



My Experiences, My Rights: Health and Wellbeing Phase One Consultation Participant Information Sheet

In 2020 we will be conducting research on the health and wellbeing experiences of disabled people in Aotearoa New Zealand. Before we begin, we want to know what health and wellbeing issues are important to disabled people. To do this, we are asking disabled people to share with us the issues they think need to be monitored.

This study is being carried out by the Donald Beasley Institute (DBI). The DBI is a disability research institute based in Dunedin.

What is this consultation about?

In Aotearoa New Zealand, essential healthcare is provided free for those who qualify through the public health system.

But sometimes disabled people don't receive the health and wellbeing treatment, care, and services they need. And sometimes they miss out altogether.

The United Nations Convention on the Rights of Persons with Disabilities is an international agreement.

It sets out what the New Zealand Government must do to make sure disabled people have the same rights as everybody else.

This includes a disabled person's right to a high standard of health, without discrimination on the basis of disability (Article 25).

It is important to understand if, and how well, this is happening.



To do this, we are asking disabled people to tell us what health and wellbeing issues we should monitor and investigate. This might include rights violations, or problematic policies. Family and close supporters of disabled people who are unable to consent to taking part in this monitoring research are also invited to contribute their views and experiences.

At the end of the consultation we will have a good understanding of what health and wellbeing issues matter to disabled people. We will use this feedback to design the next phase of monitoring interviews. Monitoring interviews will investigate the issues on a much deeper level. We will share more information about how to be involved in these interviews at a later date.

The goal of monitoring research is to give the New Zealand Government and the United Nations some good information about disabled people's health and wellbeing experiences, and suggestions on how to meet the health and wellbeing needs of disabled people in the future.

Who will be doing the consultation?

Researchers working on this project will be Umi Asaka, Dr Robbie Francis Watene and Dr Brigit Mirfin-Veitch from the DBI. We have all worked with disabled people in research for a long time, and both Umi and Robbie identify as disabled too.

How can I take part in the consultation and what will I have to do?

There are two ways you can take part in the initial consultation phase. First, you can share your views by answering a short survey. The survey is available in accessible formats through the Donald Beasley Institute website:



<http://www.donaldbeasley.org.nz/projects/disabled-person-led-monitoring-of-the-uncrpd/>

Before you begin, you will be asked to provide some basic demographic information (age, ethnicity, gender and disability type) before answering two questions:

- What health and wellbeing rights violations or issues would you like to see investigated in monitoring research?
- What public health policies, legislation, and systems would you like to see investigated in monitoring research?

Anyone who is over the age of 18 and can provide free and informed consent can participate in the survey. When you submit your answers to the survey you are showing us that you know what this study is about and that you consent to participate.

If you would like to take part in the survey, please complete the questions before midday, Friday 24th of July 2020.

The second way to participate is through a focus group. A focus group is a small group of people who share a common characteristic, such as ethnicity, gender, or type of disability. The focus groups will meet together with a DBI facilitator to discuss the same consultation questions as a group.

How do I take part in the focus group?

To take part in the focus groups we are looking for people who are over the age of 18, can provide informed consent, and who identify as:

- Māori
- Pacifica
- Rural
- Immigrants/ ethnic minorities (Asian, African, Latin American)



- LGBTQI+
- Deaf
- Family and supporters of people with complex disabilities
- Psychosocial disability/ mental health
- People with learning disabilities
- Female
- Young adults (18 - 25)

The reason we are holding focus groups with these specific groups is because research shows these groups often experience additional challenges when accessing health and wellbeing treatment, care, and services, or because they are often excluded from consultation and research. It is important that we hear from these groups of people.

If you are chosen to take part in a focus group, we will arrange any access supports you might need to participate (for example, a New Zealand Sign Language Interpreter).

Before we start the focus group, we will make sure you really do want to take part and ask you to sign a consent form. Focus group participants will be asked for their basic demographic information (age, ethnicity, gender and disability type) before discussing the same two questions as are in the survey:

- What health and wellbeing rights violations or issues would you like to see investigated in monitoring research?
- What public health policies, legislation and systems would you like to see investigated in monitoring research?

The focus groups will take about 2 hours.



What will happen with the information I tell you?

Whether you answer the online survey, or participate in a focus group, we will keep your information private. The focus groups will be recorded and transcribed, with your transcript available in plain English for you to review.

