

Experiences of disabled people with COVID-19 key to study

Telling the stories of whānau hauā (disabled people) who've had COVID-19 is critical to improving support for those who get the virus, says a leading disability rights advocate.

Dr Huhana Hickey MNZM (Ngāti Tāhinga, Whakatōhea, Tainui) is a whānau hauā champion and a senior Māori researcher for the “Impacts of COVID-19 in Aotearoa—Ngā Kawekawe o Mate Korona” study.

“New Zealand’s COVID-19 pandemic response has been developed mostly by able-bodied people,” says Dr Hickey. “We need our disabled peoples’ perspectives to be heard so we can advise policymakers on what’s needed to keep us safe during COVID.”

Dr Hickey, who has multiple sclerosis and requires a wheelchair for mobility, says some people with disabilities are at higher risk of contracting COVID-19 and of worse outcomes, due to underlying health conditions, socioeconomic inequalities and health system barriers.

Other leaders in disability research are also part of the study team, including senior Māori researcher Dr Kirsten Smiler, who is fluent in sign language.

Associate Professor Tristram Ingham, an epidemiologist who is wheelchair bound with muscular dystrophy, and Bernadette Jones, also lend their academic expertise to the study. The couple are senior kaupapa Māori researchers who specialise in disability and chronic health conditions for Māori. Dr Ingham also chairs the Ministry of Health’s advisory group on Māori disability, Te Ao Mārama.

“We’re really keen to hear from our disabled community about their experiences getting COVID-19 so we can be informed about making better experiences in the future,” says Dr Hickey.

Dr Hickey’s physical condition means she needs daily homecare support. She’s been fortunate to receive individualised health funding, which enables her to employ her own care and support team, including through lockdowns. However, many people with disabilities who choose to be cared for by an agency had difficulty obtaining care during these times, she says.

“Either the agencies didn’t have staff available or they weren’t vaccinated. You’re talking about a very vulnerable group and you’d think agencies would understand that. As disabled people we know about the risk of infections because we live with it all the time.

“As well as that, there’s still a lot of difficulty in getting out to get food and yet some people are still being declined food boxes. Often the community will look after their people once they know about them, but some disabled people can’t eat the food given by food banks because they are allergic to it. One kuia only had pasta and rice for four weeks because she was too scared to ask for help.”

About the study

The “Impacts of COVID-19 in Aotearoa—Ngā Kawekawe o Mate Korona” study aims to understand the experiences of people who have had COVID-19. Researchers want to know about the impact COVID-19 has had on the health and well-being of these individuals and their whānau.

If you're aged 16 and over, and had COVID-19 before 1 December 2021, you're invited to take part in the study by completing the surveys at <https://covid.aotearoa.com>. Alternatively, you can call **0800 800 581** or email covid.aotearoa@vuw.ac.nz.

The study is led by Dr Lynne Russell (Ngāti Kahungunu, Rangitāne, Kāi Tahu, Ngāti Porou) and Dr Mona Jeffreys at Te Hikuwai Rangahau Hauora—Health Services Research Centre at Te Herenga Waka—Victoria University of Wellington.

They head-up a multi-disciplinary team of researchers, primarily from Te Hikuwai Rangahau Hauora—Health Services Research Centre. Dr Marianna Churchward (Lotofaga, Faleasiu, Samoa) leads the Pacific arm of the research.

For more information, contact [Dr Lynne Russell](mailto:lynne.russell@vuw.ac.nz) on lynne.russell@vuw.ac.nz or 022 359 8212, or [Dr Mona Jeffreys](mailto:mona.jeffreys@vuw.ac.nz) on mona.jeffreys@vuw.ac.nz or 027 418 7455.

Additional information about the study's disability researchers

Dr Huhana Hickey: Dr Hickey has a PhD in Law from the University of Waikato. She was a solicitor at Auckland Disability Law and a Māori research fellow at the Taupua Waiora Centre for Māori Health Research at the Auckland University of Technology. Dr Hickey was the indigenous peoples' representative for the International Disability Association steering group caucus during the development of the UN Convention on the Rights of Persons with Disabilities. She is also a former member of the Welfare Expert Advisory Group and has been a Human Rights Review Tribunal member for more than 10 years. In 2015, Dr Hickey was awarded the New Zealand Order of Merit for her services to Māori and the disability community.

Dr Kirsten Smiler: [Dr Smiler](#) is a Māori research fellow at Te Herenga Waka—Victoria University of Wellington's Te Hikuwai Rangahau Hauora—Health Services Research Centre. She is a Kaupapa Māori researcher who has contributed to a broad range of the centre's research projects. Most recently, she worked on a Health Research Council-funded evaluation of the development and impact of changes in community pharmacy services, and a programme evaluation of the South-Auckland-based Mana-ā-Riki initiative commissioned by the Middlemore Foundation for Health Innovation. She also lectures on Hauora Māori (Māori health and wellbeing) for the Faculty of Health.

Dr Tristram Ingham (Ngāti Kahungunu, Ngāti Porou): [Dr Ingham](#) is a senior research fellow in the University of Otago's Division of Health Sciences—Te Wāhanga Matua Mātau Hauora at the Department of Medicine in Wellington. He is currently involved with a number of epidemiological and clinical studies. His major research interests are asthma (particularly among Maori), bronchiolitis, the role of vitamin D in respiratory health, and sleep disordered breathing. Dr Ingham is a member of the Ministry of Health's COVID-19 disability sector steering group. He also chairs the ministry's advisory group on Māori disability, Te Ao Mārama. He holds a current annual practising certificate in medicine.

Bernadette Jones (Ngā Wairiki, Ngāti Apa): [Bernadette Jones](#) is a senior research fellow in the University of Otago's Division of Health Sciences—Te Wāhanga Matua Mātau Hauora at the Department of Medicine in Wellington. She holds a current annual practising certificate in nursing.