



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

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*Executive Summaries of Report for  
Manatū Hauora | Ministry of Health*

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## KUPU WHAKATAKI OPENING WORDS FROM STUDY POU TIKANGA

E ngā mana, e ngā reo, e ngā hau e whā, tēnā rā koutou katoa,

E hara taku toa i te toa takitahi, engari he toa takitini.

My success is not mine alone, it is ours.

The greatest achievement we will have, is working together.

When COVID-19 entered our world at the beginning of 2020, we had no idea of what was yet to come. In those early days there was a lot of fear of the unknown. For Te Tangata Whenua, that fear was steeped in lived whakapapa. We lost many of our people in the 1918 'flu pandemic; all we have is nameless unmarked graves to remember them by.

I wondered, if I caught this virus, would I survive it to teach my many mokopuna from the fountain of knowledge that was passed down from my ancestors to me? Or would I die a name on a headstone with a simple message saying, 'Taken before his time', like so many of our tūpuna who bear crosses with no names?

The global response to this pandemic has seen governments the world over, make decisions for their nations in ways not seen before in our lifetimes. In Aotearoa, our Government determined pathways that were brave and without premise, to prevent deaths on the same unfathomable scale as we were witnessing overseas. However, not all decisions were made with Te Tangata Whenua in mind.

The Crown did not ask us to take a seat at the decision-making table. It did not talk with us about how we might work together to look at solutions. Te Tiriti o Waitangi tells us this is a partnership. Yet, one partner implemented a plan and expected the other to follow it.

That colonial 'rule of thumb' approach worked to divide our people and separate our communities. It planted suspicion, and there in the vacuum of voicelessness and uncertainty, grew the conspiracies about this urutā that drove wedges through whānau and hapū. As marae were forced to change tikanga, whānau were turned away, and whilst we may understand the reasons why, ultimately our mana motuhake was denied. Some of us are now trying to sew us back together again.

So, my recommendation to the Government after spending a year working alongside the Rōpū Kaitiaki and the Rōpū Rangahau on this 'Ngā Kawekawe o Mate Korona | Impacts of COVID in Aotearoa' study, is simple: Invite us to the table.

Thank you for the honour of being able to ensure this study was conducted in ways that adhere to tikanga Māori and Te Tiriti o Waitangi. I end my time on this rangahau with a story from the place I grew up in, in a valley in the mid North.

Many years ago, I had the job of trying to convince everyone in our valley to complete their Census papers. Houses were very remote; access to them was by car, horse and walking. One whare I went to, you would not even know it existed. I arrived with my Census papers and knocked on the door. An older gentleman opened the door and I stepped forward. “Matua, I’m here about the Census.” He looked at me and replied, “Ko wai koe? Ohhh, you’re Joey’s boy, eh?” “Ae, Matua.” His response: “You see that gate out there, boy? That’s my world. From that gate to my house, that’s my world. Anything outside of that, I’m not worried about. So, leave your Census papers out there and come in for a cup of tea.”

COVID-19 began somewhere in the world a long way from the isolated, winding, dusty road in the valley this Matua called home, and yet, it found its way to his whare. His world suddenly became smaller; no longer from his gate to his porch but to the insides of his whare where he would isolate from the world even further, only letting people who were close to him in. Without knowing the virus could be delivered in many ways to that very small world of his, in the end it found a way into his home. He died of complications from COVID-19.

If a pandemic should ever happen again, Te Tangata Whenua need to be at that table right from the get-go to prevent deaths like this. We do not want to be told by the Crown what is going to happen and what we have to do, to pay the consequences afterwards. We want the Crown to talk with us, at the table, so we might find solutions together. That is partnership in its true sense – the partnership that my grandfather, Te Pene e Haengatia te Tiriti o Watangi Tipene signed up to when he helped pull the logs from Motatau State Forest all the way to the Tiriti grounds to build the Treaty house.

No reira, mahi tahi tātau mō te oranga o te katoa.

Mauri ora

**Matua Witeria (Witi) Ashby** (*Ngāti Hine, Ngāti Kawa*), Pou Tikanga; Kaumatua, Te Rau Ora

## HE WHAKAMIHI

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Many have contributed to the development of this report, through participation in the study, as kaitiaki and kairangahau, and in other capacities. We gratefully acknowledge every single contribution.

We begin by recognising and remembering the many who have died from COVID-19. At the completion of this study, these included 1,861 members of whānau and families in Aotearoa who have been confirmed as dying from COVID-19; grandparents, parents, siblings, children, grandchildren, aunts, uncles, nephews, nieces and cousins, each remembered and mourned.

To those 990 participants who completed the surveys and the 62 participants who shared their experiences with us through in-depth interviews, we are immensely thankful for your time and honesty. Often, we were brought to tears by your words, describing the adversities faced, and the strengths displayed through your journeys with COVID-19. Your contribution is immeasurable, and we have aimed to give justice through this report, to your participation. We acknowledge also the many more people who reached out to the study in the hope of also sharing their stories, but who we were not able to interview, including those who were unable to participate because they contracted COVID-19 outside of the study period (after 30 November 2021).

Specific populations were focused on in this study: Māori; Pasifika peoples; those with lived experience of disability (tāngata whaikaha Māori and disabled Tāngata Tiriti); and those with long COVID.

Ki ngā mātua ki ngā whāea, taipakeke mai kaumātua mai, nā koutou mātou i ārahi ki te puna o te mātauranga, nei rā te mihi manahau. Nō mātou te māringanui, tēnā koutou, tēnā koutou, kia ora anō koutou katoa. To all those whānau Māori who gave so willingly of themselves through this study, to help others who may also traverse the same path, we thank you.

The Pasifika team also acknowledge and gratefully thank the Pasifika families who shared their experiences to help us understand the impact of COVID-19 on Pasifika in Aotearoa.

Special mention is made of those tāngata whaikaha Māori and disabled Tāngata Tiriti, and those with long COVID, who participated in the surveys and shared their intimate stories with our kairangahau through interviews.