After going through the focus group transcripts, we will use this information to plan the next stage of monitoring interviews, which we will tell you more about at a later date. Following the interviews, we will write a Project Report. While we may use some of the things you tell us in the consultations in the final Project Report and other published articles, we will make sure that nothing will be used that could personally identify you. There will be a delay between your participation in the consultation and receiving the final Project Report. It is important to note that the final Project Report might be used by Disabled People's Organisations, community health and disability support services, the New Zealand Government, and the United Nations to help them think about how they support disabled people access adequate health and wellbeing services.

If we are worried about your health or safety we will talk with you. The Research Team will not talk to any other person about you, without your consent, unless the safety of you or someone else is at risk and we are legally required to do so.

What else will happen?

The focus groups will be audio or video recorded but participants can ask to have the recorder turned off whenever they want to.

The focus group facilitators might write down notes during the focus group and after the focus group ends.



Who can participate in the consultations?

Anyone who is over the age of 18 and can provide free and informed consent can take part in this initial consultation phase using the online survey.

To take part in the consultation focus groups, participants must be over the age of 18, able to provide free and informed consent, and identify as one of the target groups listed above.

How will cultural customs be included and respected throughout the consultation?

During the focus groups all participants will be asked if there are any cultural customs or traditions they would like recognised or implemented throughout the research process. For example, at the participant's request karakia (blessing) and a mihi (greeting process) can take place before the focus group and karakia (closing blessing) at the end of the focus group.

All participants can have a support person/people with them during the focus group if they wish. However, any responses contributed by non-participating support people will not be collected as data.

What do I do if I want to take part in the focus group?

If you want to take part in the focus group, you can contact the DBI Research Team by email or by phone. We can help you fill out the Focus Group Interest Form. If you are able to fill out the Focus Group Interest Form yourself please do so by answering the questions in the form on our website:

<http://www.donaldbeasley.org.nz/projects/disabled-person-led-monitoring-of-the-uncrpd/>

or by filling out the attached Word Doc and emailing it back to us. You can also print the Word Doc, fill it out and post it to us at the DBI. If you would like to register your interest



in New Zealand Sign Language, you can also email us a video of your responses. It is ok to ask a friend, family member or a support person to help you fill out the form if you want to.

If you want to take part in a focus group, please send us your Focus Group Interest Form by Wednesday 8th of July 2020.

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The Donald Beasley Institute

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After we have received your Focus Group Interest Form someone from the Research Team will contact you and talk to you about the focus group again, just to make sure you really want to take part.

If a lot of people want to take part in the focus group consultation we may not be able to include everyone. This is not because we don't think your experience is important. Even if we can't talk with you in person, you can share your views using the online questionnaire, and we will keep you informed about the progress of the research.



Who will have access to my information, details and interview recordings and notes?

The DBI research team and transcribers will be the only people who have access to the details and information you share. We will use a code system to help make sure no one can identify you or your responses.

What will happen to the information and details I share in this research?

Everything you share with us will be kept securely at the Donald Beasley Institute for 10 years. After 10 years it will be destroyed.

What happens if I don't want to be part of the consultation?

Nothing. If you don't want to take part it is OK. No one can tell you that you have to take part in this consultation.

If you don't want to take part, but still want to know about future studies, please register your interest with DBI by phone or by email.

What happens if I decide to take part in a focus group but then I change my mind?

Nothing. It is ok to decide to take part and then change your mind. You can withdraw consent and decide to stop participating at any time and nothing will happen to you.

Who do I contact for more information?

For more information you can contact the DBI Research Team on uasaka@donaldbeasley.org.nz or 0800 878 839. The call won't cost you any money.



Who do I contact if I have any concerns about my safety?

This research has been approved by the Northern B Health and Disability Ethics Committee. This means that a group of experts have made sure that the research is safe and that we will work with people in a respectful way.

Contact details for the ethics Committee are:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

Who can I contact for Māori health support?

If you would like to speak directly with the Kairangahau Māori Research Associate for the Donald Beasley Institute, please contact our office:

admin@donaldbeasley.org.nz

Free phone: 0800 878 839

Who can I contact if I need independent advice about taking part?

If you want to talk to someone who isn't involved with the research, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

Website: <https://www.advocacy.org.nz/>