



BMJ Open Cohort profile: Ngā Kawekawe o Mate Korona | Impacts of COVID-19 in Aotearoa – a prospective, national cohort study of people with COVID-19 in New Zealand

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ABSTRACT

Purpose The COVID-19 pandemic has had significant health, social and economic impacts around the world. We established a national, population-based longitudinal cohort to investigate the immediate and longer-term physical, psychological and economic impacts of COVID-19 on affected people in Aotearoa New Zealand (Aotearoa), with the resulting evidence to assist in designing appropriate health and well-being services for people with COVID-19.

Participants All people residing in Aotearoa aged 16 years or over, who had a confirmed or probable diagnosis of COVID-19 prior to December 2021, were invited to participate. Those living in dementia units were excluded. Participation involved taking part in one or more of four online surveys and/or in-depth interviews. The first wave of data collection took place from February to June 2022.

Findings to date By 30 November 2021, of 8735 people in Aotearoa aged 16+ who had COVID-19, 8712 were eligible for the study and 8012 had valid addresses so were able to be contacted to take part. A total of 990 people, including 161 Tāngata Whenua (Māori, Indigenous peoples of Aotearoa) completed one or more surveys; in addition, 62 took part in in-depth interviews. Two hundred and seventeen people (20%) reported symptoms consistent with long COVID. Key areas of adverse impacts were experiences of stigma, mental distress, poor experiences of health services and barriers to healthcare, each being significantly more pronounced among disabled people and/or those with long COVID.

Future plans Further data collection is planned to follow-up cohort participants. This cohort will be supplemented by the inclusion of a cohort of people with long COVID following Omicron infection. Future follow-ups will assess longitudinal changes to health and well-being impacts, including mental health, social, workplace/education and economic impacts of COVID-19.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study is underpinned by a Tiriti o Waitangi Framework that ensures that the results are meaningful for Te Tangata Whenua, the first peoples of Aotearoa.
- ⇒ The use of validated questionnaires in the surveys provides results that are comparable to other national and international surveys of COVID-19 and long COVID.
- ⇒ Data on a wide range of impacts were collected, including mental health, health services and economic outcomes to get a broad view of the impact of COVID-19 and long COVID.
- ⇒ The low response rate provides an estimate of the incidence of long COVID which is imprecise; the results across all areas may also be biased, given the lack of representativeness of the cohort compared with the eligible population.

INTRODUCTION

The COVID-19 pandemic has had an unprecedented impact on the health and well-being of populations globally, differentially affecting people with poorer pre-existing health, financial and social capital. What is alarmingly clear regarding COVID-19 and what is also consistent with previous pandemics as recently as the 2009 H1N1 influenza pandemic,¹ as well as in the more distant past with the 1918 'influenza pandemic,² is that, while infectious diseases do not make inequities on their own, they hugely amplify already entrenched inequities within societies. There is evidence of pandemics' differential impact on Indigenous populations worldwide as well as in Aotearoa.^{3 4} Drawing on people's lived experiences, this study looks to understand the

impacts from COVID-19 among populations in Aotearoa already disproportionately affected by an inequitable health system.

COVID-19 was first identified in Aotearoa in February 2020. As case numbers increased internationally, Aotearoa went 'hard' and 'early' in its response.⁵ The borders were closed to non-New Zealanders and returning New Zealanders were required to enter Managed Isolation and Quarantine facilities (MIQ): those who tested negative underwent 2 weeks of isolation, while those with COVID-19 went into quarantine. Nationwide lockdowns were introduced under an alert level framework.⁶ The whole country faced lockdown restrictions from late March 2020 to early June 2020, and the main city of Tāmaki Makau Rau (Auckland) faced further lockdowns between mid-August and early October 2020.

Between early October 2020 and mid-August 2021, most infections were among those entering Aotearoa, with short, sharp regional lockdowns at various points in time. By 17 August 2021, there had been 2750 confirmed cases and 26 deaths, with around 7%–8% of cases among Tāngata Whenua (Māori, Indigenous peoples of Aotearoa) and Pasifika peoples.⁷ The Delta variant was identified in Aotearoa in mid-August 2021. The whole country moved to an alert level 4 lockdown between 17 August 2021 and 31 August 2021. Tāmaki Makau Rau remained at alert level 4 until 21 September 2021, moving to alert level 3 on December 2021. By December 2021, there was an official total of 10 220 cases: 46% of these among Tāngata Whenua and 29% among Pasifika peoples.⁷ For comparison, in the 2018 census, Māori accounted for 16.5%, and Pasifika peoples 8.1% of the population.