To the funders of this study, Manatū Hauora | Ministry of Health, thank you for your flexibility throughout this study, needed in the uncertain and changing times that this pandemic has produced. To all those who contributed to working so hard to keep people safe during the pandemic and who continue to treat and support those with COVID-19 under extremely difficult circumstances, we thank you. We recognise that, at times, those who participated in this study have been critical of their experiences, but we hope that the findings enable discussions on how we can all do better in future.

Finally, we thank the many who worked on this study, in numerous ways. This includes fellow Te Herenga Waka–Victoria University of Wellington colleagues, **Alana Hamill**, centres manager, Wellington Faculty of Health; **Nina McCullagh** and **Sarah Young**, senior communications and marketing advisors. Our sincere gratitude also to Māori mixed media visual artist, **Ephraim Russell** (*Te Aitanga-a-Mahaki, Rongowhakaata, Ngāi Tamanuhiri, Rongomaiwahine, Ngāti Kahungunu, Te Whakatohea, Rangitane, Kāti Mamoe, Waitaha, Ngāi Tahu*) for designing the study logo; Illustrator, **Huriana Kopeke-Te Aho** (*Tūhoe, Ngāti Porou, Rongowhakaata, Te Āti Haunui-a-Pāpārangī, Ngāti Kahungunu, Kai tahu, Fale’ula*) for the rest of the graphic art across the study; the many language translators from the Translation Service at Te Tari Taiwhenua | Department of Internal Affairs; and media and communications consultant, **Iulia Leilua**, director Brown Pages.

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We especially acknowledge the insights brought by each of the Rōpū Kaitiaki members with lived experience of COVID-19: **Hamuera Evans** (*Te Iwi Mōrehu*); **Jenene Crossan** (*Ngāti Tahu*); **Donna Glossop**; and **Tuala Tagaloa Tamasese Tusani**. When the study began, many in Aotearoa had no idea of the realities of the illness. Through being willing to expose your vulnerability, others were able to speak.

To all the other Rōpū Kaitiaki members, we are so grateful to you for sharing your expertise with this study: **Dr Tristram Ingham** (*Ngāti Kahungunu, Ngāti Porou*), epidemiologist, Kaupapa Māori researcher, tangata whaikaha disability researcher; **Dr Donna Cormack** (*Kāi Tahu, Kāti Māmoe*), Kaupapa Māori researcher and member of Te Rōpū Whakakaupapa Urutā; **Bernadette Jones** (*Ngā Wairiki, Ngāti Apa*), Kaupapa Māori researcher, tangata whaikaha disability researcher; **Tagaloa Dr Junior Ulu**, director Pacific People's Health, Hutt Valley and Capital & Coast DHBs; **Dr Raymond Hutubessy**, WHO, international health economics advisor; **Prof Colin Simpson**, epidemiologist; and **Prof Aziz Sheikh**, epidemiologist, lead for Scottish arm of COVIDENCE UK Study.

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Tāngata Tiriti researchers: **Dr Analosa Veukiso-Ulugia**, research fellow – Pasifika, **Dr Janet McDonald**, qualitative and disability researcher, **Dr Jacqueline Cumming**, health services researcher and health economist, **Dr Jesse Kokaua**, biostatistician – Pasifika, **Dr Lanuola Asiasiga**, research fellow – Pasifika,

**Dr Fiona McKenzie**, epidemiologist, **Dr Maite Irurzun Lopez**, health economist, **Dr Sione Vaka**, research fellow – Pasifika, **Dr Claire O’Loughlin**, qualitative researcher, **Dr Conroy Wong**, respiratory physician and clinical researcher, **Dr Megan Pledger**, statistician, **Myra McFarland-Tautau**, research fellow – Pasifika, **Tali Uia**, research assistant – Pasifika, and **James Shanly**, summer scholar.

**Dr Lynne Russell** (*Ngāti Kahungunu, Rangitāne, Kāi Tahu, Ngāti Porou*), Senior Māori Researcher, Co-Principal Investigator and Rōpū Māori Lead.

**Dr Mona Jeffreys**, Epidemiologist and Co-Principal Investigator.

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

The impact of the COVID-19 pandemic has had far reaching consequences, differentially impacting people with poorer pre-existing health, financial and social capital. Beyond these internationally felt effects, in this report we demonstrate the impacts of having had COVID-19 in Aotearoa, across a range of domains, including health, social, cultural, spiritual and financial. This study was underpinned by a Tiriti o Waitangi Framework which recognised 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. Drawing on people's lived experiences, the report points to greater impacts from COVID-19, more unmet need and greater need for support, amongst those populations already disproportionately impacted by an inequitable health system.

A major focus of this study is on system change. We identify key lessons from different aspects of the national COVID-19 response and make a series of recommendations about how Aotearoa might respond in future to new pandemics or similar crises. We have an opportunity, an imperative, to think about what the future can look like. We need a health system that is Te Tiriti o Waitangi compliant, that is pro-equity, that is anti-racist and culturally safe. Aotearoa can and must take the necessary actions to realise this future now, for the generations to come.

What is alarmingly clear with regard to COVID-19 and what is also consistent with previous pandemics as recently as the 2009 H1N1 influenza pandemic (Baker et al, 2009), as well as in the more distant past with the 1918 'flu pandemic (Wilson et al, 2012), 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 here in Aotearoa (Curtice & Choo, 2020; Cormack & Kukutai 2021). This is because we are social beings with divisions in our societies based on long histories of injustice – political, social and economic, including as a result of colonisation and racism (Krieger, 2011).

Historically, we know that inequities differentially affect Te Tangata Whenua, Pasifika peoples,<sup>1</sup> lower income, and disabled populations (Manatū Hauora | Ministry of Health, 2015; Ministry for Pacific Peoples, 2020; Tatauranga Aotearoa | StatsNZ, 2020; Te Manatū Whakahiato Ora | Ministry of Social Development, 2016). The health system in Aotearoa in non-pandemic times responds inequitably to these populations, so that any health system response to the COVID-19 pandemic had to be mindful of that from the start. By not taking an approach different to that which it has pursued in the past, it was inevitable that structural inequities already existing prior to COVID-19 would be propagated and magnified. From risk of exposure to the virus, to the likelihood of becoming sick if exposed and once sick, the potential to die or survive, the pattern of COVID-19 infection and transmission highlights the interplay of different inequities present, through direct health impacts and the indirect impacts of economic losses, social disruption, and discrimination (Cormack & Kukutai, 2021). All of these outcomes are socially structured and influenced by the histories and ongoing current realities of racism, colonialism and economic injustices in Aotearoa.

