



IMPACTS OF COVID-19 IN AOTEAROA
NGĀ KAWEKAWE O MATE KORONA



INFORMATION SHEET FOR SURVEY PARTICIPANTS

**Greetings! Kia ora! Kia orana! Tālofa nī! Fakaalofa lahi atu! Ni sa bula vinaka!
Talofa! Malo e lelei! Malo soifua manuia! Namaste! Nǐ hǎo! Neih hou!
Bonjour! Hallo! Kamusta ka! Hola! Anyeonghaseyo! Konnichiwa! Marhaba!
Zdravstvujtye! Ciao! Sah-wahdee! Vannakkam!**

We'd like to invite you to take part in this research study. Please read this information before deciding whether to or not. If you decide to participate, thank you, kia ora! If you decide not to participate, thank you for considering this request anyway. With much appreciation. Ngā mihi nui ki a koe

Who are we? Ko wai mātou?

We're a research team made up of members from Te Herenga Waka–Victoria University of Wellington and independent contractors. The coordinating investigators from Te Hikuwai Rangahau Hauora | the Health Services Research Centre at the university are **Dr Lynne Russell** (*Ngāti Kahungunu, Rangitāne, Kāi Tahu, Kāti Māmoe, Ngāti Porou*) and **Dr Mona Jeffreys**. A Rōpū Māori (the study's Māori researchers and kaitiaki) is led by Dr Russell, with the Pacific team (Pacific researchers and kaitiaki) being led by **Dr Marianna Churchward** (*Lotofaga, Faleasiu, Samoa*).



Dr Lynne Russell



Dr Mona Jeffreys



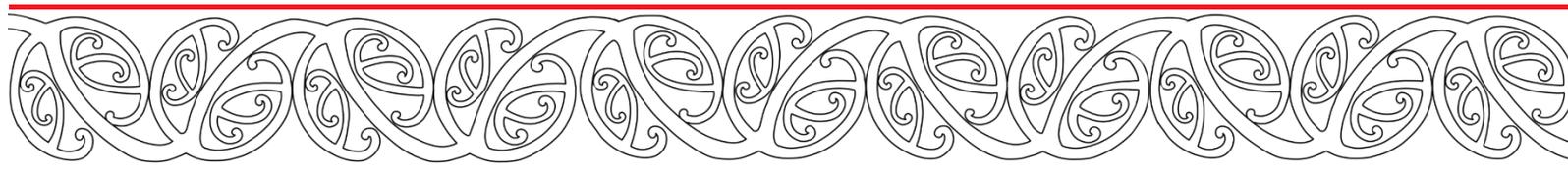
Dr Marianna Churchwood

The study is overseen by a Kaitiaki Rōpū (Governance Board) led by the Pou Tikanga, **Matua Witeria (Witi) Ashby** (*Ngāti Hine, Ngāti Kawa*) and Tāngata Whenua and Tāngata Tiriti co-chairs, **Whaea Iris Pahau** (*Te Aupouri, Te Rarawa, Ngāti Kuri, Ngāti Awa*) and **Tuiloma Lina-Jodi Vaine Samu** (*Salelesi ma Faleula; Sapunaoa i Falealili ma Pu'apu'a i Savai'i, Samoa*). The study is sponsored by the Research Trust of Victoria University of Wellington.

What is the purpose of this study? He aha te Kaupapa?

We're doing this study to find out how COVID-19 has affected people who've had it. The study aims to improve support for those in Aotearoa New Zealand who contract COVID-19.

We can learn from your experiences of what having COVID-19 has been like for you and your whānau/ family and community. By studying its impact on the health and wellbeing of people like you, we'll be able to make recommendations to government about how to provide the best support possible for others that contract COVID-19 in the future.