In early December 2021, Aotearoa moved to the COVID-19 protection framework, which comprised red, orange and green settings,⁸ the first of these being the most restrictive. The Omicron variant arrived in January 2022, with the Omicron red phase response remaining in place until March. Aotearoa moved to the Orange setting on 13 April 2022, and on 12 September 2022, the COVID-19 protection framework was retired. A comprehensive timeline of alert level changes, dates of key events and States of National Emergency can be found on the government's official COVID-19 website, 'Unite Against COVID-19'.^{6,8}

In April 2021, Manatū Hauora | New Zealand Ministry of Health (MOH) issued a request for proposals to establish a cohort of all people living in Aotearoa who had a confirmed or probable case of COVID-19. The purpose was threefold, namely to: (1) understand the health and well-being needs of people with COVID-19; (2) understand the equity issues faced by people with COVID-19 and (3) assist in designing appropriate health and well-being services for people with COVID-19.

The 'Ngā Kawekawe o Mate Korona | Impacts of COVID-19 in Aotearoa' study began recruitment of a study cohort in August 2021 and undertook the first wave of data collection and analysis through to September 2022. During this 12-month period, Aotearoa had most of

its cases: by 2 September 2022, over 1.7m New Zealanders had been recorded as having COVID-19, and there had been 1861 deaths coded as COVID-19 being the underlying cause.⁹

The first wave of the study aimed to improve understanding of the short-term and long-term physical, psychological, and economic impacts of COVID-19 on affected people in Aotearoa. The key objective was to examine the experiences of, and impacts on, individuals and their whānau | families in Aotearoa who had COVID-19 prior to December 2021. The resulting evidence will be used to identify gaps in the health and welfare systems which could be improved for the benefit of people with COVID-19. We will build on this evidence in future waves, to focus on areas of concern (eg, mental health, long COVID), as well as being able to address emerging policy questions as the pandemic, and its aftermath, progresses.

COHORT DESCRIPTION

Eligibility criteria

The cohort was established across Aotearoa. All people who had a positive COVID-19 test before 1 December 2021 or were considered a probable COVID-19 case (through having symptoms and having been in contact with a positive case), who were over 16 years of age at the time of having COVID-19, and were not living in a dementia unit, were eligible for inclusion.

The Institute of Environmental Science and Research Limited (ESR) hold a list of people with a positive COVID-19 test in their EpiSurv database. These are shared with the MOH. Contact details for all eligible participants were identified from the National Contact Tracing System (NCTS) data, the National PHO enrolment registry and the National Health Index. To maintain privacy, the MOH data team identified ineligible people and removed them from the contact list. On 8 February 2022, a letter of invitation to take part was sent from the research team, via the MOH to maintain privacy of personal details. Letters were written in English, Te Reo Māori, Samoan and Tongan. A covering letter from the then-director general of health and CEO of the MOH, Dr Ashley Bloomfield, who was a well-known figure with strong public credibility, was included, to encourage participation.

One week later, the MOH team sent a text (short message service, SMS) to all people for whom a cell (mobile) phone number was available. The MOH (via the NCTS) had recent cellphone numbers for many participants, as this was the method that public health units used for keeping in touch with people while they were in isolation. About 6 weeks after the letter of invitation was sent, a second reminder text was sent (16 May 2022).

In addition to the direct requests to participants, we used various media and social media platforms, including Māori media, and media that is aimed at Pasifika peoples. Community engagement was a key part of the work and building and developing relationships will be an ongoing process throughout the study. Senior members of the team

have close working relationships with various communities, developed during previous and ongoing projects, and other personal and professional networks. We built on these relationships to benefit our study, engaging with community leaders and with a national Facebook support group for people with long COVID.

People who were interested in taking part were directed to the study website, <http://coviadaotearoa.com>, where they could access up to four online surveys. Participants could also contact the research team directly by phone or email to request further information or discuss participation. From the completed surveys, as well as from people who contacted the study team but did not want to complete a survey, interviewees were identified for the qualitative component of the study. These were available in English, te reo Māori, Samoan, Tongan and New Zealand Sign Language.