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<sup>1</sup> A term adopted from Government documents that identify Pacific people collectively.



This is largely the scenario which has played out whereby equity was not evidenced to have been at the forefront of Government's planning, analysis, responses and policies with COVID-19. The Government's COVID-19 response was not fit for or responsive to Māori communities' lived realities, and instead took a one-size-fits-all approach which met the needs of Tāngata Tiriti. This was underscored by the Waitangi Tribunal report (2021) which found the Crown had breached the principles of active protection and equity, as well as those of tino rangatiratanga and partnership. Specifically, the COVID-19 protection framework (or traffic light system) put Te Tangata Whenua at disproportionate risk and put Māori health and Whānau Ora providers under extreme pressure. There was unanimous opposition from Māori health and Iwi leaders to the COVID-19 protection framework given the Government's failure to both design the COVID-19 response jointly with Te Tangata Whenua and through not engaging with Te Tangata Whenua to "the fullest extent practicable" (Baker, 2022). These findings had previously been echoed repeatedly by Iwi, Māori academics, public health specialists, provider organisations and communities throughout the pandemic period leading up to December 2021 and the Waitangi Tribunal's report (Gifford & Boulton, 2020; McLeod et al, 2020; McMeeking & Savage, 2020; Nielson, 2021; Parahi, 2020).

Another key area highlighted by the Tribunal was the lack of high-quality ethnicity data across all aspects of the Government's COVID-19 response (Parahi, 2020; Waitangi Tribunal, 2021), a concern which is ongoing. This has seriously affected efforts to understand what is happening for Te Tangata Whenua and to monitor the effectiveness of the health system's performance for whānau Māori, as well as hampering efforts by Māori communities to plan for both their immediate, and future, responses. Manatū Hauora | Ministry of Health will need to improve and maintain ethnicity data to meet the urgent need for high quality data for Te Tangata Whenua with regard to the COVID-19 response and for any future pandemics.

Throughout this report we have shown that Te Tangata Whenua, including tāngata whaikaha Māori, Pasifika peoples, and disabled Tāngata Tiriti have been more affected by COVID-19 and have disproportionately suffered the impacts of the Government's subsequent response to the pandemic.

We have made recommendations throughout the report which are presented specifically as they relate to each of the findings chapters. Additionally, there are a number of overarching themes which cross several chapters, relating to an urgent need for service improvements and the collection and timely reporting of information to ensure the best possible outcomes for those who continue to be underserved by the health and social service systems. We particularly stress the need to:

- Ensure that the ongoing Government COVID-19 response at all levels, and for any future pandemics, be based on Te Tiriti o Waitangi and that all processes, decisions, management and monitoring approaches are responsive to Māori communities' lived realities.
- Involve leaders and experts from all key populations in policy design and response delivery. This will bring a stronger understanding of local needs and a stronger understanding of how future Government policies and responses can best work with local communities. It will also enable trusted local health champions to take the lead in communications around future pandemics.
- Ensure that information and messaging for Te Tangata Whenua, including tāngata whaikaha Māori, for Pasifika peoples, and for disabled Tāngata Tiriti happens at the same time or first, not with major time lags following the information being made available to the general public.
- Significantly reduce barriers to access to primary health care, especially for Tangata Whenua, including tāngata whaikaha, for Pasifika peoples, and for disabled Tāngata Tiriti. It has long been

recognised that poor access to primary health care is a major barrier to optimal health, and that these barriers contribute to significant inequities in health and wellbeing in Aotearoa. Survey participants in this study reported cost barriers to obtaining prescriptions and accessing GP services, and those that did use services required many visits. This not only directly affects people's health by not getting access to services in a timely way, but it also puts already struggling whānau and families under greater financial pressure.

- Recognise the essential role that community-led providers played in the pandemic and the success they had in advocating for and pro-actively supporting their communities. New and more flexible funding allowed them to move swiftly to meet a wide range of needs. This is another clear demonstration of their value in the Aotearoa health and social services systems. Appropriately funding such providers in the future will enable them to support those whānau and families with ongoing needs from the pandemic (including long COVID) and to tackle other pressing health issues.
- Deliver a wider range of more integrated services in the future. Throughout this report, there is mention of the breadth of services being delivered or required by those with COVID-19 (e.g., food parcels, wellness checks, mental health support). This points to the need for a wider scope of services to support whānau and families' wellbeing. There were also reports of too much contact from too many organisations. Better integrated services would serve us well in future, including during future pandemics.
- Proactively develop a plan for mental health to deal with the fallout of the COVID-19 pandemic as well as future ones. Support providers to be able to offer mental health services alongside the other services they provide, including to whānau or family members of those who are unwell.
- Understand the impact that stigmatisation had throughout the pandemic and in a range of settings and implement a plan to reduce stigmatisation for those who become infected and for those seeking support.
- Revisit the recommendations of the Welfare Expert Advisory Group (2019), particularly in relation to modernising and simplifying income support policies, to ensure that all those in Aotearoa are enabled to meaningfully participate in the community, and work to align ACC, health, and social welfare policies and funding arrangements to remove inequities in social support.
- Reconsider sick leave and employment support policies to ensure that in future pandemics or crises people are able to take time off work when unwell; encourage employers to work more flexibly; and provide education to employers so they can support their employees and reduce stigmatisation within workplaces.
- Develop consumer-led long COVID services, integrated with primary health care services. Those enrolled with the service would be assigned a case manager who engages with them and their whānau or family through an initial assessment and plan, and then assists with ensuring wraparound whānau-focused services, including support to return to work if appropriate.