This study is open to everyone in Aotearoa New Zealand who has had COVID-19. This includes people who had it mildly or badly, or who had it at the beginning of the pandemic or more recently. You do not need to have had a positive COVID-19 test to take part; we are also interested in probable cases. To make sure that the voices of all people are heard in the results, we want as many people as possible who have had COVID-19 to participate. There are two parts to the study:

1. **Surveys** that can be completed online at covid.aotearoa.com or you can ring us on 0800 800 581 if you need any help with them.
2. **Interviews** with some people who have had COVID-19 in Aotearoa New Zealand.

THIS PARTICIPANT INFORMATION SHEET IS SPECIFICALLY ABOUT THE SURVEYS.

How can you help? Āwhina mai?

There are four surveys included in this study:

- ✓ **One about the support you needed when you had COVID-19.** For some people, COVID-19 was challenging. We ask about some of the challenges from when you first got COVID-19, and any support you got, or would have liked, to deal with these challenges. We also ask how things are for you right now.
- ✓ **One about your health and the health services you used after getting COVID-19.** Some people were at home for the whole time that they had COVID-19, but others were in an isolation or quarantine facility (e.g., MIQ hotel). Some people have also been treated unfairly or discriminated against because they've had COVID-19. We ask how things were for you when you first got COVID-19 and the health care that you received. We also ask about the doctors, nurses and other health workers that you might have seen since.
- ✓ **One about the financial cost of having COVID-19.** We ask how different things were for you before you got COVID-19, compared to after, to work out the cost of COVID-19. For some, that cost has included being in hospital. We ask who (if anyone) helped care for you and how it has been talking with health providers about COVID-19 face-to-face, by phone or through video consultations.
- ✓ **One about your experience of Long COVID (if you have ongoing symptoms of COVID-19 after no longer testing positive for it).** For some, COVID-19 symptoms continue for an extended time. We ask about the care that's given and your ideas of what changes could be made to help those with Long COVID.



You can do one, two, three or all of the surveys.



All questions are optional and you can stop part way through and return to complete later.



Each survey should take between 10 to 20 minutes to complete.



To thank you for your time and expertise, if you take part in the surveys, you can choose to enter a prize draw for one of eight \$300 Prezzy Cards. Each survey that you answer gives you two entries to the draw.

At the end of the survey, there is an option to download a copy of your responses. We also ask whether you would like to be contacted again in the future, to see how you are doing. You can choose whether



or not to agree to this. If you do, we will ask for your contact details. To protect your privacy, your contact details will be separated from your survey responses. If you do agree but change your mind later, you can request not to be contacted again at any time.

Health Information Pārongo Hauora

We would like to link your survey information with health information that the Ministry of Health has about everyone in Aotearoa New Zealand. We need your permission to do this. The information/ data that would be linked is about:



Your COVID-19 illness (e.g., the strain of COVID-19 you have). This would have been collected when you first got COVID-19.



Any times you have gone to hospital (staying overnight, or visiting outpatients and emergency departments). This will include dates of when you went, and the diagnoses you received there. It includes times before you had COVID-19 as well as afterwards.



Whether you have a GP, and the date when you last visited them. *It is important for you to know though, that we will not get any information about your health from your GP.*



COVID-19 vaccinations (e.g., what vaccine/s you had and when you had them) to study the effect of vaccination on people who have had COVID-19.



Medicines that you were given by a pharmacist (dispensed) before you had COVID-19, and medicines that were dispensed since you had COVID-19. This information is held by the Ministry of Health; we will not get this from your GP.

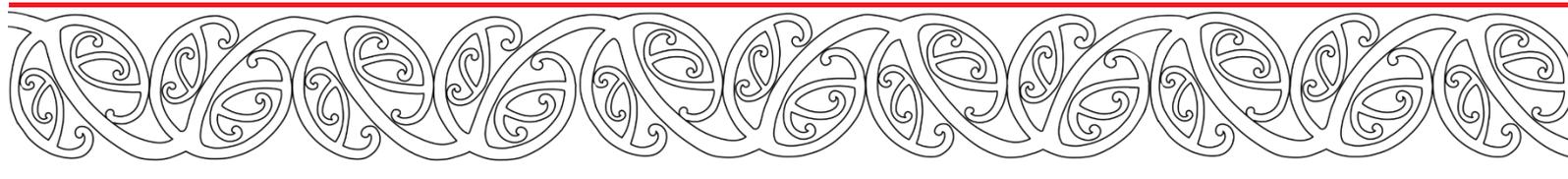
You can choose whether to agree to this data linkage or not in the online consent form in the surveys. If you give us permission to link your information/ data, we will provide proof of this agreement (your consent) to the Ministry of Health, so they can securely transfer your information/ data to us.

