whenua representation is a notable absence. There is perhaps an assumption that assessors, funders and people in management roles will not be Māori, as there is no strategy to target them for recruitment to the study.



Nonetheless, there is an intention to recruit Māori for the survey and to specifically select them (n=3, 13%) for an individual interview in phase 2. In my view, the lack of existing relationship and the anonymous data collection strategy (survey) make it very unlikely that Māori will volunteer to participate in the study.

Because Māori representation is important, I suggest building in capacity to purposively recruit new participants for phase two in case there were insufficient Māori participants in phase one. I would also recommend that the Māori participants in phase two be brought together for a focus group, in a “hui” style interview.



The research team might also be advised to reflect on their stated ethical commitment to “avoid any sense of coercion to participate will be taken (for example no cold-calling about the study will occur)”. In their consultation document, *Draft National Ethical Standards for Health and Disability Research*, the National Ethics Advisory Committee Kāhui Matatika o te Motu propose a dual structure of te ara tika principles alongside the bioethical principles currently guiding the deliberations of ethics committees. That brings concerns about privacy and avoidance of any suggestion of coercion alongside the importance of manaakitanga and whakapapa. The depth of relationship these concepts imply requires more than a request, or a written notification of an opportunity to participate in a study.



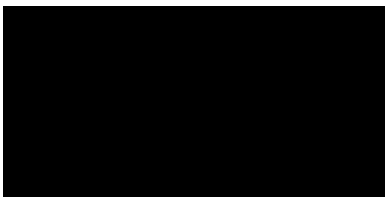
Dissemination of findings:

There is emphasis on recruiting assessors and disseminating findings via the occupational and physiotherapy professional associations’ special interest groups. I do not know the membership status of the physiotherapy association, but Occupational Therapy New Zealand Whakaora Ngangahau Aotearoa has only about 50% membership. Working through the registration body would achieve broader coverage of specialist and general wheelchair assessors



Study budget:

To do justice to this study, the proposed budget appears too small. I urge funding the study to allow for engagement with Māori and travel to wheelchair users, carers and significant others who live remotely from specialist wheelchair services to conduct individual and focus group interviews.



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