While this study found the overall health response for Te Tangata Whenua was insufficient, the unmet need in health services was highest for tāngata whaikaha Māori, highlighting the urgent need for specifically tailored approaches for this population if equitable outcomes are to be achieved. This has been underscored in the Inquiry which found that many of the issues those with lived experience of disability identified in the first two years of the COVID-19 response persisted or had worsened during the Omicron outbreak, and that the Government response to the widespread community transmission of the Omicron variant did not sufficiently protect tāngata whaikaha Māori and disabled Tāngata Tiriti, or their whānau and families (Baker & King, 2022). A commitment from Government that those with

lived experience of disability will be involved at the start of any design and decision-making is an obvious starting point to ensure their needs and priorities are visible and that solutions are appropriate. System mechanisms that respond in a timely manner should be prioritised to ensure easy-to-use, accessible options for tāngata whaikaha Māori and disabled Tāngata Tiriti to report adverse reactions or unmet health needs. It is also very important that health providers recognise that health issues will not all necessarily be related to a disability; new issues may arise for this population thus, the need for holistic assessment and treatment is key.

Pasifika communities have collective obligations which emphasise the importance of including Pasifika leaders in planning for future pandemic events to effectively and efficiently reach diverse and emerging Pasifika communities. Pasifika families live on the margins of socioeconomic sustainability and too many Pasifika families live with extreme hardship. As a consequence, many were faced with socioeconomic hardship during the pandemic that will have serious ongoing consequences. Pasifika are still developing a strong financial infrastructure that is vulnerable in times of sustained economic uncertainty. This is important to remember when considering Pasifika responses to future pandemic events.

Another key finding of our report is the impact of ongoing symptoms of COVID-19, that affect around 22% of people who have had the illness. As has been seen overseas, this report shows how people with long COVID are significantly affected in their ability to live their lives as they did previously. Long COVID has resulted in a newly disabled population of people who need ongoing support and the development of new, and improved access to existing, multi-disciplinary, integrated and consumer-led services. Paula Tesoriero, Disability Rights Commissioner and new CEO of Whaikaha - Ministry of Disabled People, has identified that for many people, long COVID meets accepted criteria of disability, and thus should open doors for additional support (Tesoriero, 2022). The lack of support for those with long COVID highlighted in this report emphasises this need.

Tracking and ensuring appropriate services for people with long COVID will require robust data. Although a start has been made with the publication of ICD and SNOMED codes to record long COVID, the accuracy and completeness of the use of these codes are paramount. Coupled with this, unless changes are made to improve the quality of the source ethnicity data, future inequities in the management of, support for and outcomes from long COVID will not be able to be assessed. High quality data for Te Tangata Whenua, including tāngata whaikaha Māori, with all information broken down by ethnicity, available at the same time as total population information, is needed. This will require Manatū Hauora | Ministry of Health to improve and maintain ethnicity data for Te Tangata Whenua and ensure that data on both tāngata whaikaha Māori and disabled Tāngata Tiriti is collected comprehensively and accurately.

A structural level approach to health would see Cultural Safety embedded across all the sectors that are upstream predictors of health and health equity. The need for inter-sectoral work is of particular importance, given our understanding of the wider social determinants of health, and their contribution to Māori health inequity. As argued by Metzl & Hansen (2014), if stigma-related health inequity is due to structural causes, rather than only due to encounters between an individual and a health care professional, then anti-racism education (Jones et al, 2019; Talamaivao et al, 2021) must include not only the individual but also be embedded at the level of the healthcare system and structure (i.e., policy and political level).

We see Cultural Safety training and understanding as essential for all people working in the areas of health, education, social services, policy and media. Cultural Safety is a critical education approach which was developed to make explicit the causal links between colonisation, institutional racism, power, and social justice as fundamental to understanding and, importantly, taking action to address health inequity (Ramsden, 2000; Ramsden, 2002). Cultural Safety recognises that understanding and confronting power imbalances and racism, across the health system, within organisations and among the individuals who work in them, rightly shifts the responsibility back onto those systems, institutions and health workers to address the poor performance of services in meeting the health realities of Māori and all peoples experiencing inequitable health outcomes (Health Quality and Safety Commission (HQSC), 2019; Matheson et al, 2018).

In summary, the report we provide indicates the need for a systems approach to maximising equity and health during a pandemic. This paradigm shift is one critical step toward recognition of the true relationship that underpins Te Tiriti o Waitangi, through tino rangatiratanga for Tāngata Whenua. As the health system in Aotearoa undergoes substantial changes, now is the time for these changes to be implemented, for the benefit of everyone.

## TE WHAKARĀPOPOTOTANGA – MĀORI EXECUTIVE SUMMARY – TE TANGATA WHENUA

Te Tangata Whenua have experienced devastatingly higher rates of mortality and morbidity when compared to Tāngata Tiriti during previous pandemics and other infectious disease outbreaks (Durie, 2020; Pihama & Lipsham, 2020). Early in the COVID-19 pandemic, it was recognised that structural inequities already entrenched across all areas of health and social services, including differential access to health care because of colonisation, racism, and significant financial and cultural barriers, had the potential to be magnified to an even greater degree as part of the COVID-19 response efforts (McLeod et al., 2020). This, together with a high prevalence of chronic conditions, as well as disease onset at a younger age contributing to high mortality and morbidity rates (Manatū Hauora | Ministry of Health, 2018), raised serious concerns about the potential effects of COVID-19 for Te Tangata Whenua (King et al., 2020; Espiner, 2020; Jones, 2020). A key area of concern was “the inadequate focus on Māori health equity in pandemic planning within the health and disability system and in the whole-of-Government ‘one-size-fits-all’ approach” (King et al., 2020).

The absence of an equity approach and meaningful engagement with Te Tangata Whenua in the Government’s pandemic strategy had several implications, including a lack of collection and timely analysis of high-quality ethnicity data across all aspects of the Government’s COVID-19 response (Parahi, 2020; Waitangi Tribunal, 2021). Against a backdrop of already well-known issues regarding the quality and completeness of ethnicity data within official statistics (Cormack & Harris, 2009), this has had, and continues to have, serious implications, including the likely underestimation of COVID-19 cases and hospitalisations amongst Te Tangata Whenua, the prevention of effective monitoring of how the system is performing (or not) for whānau Māori, and the hampering of efforts by Māori communities to plan for both their immediate, as well as future, responses. Thus, the findings from Tāngata Whenua in this study are even more important, with the use of self-identified ethnicity ensuring more accurate data and providing an important opportunity to speak directly with groups who were actively ignored and marginalised in the COVID-19 response itself.