Informed consent

The participant information sheet and consent form was presented at the beginning of the online surveys. For people who completed surveys over the phone, the study information was explained verbally, and oral consent obtained. For the interviews, consent was obtained at the beginning of the interview, including the cohort member, and any other whānau | family members who contributed to the interview. Interviewees were given the option of being identified alongside any of their quotes in any dissemination of findings, in support of their continued ownership of their experiences and story. Those who did not want to be identified were given pseudonyms. For interviews where people aged under 16 were present, assent to participate was obtained from the young person, and countersigned by an adult caregiver. No whānau | family was chosen to take part because of children having had COVID-19, and no children were directly invited to take part.

Completed data collection

The study was designed as a mixed-methods study, with quantitative (survey) and qualitative (interview) components. Most but not all people who had an in-depth interview had completed one or all surveys. Quantitative data were collected between February and June 2022; qualitative information was gathered between April and July 2022.

Quantitative surveys were presented via the online survey platform Qualtrics. If participants preferred, they could complete these over the phone with one of the research team members. Respondents were first presented with the participant information sheet and consent form, followed by demographic questions. After this, there were four surveys, which could be completed in any order. These covered the following areas: (1) support and well-being, (2) health and health services, (3) economic and financial impacts and (4) long COVID. Key domains covered are shown in [table 1](#). Each survey took 15–20 min to complete, although some people took

up to 1 hour per survey. These could be returned to at a later date, so participants did not need to complete them in one sitting. None of the questions were compulsory, and all had a ‘I do not know/I prefer not to answer’ option.

Purposive sampling from survey participants was used to identify groups in which we were particularly interested in for in-depth interviews: Māori, Pacific people, disabled people, people who were infected through their workplace and whānau | families where multiple members of their household/whare contracted COVID-19. In alignment with Indigenous and cultural data sovereignty principles, those who identified as Māori were interviewed and their data analysed by kairangahau Māori (Māori researchers). Those who identified as Pasifika were interviewed by Pasifika researchers and their data analysed by Pasifika researchers. Where people identified as more than one of those two ethnicities for the qualitative interviews, interviewees were given the choice of whether to be interviewed by kairangahau Māori or Pasifika researchers.

A total of 58 interviews were conducted with 62 participants, either in the person’s home or virtually (by Zoom or phone). Interviews lasted for 45–90 min and were recorded and transcribed verbatim. The interview schedules covered peoples’ experience of COVID-19, the impact that it has had on participants and their whānau | families and allowed participants to discuss their ideas about what services could be changed that would have made things easier.

Future data collection

We plan future data collection, using many of the same measures for survey participants, to establish ongoing impacts of COVID-19 in the cohort. Given the change in the government’s response to COVID-19, from an ‘elimination strategy’ to a ‘minimisation and protection framework’,¹⁰ the focus on the questions will also change, to be able to inform the Government’s and the health system’s response to the ongoing pandemic.

Further data collection is planned for 2023 including the follow-up of participants in the cohort who had ongoing symptoms of COVID-19 alongside a cohort of people with long COVID following Omicron infection, with the aim of establishing the prevalence, duration and determinants of mental distress among people with long COVID and identifying how to best align mental health services to address these.

Tiriti o Waitangi Framework

In 1840, Te Tiriti o Waitangi (the Treaty of Waitangi) affirmed the sovereignty of hapū and provided for the British to exercise governance over their own people. Built on trust and good faith, it provided the foundation for an ongoing relationship of mutual benefit and power-sharing between Te Tangata Whenua and all who were to come. Those same building blocks reinforced this study, recognising the special place of Te Tangata Whenua in