What will happen to the information you give? Ka haere tō kōrero ki hea?

None of the *survey* information that you share with us will be given to the Ministry of Health, any health provider, or anyone else. Your name or any information from which you could be identified will not be used in written reports or presentations that come out of this study.

If you agree to data linkage, we will pass your personal details (name, address, date of birth and NHI number) to the Ministry of Health, so that they can transfer the correct information/ data to us. If you do not agree to data linkage, we will still pass on your personal details, to ensure that the Ministry of Health does not transfer any of your data to us. We will protect your identity by grouping together the survey information that you share with us with other people's information, and just reporting on these groups. Most of the results will be presented as percentages (%) in the final report; other statistical methods will also be used.

You can change your mind and withdraw from this study, without needing to give a reason. You will need to contact the research team to do this (contact details at the end of this Information Sheet). If you withdraw, we will try to destroy all information that you provided in any surveys. If you completed the surveys anonymously, this might not be possible. If your information/ data has already been analysed along with other peoples', we may not be able to remove it from our results and basic



information about you (your age, gender and ethnicity) will be kept for reporting purposes. De-identified health information relating to you (which will not allow you to be personally identified) will also be retained.

All information you provide will be held securely on password-protected, University servers, and only members of the research team who need to see the information will have access to it. Your information will be destroyed in 2032 (10 years after the completion of the data collection). If you share your contact details, for one or more reasons (e.g., entry into the prize draw/ maybe taking part in future research/ agreeing to data linkage) we will store these details (name, address, date of birth etc.) in a separate place to the rest of the survey information.

What will this study produce? He aha te putanga?

The findings from this study will be reported to the Ministry of Health in 2022 and may also be used in academic publications, conferences and community presentations. The report to the Ministry of Health will include recommendations on how to improve services supporting people in Aotearoa New Zealand who contract COVID-19. If you wish, you can receive an emailed summary of the study's findings.

If you accept this invitation, what are your rights as a research participant? He aha ō mōtika?

It's up to you if you take part in this study or not. You will not be paid to participate and it will not cost you anything other than your time and your willingness to share your experiences of the impact of COVID-19 on you and your whānau/ family and community with us.

If you do decide to participate, you have the right to:

- ✓ ask any questions about the study at any time;
- ✓ change your mind about participating and withdraw from the study; and
- ✓ receive an emailed copy of a summary of the study findings.

You can choose whether or not you agree to this data linkage. If you do not agree, we will not ask the Ministry of Health for any of this personal information/ data in which you can be identified.

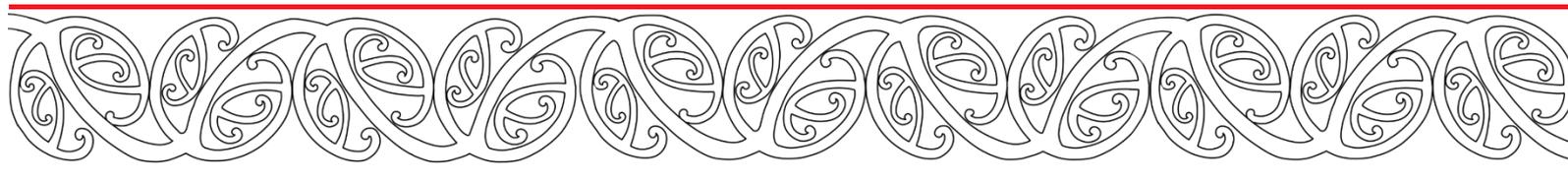
If you have any questions or problems, who can you contact? Me whakapā ki a wai?