Te Tangata Whenua findings come from 18 interviews with 12 wāhine and six tāne, and 161 surveys; 80% of survey participants were female.<sup>2</sup> The average age of interviewees at the time of contracting COVID-19 was 53 years. Half (n=9) were infected in the early stages of the pandemic (March or April 2020) and a third (n=6) towards the end of the study period (October or November 2021). Two interviewees reported contracting the virus through their workplaces, four spent time in MIQ, three were hospitalised with symptoms, and the majority (n=14) reported ongoing symptoms of COVID-19 three months or longer after first contracting it.

The average age of the survey participants when they contracted COVID-19, was 40 years. Fifty-five percent worked full-time; of those who reported their household income, for about two thirds, this was over \$70,000. About half lived in households of five or more people, and a fifth lived in

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<sup>2</sup> Findings relating to tangata whaikaha Māori are presented in ‘Te Whakarāpopototanga – Ngā Tāngata Whaikaha | Executive Summary – People with Lived Experience of Disability’ section of this report and findings relating to Te Tangata Whenua experience of long COVID are presented in the ‘Kowheori Mauora | long COVID’ section of this report.

overcrowded conditions. Most survey participants lived in the upper or central North Island – many in large towns or main centres – but about a quarter lived in small towns or rurally. Of the 138 who identified their Iwi, 25 identified first as Ngāpuhi, 16 as Tainui and 12 as Ngāti Porou. Other main Iwi identified were Maniapoto, Ngāti Kahungunu and Kāi Tahu.

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## NGĀ KITENGA - MĀORI

### STUDY FINDINGS – TE TANGATA WHENUA

Fewer than half (43%) of survey participants had seen a General Practitioner (GP), whānau doctor or nurse because of COVID-19 or related issues. The most frequently reported barriers to seeing a GP were not being able to get an appointment (19%), and affordability (12%). Compared to Tāngata Tiriti survey participants, Tāngata Whenua had more severe illness, based on the need for oxygen, length of stay in hospital, and being in an Intensive Care Unit/High Dependency Unit (ICU/HDU).

Tāngata Whenua interviewees struggling to get their basic needs met due to living rurally, or in overcrowded, intergenerational homes, turned to established relationships with Iwi, Māori health providers, or their wider communities for support when the public health system response was left wanting. Among survey participants, help came from whānau (81%) and neighbours or friends (60%). A quarter also reported receiving help from the community; a level of support akin to that received from Whānau Ora providers (25%), Māori health and social services (21%), and Iwi (20%).

Interviewees highlighted several barriers which affected all phases of their COVID-19 journey. These ranged from anxiety-provoking difficulties sourcing tests and receiving test results, to not being able to see primary health care providers because of wait times for appointments, and affordability. Some interviewees spoke of their sense of alienation while being in hospital during the pandemic. One tangata whaikaha Māori interviewee spoke about the racism she experienced and witnessed in her interactions with doctors and nurses when she was hospitalised with COVID-19.

In terms of self-isolation, Tāngata Whenua felt that important logistical and economic realities made it difficult for whānau to follow official advice. Whānau were not always able to either assist or call on wider whānau networks for help where those whānau supports were now themselves experiencing COVID-19; significant and ongoing economic constraints with no credit cards made ordering food online impossible; and living rurally where access to food, health and social support services may be lacking, was particularly challenging.

The importance of having the COVID-19 vaccine was highlighted by several Tāngata Whenua interviewees and reinforced by the fact that 91% of Tāngata Whenua survey participants had at least one dose of a COVID-19 vaccine. Survey participants reported a range of physical symptoms from COVID-19, ranging from minimal to significant illness. The most common symptoms, also reported by all population groups surveyed, were fatigue, aches, muscle weakness, headache, shortness of breath, cough, brain fog, fever, and sleep difficulties. The prevalence of pre-existing health conditions was higher in Tāngata Whenua compared to Tāngata Tiriti survey participants, including: asthma 64% vs 40%; high BMI ( $\geq 30\text{kg/m}^2$ ) 61% vs 31%; and anxiety 50% vs 22% (respectively).

When talking about their symptoms, several Tāngata Whenua interviewees described this as the most unwell they had ever felt before. The time taken to ‘recover’<sup>3</sup> from COVID-19 infection varied from days to some months.

Interview and survey responses highlighted the range, depth, and multifaceted nature of challenges to mental and emotional wellbeing posed by COVID-19. Tāngata Whenua survey participants reported high levels of anxiety and depression (35% using validated scales). Common concerns were worries about passing on COVID-19 to others within (91%) and outside (83%) of the whānau and feeling scared about what might happen to them while having COVID-19 (73%).

Stigma associated with having COVID-19 was also noted by survey participants, with over one third (35%) reporting they felt they could not tell whānau or friends they had contracted the virus. A key theme identified by interviewees in relation to stigma was feeling judged by society, whānau members, community and workplace colleagues. Importantly, a study recruitment criterion was those who contracted COVID-19 prior to December 2021. Once the Omicron variant entered Aotearoa in December 2021 and numbers of COVID-19 positive cases skyrocketed, the stigma associated with contracting the virus likely dissipated as it became more normalised for people to use rapid antigen tests (RATs) and share their results through social media.

Impacts on social wellbeing varied depending on which phase of the pandemic Aotearoa was experiencing. Interviewees referred to a change they observed amongst the nation, from one where there was a communal sense of caring shown early on in the pandemic, to another where, as time went on, people focussed more on themselves. One kuia saw this shift as being an indication that we had become disconnected from one another. As a communal culture, the focus in Te Ao Māori is on the community or groups rather than an individual. So, to witness *“this very individualistic rather than community-orientated way of thinking, was a real disappointment”* (Kuia, Mar 20).

In terms of social support, Tāngata Whenua survey participants would have liked food parcels (27%), help with errands (25%), help collecting prescriptions (27%) and more information about COVID-19 (30%). Heavy reliance on and trust in whānau explains why not all interviewees described needing social support. Several also expressed the view that assistance from outside agencies and organisations was not necessary because of a deep-seated belief that others were more deserving.