Table 1 Key question domains and sources

Demographics	Age, gender, ethnicity, income, education, household size, country of birth, household language, disability (Washington Group Short Set ¹³) Overcrowding, calculated as persons per bedroom ¹⁴
Pre-COVID-19 health	Self-reported long terms conditions (New Zealand Health Survey (NZHS) ¹⁵)
Current health	Mental health (PHQ-2, ¹⁶ GAD-2 ¹⁷), health-related quality of life (EQ-5D-5L ¹⁸)
Initial COVID-19 symptoms	Probable versus confirmed diagnosis, barriers to getting tested; check-list of 31 symptoms; others in household with symptoms
COVID-19 treatment	Hospital admission or not; duration of admission; admission to ICD/HDU; receipt of oxygen
Support during COVID-19 infection	Social, mental health, employment support received or needed Source of support
Worries relating to COVID-19	List of 15 concerns ¹⁹ Change in life satisfaction ¹⁹
Isolation	Time spent in MIQ or isolating at home
Persisting symptoms/ long COVID	UK NHS 'long COVID' symptom list ²⁰ and duration; impact of activity on symptoms; adequacy of health and social care received; challenges with healthcare; other challenges
Health service usage	Primary healthcare and hospital use (number of visits, nights spend in hospital); costs of accessing care; barriers to accessing healthcare (NZHS ¹⁵)
Patient experience	Primary care patient experience survey questions ²¹
Employment	Employment status, hours worked Unpaid work Change in circumstances Job loss due to COVID-19 or the pandemic
Income	Household income; Change in household income due to COVID-19; Household financial struggles ¹⁹
Discrimination and stigma	Measures of stigma associated with COVID-19, adapted from Stigma Scale for Chronic Illnesses ²² Discrimination due to COVID-19 infection adapted from NZHS ¹⁵
Costs of treating COVID-19 and associated longer-term conditions	Medical costs for families and health system, for example, costs of hospitalisations, consultations, tests, X-rays, medicines Non-medical costs, for example, costs of transport, accommodation, carers Indirect costs: loss of income, sick leave days, wages lost due to COVID-19 and associated conditions for both patient and caregiver
COVID-19 Vaccination	Vaccine status; date(s) of vaccination(s)

EQ-5D-5L, EuroQol-5 dimension-5 level; GAD-2, Generalised Anxiety Disorder; HDU, high dependency unit; ICD, intensive care department; MIQ, Managed Isolation and Quarantine; NHS, National Health Service; PHQ-2, Patient Health Questionnaire.

Aotearoa and the rights and responsibilities associated with this indigeneity.

The study was underpinned by a Tiriti o Waitangi Framework which recognises the relationship between Te Tangata Whenua (the first peoples of Aotearoa) and Tāngata Tiriti (all others who have come to Aotearoa to live), as fundamental to positive research outcomes. We have reflected our commitment to Te Tiriti o Waitangi, and Māori health and well-being, through our team composition, our study design and our proposed reporting schedule; the study is led in a Tiriti-based partnership by one Māori and one non-Māori. The Māori lead is responsible for the recruitment of Māori staff, the collection, analysis and interpretation of Māori data, as well as overall coleadership of the study. The tikanga (customary procedures) associated with this framework was to aim for:

- ▶ Equal membership of Tāngata Whenua and Tāngata Tiriti.

- ▶ Shared leadership of Tāngata Whenua and Tāngata Tiriti.
- ▶ Acknowledgement of the place of Tāngata Whenua perspectives in decision-making through key values and beliefs from Te Ao Māori.
- ▶ A co-operative and shared relationship when working on all issues of interest and concern to the study and on all matters that related to the study's support.
- ▶ Strategies, tikanga, policies, procedures, kawa and practices that reflected a two-world view, woven into the relationship.
- ▶ Collective decision-making that operated on consensus rather than a voting system, to encourage the articulation of diverse views rather than a single or dominant viewpoint.

Rōpū Kaitiaki | Advisory Board

The purpose and general role of Te Rōpū Kaitiaki | the Advisory Board is to provide practical guidance and

advice throughout the duration of the study for example, helping to promote the research to relevant communities for participant recruitment, contributing to discussions around the research approaches, and reading and commenting on preliminary findings and final reports.

In keeping with the Te Tiriti o Waitangi Framework, Te Rōpū Kaitiaki | the Advisory Board has two co-chairs, one Te Tangata Whenua and one Te Tangata Tiriti, and is supported by a Pou Tikanga (Māori elder) who guides us in protocol.

Data sovereignty

Te Tangata Whenua rights and interests in data derive from inherent rights as Indigenous peoples, and unique relationships with land, water and the natural world. These rights are recognised in Te Tiriti o Waitangi and the United Nations Declaration on the Rights of Indigenous Peoples.¹¹ In accordance with the Tiriti o Waitangi Framework which underpins this study, the 'inherent rights and interests that Māori have in relation to the collection, ownership and application of Māori data' are acknowledged and privileged.¹¹

Strengths and limitations of this study

There are a number of key strengths of the cohort. First, the research was designed and carried out with an underpinning of a Tiriti o Waitangi Framework. This approach recognises the relationship between Te Tangata Whenua (the first peoples of Aotearoa) and Tāngata Tiriti (all others who have come to Aotearoa to live), as fundamental to positive research outcomes. It results in a true commitment to Māori Data Sovereignty, as all the data pertaining to Māori were collected, analysed and interpreted by the Māori research team.

