

Experiences of disabled people in accessing healthcare during COVID-19 pandemic: Short and long-term impacts on health outcomes

INFORMATION SHEET FOR PARENT/LEGAL GUARDIAN/CARER/SUPPORT PERSON OF INDIVIDUALS WITH DISABILITIES

Tēnā koe/ Tēnā koutou katoa,

You are invited to take part in this research. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

Ko wai mātou / Who are we?

Our names are Solmaz Nazari Orakani, Karen McBride-Henry, Tara Officer, Michael Roguski, and Gretchen Good, and we are academic staff members at Te Herenga Waka—Victoria University of Wellington and Massey University. Solmaz and Gretchen are members of the disability community and Karen is the parent of two disabled children. We are a research team undertaking this study about experiences of disabled people in accessing healthcare during COVID-19 pandemic and various lockdowns.

He aha te whāinga mō tēnei rangahau / What is the aim of the project?

This research is being done to understand the experiences of disabled people in accessing healthcare during the COVID-19 pandemic and various lockdowns. We want to talk with disabled people and conduct research that improves access to healthcare in the short-term and supports improved health outcomes in the long-term, especially during a pandemic. Currently, research suggests that COVID-19 resulted in a range of challenges for the disability community, but we do not know much about what has happened in New Zealand for people with disabilities. This research has been approved by the Te Herenga Waka—Victoria University of Wellington Human Ethics Committee (approval number: 0000030121).

Ka pēhea tō āwhina mai / How can you help?

You have been invited to participate because you are a parent/guardian/carer/support person of an individual under 18 years of age with a disability. If you agree to take part, one of the three research team members will interview you. The interview could occur in-person in a quiet environment, such as your home, or via Zoom as agreed with the research team. The interviewer would ask you questions about the impact of the COVID-19 pandemic and various lockdowns on your access to healthcare. The interview will take around 45 minutes and will be audio/Zoom-recorded with your permission and transcribed later.

In order to ensure researcher/participants safety during COVID-19 'traffic light system', the following measures are taken for *in-person* interviews:

- the interviewers are fully vaccinated

- the participants are fully vaccinated
- the support people are fully vaccinated
- keeping social distancing and mask wearing
- if participants are not able to wear masks, the interview will be conducted online
- should the interviewers experience COVID-19, cold and flu symptoms, the interview will be postponed or moved online
- participants will be asked to inform the research team should they experience COVID-19, cold and flu symptoms, so the interview can be postponed or moved online

You can choose not to answer any question or stop the interview at any time, without giving a reason. Whether or not you decide to take part, your decision will not disadvantage you in any way. You can withdraw from the study by contacting Solmaz Nazari Orakani at any time before the 01/03/2023. If you withdraw, the information you provided will be destroyed or returned to you. You can also contact any member of the research team (details below) to ask questions before you consent to participate.

Ka ahatia ngā kōrero ka tukuna mai / What will happen to the information you give?

This research is confidential*. This means that the researchers named below will be aware of your identity, but any identifying information will be removed from the research data so your identity will not be revealed in any reports, presentations, or public documentation.

A transcriber, not part of the research team, will type up the audio recording of your interview; confidentiality rules bind this person from discussing the interviews and the transcription with any other person. Apart from the transcriber, the only other people to have access to this information will be members of the research team. All written information will be kept locked in a filing cabinet at the Victoria University of Wellington campus. All electronic files will be kept in password protected computers at the Victoria University of Wellington campus. At the completion of the study, all research material obtained from the study will be kept by a research team member in a locked filing cabinet, on the University campus until the 31/01/2029, after which it will be destroyed.

He aha ngā hua o te rangahau / What will the project produce?

The information from this study will be included as part of the overall exploration of experience of disabled New Zealanders. The findings from this study may also be presented as a conference presentation and published in academic journals. As a pseudonym/code will be used for you, your name will not be linked to your responses, and you will not be identified in any of the reported data.

The possible benefits of participating in this research will be that you can have your experiences and perspective heard in a way that may influence how health policy will be designed to minimise pandemic's negative impacts and improve the health outcomes of disabled people.

We will provide you with a \$50.00 voucher as a way of saying thank you for your participation in the interview.

We do not anticipate that the interview will cause you any distress, such as sadness, anxiety, frustration and fear; however, if you become upset during the interview or feel uncomfortable, we will take a break or stop altogether – it will be up to you. We can also pause the interview if you need to at any stage. You are also welcome and encouraged to bring a support person to be with you during the interview if you wish. A support person will sign a confidentiality agreement, which means they cannot talk or

* Confidentiality will be preserved except where you disclose something that causes me to be concerned about a risk of harm to yourself and/or others.

discuss the interview with anyone else.

Ki te whakaae mai koe, he aha ō mōtika hei kaitautoko i tēnei rangahau / If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question;
- ask for the recorder to be turned off at any time during the interview;
- withdraw from the study before 01/03/2023;
- ask any questions about the study at any time;
- receive a copy of your interview transcript
- read over and comment on a written summary of your interview.

Mehemea ngā pātai, he raruru rānei, me whakapā ki a wai / If you have any questions or problems, who can you contact?

Please read this information sheet carefully. If you agree to take part, contact Solmaz Nazari to let her know of your decision (contact details below).

This information sheet is for you to retain so that you have a reminder of what is involved in the research and your rights. It also has the contact details of the researchers. A consent form will be provided to you if you decide to participate in the research. If you agree to participate, the consent form will need to be signed before your interview. Alternatively, you can verbally consent to participate at the beginning of the interview.

If you have any questions, either now or in the future, please feel free to contact the research team:

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He kōrero whakamārama mō HEC / Human Ethics Committee information

If you have any concerns about the ethical conduct of the research, you may contact the Te Herenga Waka—Victoria University of Wellington HEC Convenor by emailing hec@vuw.ac.nz.