Nearly two thirds (64%) of survey participants had time off work or study in the first month that they had COVID-19. Several interviewees had returned to work too early in their post-COVID ‘recovery’ necessitating further time off, while others felt compelled to return to work due to their financial circumstances. Interviewees spoke of the challenges of home schooling tamariki. For those from Tāmaki Makau Rau, this was especially difficult as they navigated multiple, prolonged lockdowns.

Twelve percent of Tāngata Whenua survey participants reported their whānau were doing worse since having COVID-19, and nearly a quarter (23%) reported their whānau needed more support. A possible explanation for this, as shared by interviewees, related to the importance of intergenerational relationships where Te Tangata Whenua often have collective responsibilities across different

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<sup>3</sup> As ‘recovery’ is a contested concept amongst those impacted by long COVID, the term and its derivations are placed in single quotation marks throughout the report.

households. COVID-19 disrupted these relationships by forcing Tāngata Whenua to be apart from whānau with significant stress on collective wellbeing caused by this separation.

From a Te Ao Māori perspective, wellbeing is a collective, rather than individualistic, phenomenon. Thus, it is difficult for an individual to experience wellbeing if the collective whānau wellbeing is compromised. When factors that typically uphold whānau wellbeing – relatedness and connectedness – were severely affected through the forced separation of whānau by isolation protocols, a significant breakdown occurred. On the other hand, prioritisation of collective wellbeing also had a positive impact with interviewees describing the various ways in which they had established their own tikanga within their whare to keep safe and remain connected, such as implementing stringent procedures for preparing and delivering food to COVID-19 positive whānau.

One of the greatest impacts of COVID-19 on Te Tangata Whenua was the disruption to tikanga, particularly the inability to collectively grieve ā-tinana through tangihanga. Tangihanga, the “enduring Māori ceremony” for mourning the dead has “changed little” over time, despite colonisation, and is considered a bastion of cultural identity, a cultural imperative (Higgins, 2011). Among Tāngata Whenua survey participants, 23% reported missing a tangihanga or funeral of someone they cared about. Not being able to fulfil cultural imperatives associated with tangihanga felt abnormal to interviewees. Around one in five survey participants also reported that missing church or another religious service due to the pandemic was a concern for them.

Given the “important role” the dead play in tikanga Māori (Higgins, 2011), it is not surprising that several Tāngata Whenua interviewees spoke with sadness at the number of deaths from, or related to, COVID-19 in Aotearoa and worldwide. Mātauranga Māori surrounding wairuatanga underpins Te Tangata Whenua understandings of and responses to wellbeing and ill-health, and death.

A small proportion of Tāngata Whenua survey participants (5%) lost their jobs because of having COVID-19, or because of the pandemic (7%). Despite the low rate of job loss, more than half (57%) reported money/financial worries, and a high proportion (42%) reported a decrease in household/whare income in the first month of having COVID-19. Forty-one percent strongly agreed or agreed that they had struggled to pay for basic living costs in the first month of having COVID-19.

Tāngata Whenua interviewees spoke with relief about the Government financial support for employees who found themselves unable to work due to COVID-19. However, some described having little choice but to return to work even when they should have been isolating.

On average, each Tangata Whenua who accessed primary health care for COVID-19 costs, paid over \$100. Among those that reported additional costs related to having COVID-19, the highest average costs were paid for supplements, followed by non-medical costs (such as babysitting and transport), and then medical test costs. On average, each Tangata Whenua who bore additional COVID-19 costs paid \$491. The direct medical costs for Tāngata Whenua hospitalised with COVID-19 was estimated at around \$57,900 per person.



## RECOMMENDATIONS – TE TANGATA WHENUA

1. The ongoing Government COVID-19 response at all levels, and for any future pandemics, be based on Te Tiriti o Waitangi to ensure that all processes, decisions, management and monitoring approaches are responsive to Māori communities' lived realities.
2. Sustainable, long-term funding for providers with track records of supporting Tāngata Whenua with COVID-19 be established and maintained. This will require a transfer of funding and resources to Māori and community based/Iwi providers to ensure locally-embedded, locally-relevant responses from people who know their communities, are supported.
3. Structural barriers to health care and advice are minimised by providing sustainable funding to local community/Iwi networks who understand Tāngata Whenua realities well. These networks can offer culturally-safe, needs-driven support that leverages existing relationships, serves the current realities of whānau – like living in intergenerational homes - and connects people with the specific types of support they need for their particular circumstance.
4. Primary health care, as a key environment for the prevention, early detection and management of COVID-19, must remove all financial barriers, in order to ensure Te Tangata Whenua accessibility to services.
5. Mental health support for Te Tangata Whenua must be a core feature of health service provision in any future pandemics to mitigate feelings of collective loss, loneliness, isolation, and anxiety, especially where self-isolation may be necessary.
6. Public health messaging includes self-help emotional resilience strategies for dealing with common anxieties, like the threat of passing illness on to others, worrying about the health of friends and whānau, or fears of leaving the house again after isolation. Self-help strategies are recommended as a way for whānau/Iwi/communities to empower themselves rather than relying on the public health system where they may encounter the types of well-documented structural barriers that could preclude access to this important support.
7. The significance, magnitude and holistic nature of mental health impacts from navigating COVID-19 is acknowledged by continuing to fund research that will guide the development of COVID-19-specific mental health support tailored for Tāngata Whenua-specific needs, including the lasting impacts of extended lockdowns. Funding for evaluation of mental health initiatives is also recommended so that learning can be shared across different communities/Iwi.
8. Public health advice needs to take collective wellbeing into account, rather than treating COVID-19, and any future pandemics, as an experience that only impacts infected individuals. This includes the provision of public health guidance and information which considers the realities of intergenerational households/relationships so that advice is relevant and realistic.
9. Te Tangata Whenua receive ongoing advice and messaging from trusted health champions in their communities about common symptoms of COVID-19. This can serve to minimise anxiety about what might happen while experiencing COVID-19, particularly for people with serious pre-existing health conditions. It is recommended that advice includes strategies for managing common symptoms, like fatigue, in a realistic way for themselves and their whānau.

10. Mātauranga Māori surrounding wairuatanga is significant to Te Tangata Whenua understandings of and responses to wellbeing and ill-health. Recognising that some Tāngata Whenua draw on a range of knowledge informed by science and public health alongside mātauranga Māori can aid in pandemic planning in terms of the communication of information for Te Tangata Whenua.