Second, the use of validated questionnaires in the surveys provides results that are comparable to other national and international surveys of COVID-19 and long COVID, the latter as defined by the WHO.¹² Comparable with national data is particularly important, to allow a delineation of the impacts of having SARS-CoV-2 infection itself as opposed to that of the pandemic. Comparison with international data means that analyses from Aotearoa can contribute to the international understanding of the impacts of COVID-19, acknowledging that the context of the pandemic in Aotearoa was quite different to that in many other countries worldwide.

The study is also strengthened by the breadth of the impacts that were collected. These included mental health, health services, social services and well-being, barriers to care and economic outcomes to get a broad view of the impact of COVID-19 and long COVID. It does mean that the depth of some of the quantitative measures is limited. However, the complementary qualitative interviews allowed some of these areas to be explored in more detail, and some of these areas will be addressed and further explored in follow-up surveys.

The main limitation of the cohort is the low response rate. Although this is not necessarily going to result in

selection bias, it may mean that the results across all areas may be biased, given the lack of representativeness of the cohort compared with the eligible population. Given the promotion of the study to people with long COVID, we are likely to have an overestimate of people with long COVID represented in the cohort; an accurate estimate of the incidence of long COVID is therefore unclear.

A further limitation at the time of writing is the lack of validation of the self-reported measures. Ethical approval and consent for linkage to administrative databases to confirm COVID-19 strain, general practitioner (GP) enrolment, hospitalisation, vaccination and medications has been obtained. Performing these linkages is dependent on receipt of further funding.

Patient and public involvement

Four people with lived experience of COVID-19 (two with long COVID) were involved in the development of research data collection tools, through membership of the Rōpū Kaitiaki | Advisory Board. Study results were disseminated to participants via email/post at the end of the first year of the study. In addition, results contribute to lay webinars regarding COVID-19 and long COVID to which the research team contribute.

Collaboration

Initial data analyses and publications will be generated by study investigators. The research team is open to potential research collaborations (see the 'Data availability statement'). Given the Tiriti o Waitangi Framework which underpins this study, the inherent rights and interests that Māori have in relation to the collection, ownership and application of Māori data are acknowledged and privileged. Any potential collaborations will need to adhere to these principles.

Survey participants

ESR identified 8735 people who had a positive COVID-19 test prior to 1 December 2021. As shown in [figure 1](#), approximately 8012 letters were delivered. This is an estimate, as the MOH did not have the time or resources to identify exactly how many letters were returned to them as the sender, or the ethnicity of the people whose letters were not delivered. For this reason, response rates by ethnicity are not able to be calculated. Of the letters delivered, supplemented by two reminder SMS messages and a media and social media campaign, 1227 people began a survey, and 990 people completed at least one of the four available surveys. The data reported here pertains to the 990 people who completed one or more of the four surveys by 30 June 2022. As no questions were compulsory, not all analyses contain results relating to the full 990 people.

At least one survey was answered by 161 Tāngata Whenua, 64 Pasifika peoples and 779 non-Pacific Tāngata Tiriti. The sociodemographic breakdown of the cohort is provided in [table 2](#). Twenty-two per cent of Tāngata Whenua, 17% Pasifika and 14% non-Pacific Tāngata