For many people, having COVID-19 has been a difficult time. Remembering what you and your family/ whānau and community went through, as you answer the surveys, might be hard.

If you are Māori and require cultural support outside of your whānau, you can speak with a member of the Rōpū Māori by calling 0800 800 581. If you are a Pacific person and require cultural support outside of your family, you can speak with a member of the Pacific team by also calling 0800 800 581.

For further support, please contact your or family/ whānau doctor or another GP, or free call or text 1737 to talk to a trained counsellor. More information on places to get support is available at <https://depression.org.nz/covid-19/>

If you have any other questions please feel free to contact any of the lead investigators on 0800 800 581 or email covid.aotearoa@vuw.ac.nz There is more information about the study, including how to do the surveys, on our website: covid.aotearoa.com.



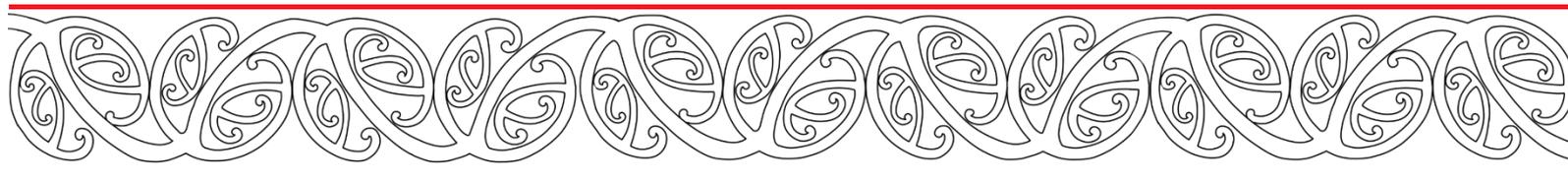
This study was approved by the Health and Disability Ethics Committee on 25/01/2022 for three years (Ref. number: 2021 EXP 11900). If you have any concerns about the ethical conduct of the study, you can contact the Chair of this Committee by emailing hdec@health.govt.nz.

To talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on 0800 555 050 or by emailing advocacy@advocacy.org.nz. Or you can check out this website: <https://www.advocacy.org.nz/>.

Thank you for generously sharing your time, experiences and knowledge with the study team.

Dr Lynne Russell and Dr Mona Jeffreys

Principal Investigators for the *Impacts of COVID-19 in Aotearoa | Ngā Kawekawe o Mate Korona* study



CONSENT FORM FOR SURVEY PARTICIPANTS WHO ARE TAKEN THROUGH THE SURVEY OVER THE PHONE OR IN PERSON (TO BE EMAILED)

This Consent Form will be held for 10 years.

By signing this form, I confirm that:

- ✓ I have read the Information Sheet or the study has been explained to me.
- ✓ It is my choice to take part.
- ✓ My questions have been answered to my satisfaction.
- ✓ I know how to contact the research team if I have any further questions.

I understand that:

- ✓ I can ask further questions at any time.
- ✓ The study findings will be used in a written report to the Ministry of Health and may also be used in associated academic publications, conferences and community presentations.
- ✓ My identity will remain confidential to the researchers.
- ✓ My name will not be used in any reports of findings and utmost care will be taken not to disclose anything that could identify me.
- ✓ I may withdraw from this study, without giving a reason. Any information that I have provided in any of the surveys will be destroyed, unless it has already been analysed alongside other people's. Basic information about me (my age, gender and ethnicity) and my de-identified health information will be kept for reporting purposes.
- ✓ All identifiable information I have provided will be destroyed in 2032.

I agree to:

- ✓ Take part in this study by doing at least one survey.

Name: _____

Signature: _____ Date: _____

DO YOU:

Give your permission for your survey data to be linked with your Ministry of Health data? YES NO

Want to receive an emailed summary of the findings of the study? YES NO

If 'yes', please provide your email address below.

My email: _____