## TE WHAKARĀPOPOTOTANGA – NGĀ TĀNGATA MOANA NUI A KIWA EXECUTIVE SUMMARY – PASIFIKA PEOPLES

Understanding Pasifika peoples' experiences of COVID-19 is a priority of the study. Our aim is to support and inform the Government's ongoing COVID-19 recovery and future pandemic planning for Pasifika communities. This Executive Summary illustrates the resilience of Pasifika families<sup>4</sup> and the service providers which supported Pasifika communities challenged by COVID-19.

Fifty-nine Pasifika participants completed one of the four surveys, with most being Samoan (41%) followed by Cook Islands (32%) and Tongan (24%). A further 24% were also Māori while a similar proportion were European. Most (61%) were born in Aotearoa and comparatively few used their Pasifika languages at home. Seventy-seven percent of survey participants were women, and most were older than 30 years, with the average age being 40.

The qualitative sample comprised 12 families (some from the online survey) who spoke about their experiences with COVID-19 through talanoa – a Pasifika process of engagement and discussion. Families were interviewed in their preferred language. Two families opted for interviews in their own Pasifika language. Of the 12 families – three identified as Cook Island; four identified as Tongan; and five identified as Samoan. There was a mix of Aotearoa-born, and Pacific-born, with an age range from 32 years and over. In the qualitative interviews, Pasifika peoples aged 30 years and under are not represented. This is a limitation of the study, because while some experiences of young people were reported, it was from a secondary source, for example, a family member may have referenced them in their interviews. It is imperative this age cohort is represented in future studies about Pasifika peoples living with COVID-19.

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## NGĀ KITENGA – NGĀ TĀNGATA MOANA NUI A KIWA STUDY FINDINGS – PASIFIKA PEOPLES

One third of Pasifika survey participants (36%) had seen a GP for COVID-19, and 8% had seen a GP four or more times. Pasifika peoples reported their GP did not spend enough time with them at a much higher rate than other populations (57%), while 33% (similar to other populations) felt they were involved in decision-making about their care.

Most Pasifika families received support from family while they had COVID-19 (89%). Public health/contact tracing staff, employers, foodbanks, local communities, neighbours and friends and Pacific Health and Social Services Providers were other commonly reported sources of support.

Health care providers who proactively worked in Pasifika communities tended to successfully engage with Pasifika families. Pasifika interviewees very much appreciated and recognised the importance of this wider community support, especially that offered through Pasifika provider organisations, with Pasifika staff and those who spoke Pasifika languages.

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<sup>4</sup> Interviews were with Pasifika individuals, but we refer to them in the report as 'Pasifika families', 'families' or in some instances, 'Pasifika participants'.

The most common barrier identified by survey participants for not getting a test for COVID-19 was that the tests were not readily available (23%). Length of time to get an appointment was the most common reason given by Pasifika participants (23%), for not seeing a GP because of COVID-19 when they needed to.

Fourteen percent of participants reported having a prescription for themselves but not being able to afford to collect all of it from the pharmacy. In addition, 27% of Pasifika survey participants reported that they had not had help collecting prescriptions when they had COVID-19 (either at home, or in an isolation facility), but that this help could have been useful. Pasifika interviewees did, however, appreciate the ability to drive through or have prescriptions delivered to them.

Some interviewees had difficulty in accessing hospital care, including from MIQ. A higher proportion of Pasifika peoples spent time in MIQ and were there for more days than other populations, although they were less likely to be in MIQ on their own. Some Pasifika interviewees were positive about being in MIQ, and felt well looked after, while others had difficulties with some facilities and staff, including with getting help when family members became very unwell.

Pasifika families understood the rationale for the isolation guidelines and were keen to abide by them, but implementing them proved very difficult for some and near impossible for others. Organising separate living spaces in households was easy for some families who isolated on their own; or lived in houses with bedrooms that had separate entrances and facilities. For others isolating away from families proved untenable, particularly for those with young children. Families felt the Government lacked understanding of household and living arrangement challenges faced by many Pasifika families.

While the COVID-19 vaccination rates for Pasifika adults are over ninety percent (91.4%) (Manatū Hauora | Ministry of Health, 2022d), the vaccination rollout was met with some trepidation, and there were mixed reactions amongst Pasifika families. Some got vaccinated as soon as they were eligible because of family influence, or employment requirements. Others held strong beliefs against the vaccine influenced by spirituality and suggested that hard-line campaigns felt 'racist' and discriminatory against Pasifika peoples. Vaccination beliefs created divisions and disagreements between families and their social groups. Pasifika families who chose not to vaccinate were unapologetic of their decision, yet felt discriminated against by others including family, community, and society.

In the first month of getting COVID-19, the most commonly reported symptoms for Pasifika peoples were fever (83%), fatigue (78%), aches or headaches (82% each), brain fog (81%), muscle weakness (77%) and congestion (71%). The way people were affected, and the duration of the illness, was quite variable; some had no symptoms, some had relatively mild symptoms, and some reported being extremely sick.

A third of Pasifika survey participants were shown to have anxiety or depression, 18% reported they got some help in the form of someone to talk to or other mental health support. A further third (33%) of Pasifika participants reported that they did not receive any mental health support but acknowledged that it would have been useful. Amongst interviewees, families' responsibilities to protect others, anticipation of catching the virus and spreading it, uncertainty about how the virus would affect families, social restrictions and non-disclosure that led to loneliness, were some of the reasons mentioned by families that contributed to the decline of their emotional and mental

wellbeing. Media publicity and reporting of COVID-19, along with feeling judged by others, fed into feelings of stigma and discrimination against individuals, families and communities, and contributed to families' non-disclosure to preserve their privacy. A lack of understanding of the virus and public awareness were considered to be the source of these judgements. It should be noted that individual Pasifika participants reported mental distress through their interviews, through different forms of disconnectedness including social, spiritual, community and society. Pasifika participants referenced mental distress as affecting themselves and their families.

Survey participants were asked what social support would have been useful when they had COVID-19. For Pasifika families, the most common support mentioned was help in collecting prescriptions, help with groceries or errands, and food parcels. Pasifika interviewees often expressed the view that there were other families needing more support.