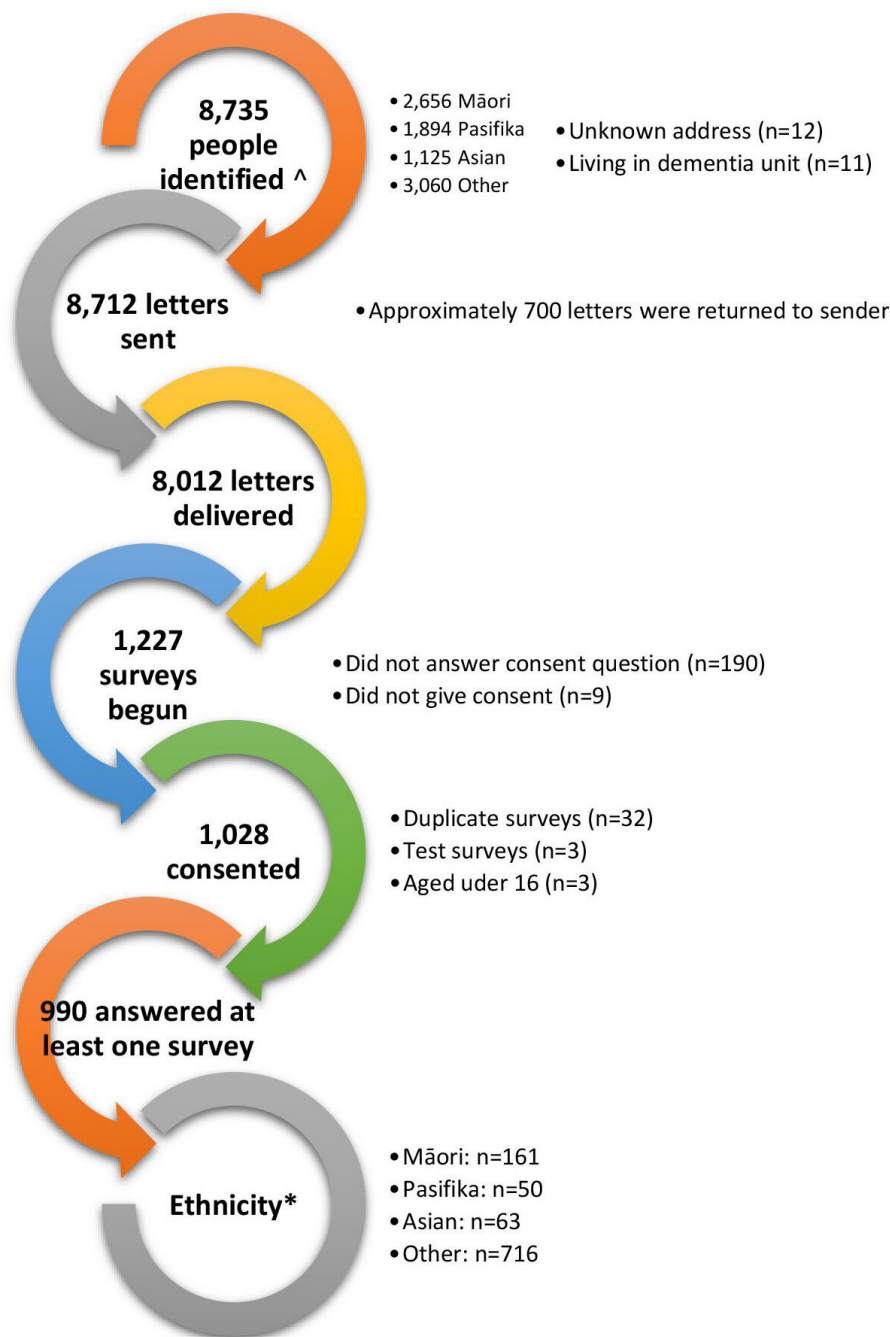


Figure 1 Study participants. [^]Prioritised ethnicity (13), based on Ministry of Health data, not necessarily self-identified.

*Prioritised ethnicity, based on self-identification. Analyses of Pasifika peoples use total ethnicity (13), and therefore, include more than 50 people.

Tiriti reported having a disability: defined as any self-perceived limitation in activity resulting from a long-term condition or health problem lasting longer or expected to last longer than 6 months or more and not completely eliminated by an assistive device.¹³ Forty-three per cent of Tāngata Whenua, 47% Pasifika and 23% non-Pacific Tāngata Tiriti lived in households of 5–8 people and 8%, 25% and 1%, respectively, lived in households of nine or more people. Approximately one-fifth of Tāngata Whenua and non-Pacific Tāngata Tiriti, and two-fifths of Pasifika lived in overcrowded conditions.

The majority of our cohort had COVID-19 in 2021, although non-Pacific Tāngata Tiriti were more likely than Tāngata Whenua or Pasifika peoples to have had COVID-19 in 2020. Most had a positive COVID-19 test, although many did not report whether they did or not. A small proportion of Tāngata Whenua, Pasifika and non-Pacific Tāngata Tiriti survey participants thought it likely that they caught COVID-19 at work. About one third had others with COVID-19 in the household at the same time as they did; this was more common for Tāngata Whenua than Tāngata Tiriti. About 10% of Tāngata Whenua, one

Table 2 Demographic details of survey cohort

	Self-identified ethnicity					
	Tangata Whenua (n=161)		Pasifika peoples (n=64)		Non-Pacific Tāngata Tiriti (n=779)	
	n	%	n	%	n	%
Gender						
Females	128	80	49	77	472	61
Males	31	19	13	20	241	31
Other/not stated	2	1	2	3	66	8
P value	<0.001		0.034			
Age						
16–24	20	12	11	17	73	9
25–44	83	52	36	56	255	33
45–64	39	24	10	16	254	33
65+	*		*		90	12
Not stated	*		*		107	14
P value	<0.001		<0.001			
Region						
Upper North Island	87	54	51	80	293	38
Central North Island	39	24	*		115	15
Lower North Island	15	9	*		112	14
South Island	15	9	*		147	19
Not stated/not in Aotearoa	5	3	1	<2	112	14
P value	<0.001		<0.001			
Education						
School	63	39	20	31	128	16
Postschool	37	23	15	23	161	21
University	48	30	23	36	388	50
Not stated	13	8	6	9	102	13
P value	<0.001		<0.001			
Employment*						
Homemaker	22	14	*		43	6
Full-time	89	55	31	48	396	51
Part-time	12	7	*		102	13
Casual	*		*		47	6
Unemployed	17	11	*		18	2
Student	17	11	11	17	50	6
Retired	*		*		59	8
Prefer not to say	1	<1	4	6	12	2
Rurality						
Main centre	98	61	49	77	418	54
Large town	13	8	*		79	10
Smaller town	24	15	*		84	11
Rural	19	12	*		68	8
Not reported	7	4	5	8	130	17
P value	0.001		0.14			
Disability						
Yes	35	22	11	17	107	14

Continued

Table 2 Continued

	Self-identified ethnicity					
	Tangata Whenua (n=161)		Pasifika peoples (n=64)		Non-Pacific Tāngata Tiriti (n=779)	
	n	%	n	%	n	%
No	114	71	50	78	541	69
Not reported	12	7	3	5	131	17
P value	0.001		0.037			
People in household						
Lives alone	15	9	*		168	22
2–4 people	64	40	13	20	436	56
5–8 people	69	43	30	47	168	22
9+ people	13	8	16	25	7	1
P value	<0.001		<0.001			
Overcrowding ¹⁸						
>2 people per bedroom	31	19	25	39	142	18
≤2 people per bedroom	130	81	39	61	637	82
P value	0.76		<0.001			

Ethnicity is total response, therefore, people who identified as Māori and as Pasifika are included in both the Tangata Whenua and Pasifika Peoples columns; these columns should not be compared statistically. P values compare the relevant column to non-Pacific Tāngata Tiriti. *Cells with fewer than 10 people, other than where the category is 'not stated' have been suppressed. Since people could report more than one type of employment, % do not add up to 100%.

quarter of Pasifika peoples and one-fifth of non-Pacific Tāngata Tiriti had COVID-19 at a time when the country, or the region in which they live, was in lockdown.

A comparison is provided for our survey cohort against the eligible population with notified COVID-19 in table 3. Our cohort was more likely to be female (64% vs 50%), older (34% vs 23% aged 50 years or over) and less likely to be Tāngata Whenua (16% vs 30%), Pasifika peoples (5% vs 22%) or live in Auckland or Northland (43% vs 67%) than the eligible population. The cohort is, therefore, not representative of all eligible people who had COVID-19 in Aotearoa prior to December 2021. The external validity of results should be considered in the light of this potential selection bias.

Interview participants

A total of 58 interviews were conducted with 62 people who contracted COVID-19 in Aotearoa. Six of the interviews were not included in the analysis from which findings are reported here because they did not meet the criteria for inclusion (eg, they were with people who contracted COVID-19 after 1 December 2021). Although the intent was for equal Tāngata Whenua and Tāngata Tiriti participation, only 35% of the 52 study interviewees (n=18) were Tāngata Whenua. The remaining 65% included both Pasifika (n=12) and non-Pacific (n=22) Tāngata Tiriti interviewees. The average reported age of interviewees when they contracted COVID-19 was 48 years.

Thirty-five interviewees indicated symptoms of Long COVID, and 17 reported a disability. Eight of those who reported disability also reported having the disability

prior to contracting COVID-19. This means just under half of the interviewees who now identify as disabled do so because of ongoing symptoms of COVID-19.

Interviewees contracted COVID-19 across the entire study period; four indicated they were hospitalised with COVID-19, 13 contracted COVID-19 through their workplace and 11 spent time in MIQ facilities.

FINDINGS TO DATE

Data were collected on impacts across a range of domains including physical and mental health, social, family, spiritual, cultural and financial well-being, as well people's experiences of health and social services, and the government's national pandemic response. Results reveal greater impacts from COVID-19, more unmet need and greater need for support, for those populations in Aotearoa who are already disproportionately affected by an inequitable health system, specifically Māori as Tangata Whenua, Pasifika peoples and people with lived experience of disability.

Given the breadth of intent of the cohort, we report here on key findings in relation to three areas: (1) Experiences of Health and Social Services; (2) Mental health impacts of COVID-19; and (3) long COVID. The full report has been submitted to the MOH and will be available on our website in early 2023 (<http://covid.aotearoa.com>).

Experiences of health and social services

The cohort was high users of primary healthcare. One in nine saw a GP four or more times for COVID-19-related

Table 3 Comparison of the survey cohort with the eligible population

	Eligible (8753)	Respondents (n=990)
Gender		
Female	4331 (50%)	637 (64%)
Male	4386 (50%)	285 (29%)
Other/missing	18 (<0.1%)	68 (7%)
Age		
16–19	719 (8%)	21 (2%)
20–29	2530 (29%)	163 (16%)
30–39	2101 (24%)	192 (19%)
40–49	1387 (16%)	149 (15%)
50–59	1152 (13%)	178 (18%)
60–69	570 (7%)	106 (11%)
70+	275 (3%)	53 (5%)
Not stated/missing	1 (<1%)	128 (13%)
Prioritised ethnicity²³		
Māori	2656 (30%)	161 (16%)
Pacific	1894 (22%)	50 (5%)
Asian	1125 (13%)	63 (6%)
Other	3060 (35%)	716 (72%)
Region		
Auckland/Northland	5832 (67%)	421 (43%)
Central North Island	725 (8%)	155 (16%)
Lower North Island	341 (4%)	132 (13%)
South Island	512 (6%)	164 (17%)
Missing/overseas	1325 (15%)	118 (12%)
Year of COVID-19 infection		
2019/2020	1943 (22%)	340 (34%)
2021	6792 (78%)	650 (66%)

reasons, with disabled people more likely to have multiple GP visits. And yet many could not get an appointment to see a GP. There were barriers to getting tested, and distressing delays in getting COVID-19 test results. Overall, 1 in 8 Tāngata Whenua and 1 in 15 Tāngata Tiriti could not afford a prescription. There was a range of experiences with hospital care, with some feeling frightened, isolated and alone. Others raised concerns over how staff interacted with them, with some staff seemingly fearful of those with COVID-19.

Mental health impacts

The cohort experienced high levels of anxiety and depression; these were higher in people who had COVID-19 than in the general population. Anxiety and depression were much higher among disabled than non-disabled people. A major concern for most people was passing COVID-19 on to whānau. Inaccurate and negative reporting in the media alongside the influence of social media contributed

to increased levels of stress and stigma. Mental health support was an important area of unmet need identified by around one-third of participants. Among tāngata whaikaha Māori, mental health support was significantly less than among non-disabled Tāngata Whenua, despite the need being greater.

Long COVID

A high proportion of our cohort experienced ongoing symptoms or long COVID. About one in five had symptoms that lasted for 3 months or longer, although given the involvement of the long COVID Facebook support group in promoting the study, this might be an overestimate and reflect the impact of selection bias in the cohort. Ongoing symptoms beyond 3 months were higher for people who had heart disease or obesity before getting COVID-19. The physical and mental health impacts of long COVID significantly affected lives, resulting in anxiety or depression. Long COVID disability also affected people's sense of identity. There was a lack of understanding of long COVID by health professionals, and a lack of good information on where to get help. Many people were unaware their symptoms could be long COVID. Half received support from their GP; 1 in 6 saw their GP at least four times, and 1 in 10 did not see a GP when they wished to because they could not afford it. Many were concerned about not knowing when the effects of COVID-19 would end and felt scared about their future health.

CONCLUSION

The Ngā Kawekawe o Mate Korona | Impacts of COVID-19 in Aotearoa is the only nationwide study of the impacts of COVID-19 in Aotearoa to date. It forms a strong base from which to continue to understand the medium to long term impacts of COVID-19. Future plans for 2023 include follow-up of participants in the cohort who had ongoing symptoms of COVID-19. This cohort will be supplemented by the inclusion of a cohort of people with long COVID following Omicron infection, with the aim of establishing the prevalence, duration and determinants of mental distress among people with long COVID and identifying how to best align mental health services to address these. Future follow-ups will assess longitudinal changes to health and well-being impacts, including mental health, social, workplace/education and economic impacts of COVID-19.

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