Around two-thirds of Pasifika survey participants had time off work or study, with an average of 15 days off. Pasifika interviewees had a range of experiences with their employers, with some not always providing information about sick leave arrangements. Eighteen percent of Pasifika survey participants reported they were "doing worse" since having COVID-19 (the highest rate amongst ethnic groups) and 21% said they needed more support. Pasifika interviewees talked about the emotional distress they felt once they were so unwell that they became dependent on the support of others. Feeling like a burden on their families caused them significant stress.

For Pasifika families, keeping in contact with each other is expected, even obligatory. It is also important to be able to fulfil cultural obligations in an appropriate way. The Pasifika community adapted to the changing circumstances and rules of COVID-19 lockdowns. The Pasifika norm for any event (i.e., unlimited numbers expected to attend) changed to a 'new' norm of limited numbers at events, but open online access. Christianity and faith remain important to many Pasifika families, with almost half of survey participants reporting concerns over missing church or other religious services (the highest rate amongst ethnic groups). In practice, most Pasifika families interviewed were not influenced negatively by their participation with their church communities. Church obligations in giving were not fulfilled and some families felt relief from not contributing financially. Around a quarter of Pasifika survey participants missed a funeral due to COVID-19, but online access allowed them to pay respect and fulfil cultural obligations.

Job loss affected only a few Pasifika survey participants (8%). However, almost half reported money worries, 40% reported decreased incomes, and 45% reported struggling to pay basic living costs in the first month of having COVID-19. While the COVID-19 subsidy for leave came through Te Hiringa Tangata | Work and Income and was applied for by employers, participants who approached Te Hiringa Tangata | Work and Income did not find them helpful. Also, the subsidy was a subsidy, not full pay, so participants did not have enough to cover rent, bills and food. Interviewees found one particular Pasifika provider to be helpful with their advice and ability to support people with their utility bills as well as food parcels.

Most Pasifika families had very little understanding of what long COVID was. This led to a degree of uncertainty of its existence and any implications. In the absence of a definition, families had doubts that their ongoing COVID symptoms might be related to the virus. This was reinforced by health professionals who, in some cases, dismissed family concerns. Pasifika families wanted a specific

definition of the symptoms of long COVID, to ensure they received treatment and care, particularly for the purposes of returning to regular employment and accessing support from their employers.

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## NGĀ TAUNAKI – NGĀ TĀNGATA MOANA NUI A KIWA

### RECOMMENDATIONS – PASIFIKA PEOPLES

1. Promote proactive health services - Pasifika people thrived when health services appropriately and effectively anticipated and provided for their specific needs and responded in a culturally accepted manner. Proactive intervention rather than reactive responses from health services mattered to Pasifika families. Consider telehealth/zoom consultations; follow-up calls; home visits; non-judgemental behaviour to the uptake of services; the usage of Pasifika languages; the use of relevant language that appeals to Pasifika people, including Pasifika young people.
2. Restore Pasifika people's confidence in a health system that was stretched during COVID outbreaks and is now under a workforce crisis. Provide open and honest communication, invest in initiatives that provide accessible and effective options, when access to primary health care is hindered.
3. Prioritise the continuation of funding Pasifika-led community health and social organisations to ensure continued support is responsive and appropriate for Pasifika families. The best services clearly communicated what they could provide and tailored their support to the needs of Pasifika families.
4. Prioritise pathways for Pasifika families to access short-term financial support. Financial difficulties and financial instability during the pandemic can result in Pasifika families struggling to buy essentials. Without savings to mitigate against financial hardship, families plunged further into debt, exacerbating deprivation.
5. Engage in meaningful relationships working alongside Pasifika families, community and leaders, at decision-making levels, who understand best the evolving cohorts of the Pasifika community. The Government must demonstrate a commitment to a holistic response through understanding diverse cultural values, beliefs, world views and languages. Reciprocity, respect, and building significant relationships with Pasifika peoples are critical and often occur through personal contacts. For example: Involve Pasifika leaders at all levels in the planning and implementation of future COVID and pandemic events from the outset.
6. Improve access to good quality, appropriate mental health care for Pasifika families to mitigate against the distress brought on, or exacerbated by, the pandemic. Ensure the different cultural needs, world views and perspectives of mental distress of each Pasifika group is carefully considered. Use Pasifika languages, when and where possible, and terminology to promote positive messaging around mental distress.
7. Make solid and reliable community MIQ facilities available to support Pasifika families. They have a place in future pandemics to support Pasifika families who may find it challenging to self-isolate at home. The decision to isolate at an MIQ facility or at home should be made by the family. An assumption that Pasifika families have support systems in place is not always the reality.
8. Identify the main carer/s of families and provide accessible and appropriate support to avoid burn-out, particularly during episodes of COVID-19. Main carers with young children, who care for family members who live with a disability, elderly or large extended families must be prioritised for support.

9. Consider media regulations regarding their ethical obligations, greater accountability, and control of media breaches of privacy and/or fuelling community discrimination against Pasifika or vulnerable communities. The Government response was not enough to protect the community during the two major outbreaks. Actively prepare to address the subtleties and overt ways in which Pasifika individuals, their families and communities are targeted during a national crisis that affects and impacts the Pasifika community. A great deal of stigma, racism and discrimination was levelled against the Pasifika community during the early COVID-19 outbreaks.

## TE WHAKARĀPOPOTOTANGA – NGĀ TĀNGATA WHAIKAHA EXECUTIVE SUMMARY – PEOPLE WITH LIVED EXPERIENCE OF DISABILITY

Disability is 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 six months or more, and not completely eliminated by an assistive device.

One quarter of Tāngata Whenua survey participants reported living with a disability, with 74% of those being wāhine. More than half (58%) of these tāngata whaikaha Māori were in the 25-44 years age group with 30% aged 45-64 years. Forty percent worked full-time and most lived in the upper North Island and in a main centre. Just over half lived in households of five or more people, and more than a quarter lived in overcrowded conditions. Six interviews with tāngata whaikaha Māori were also conducted, of which just one was with a tane Māori.

Seventeen percent of Pasifika survey participants reported living with a disability; 73% were female. Most (55%) were in the 25-44 year age group with 36% aged 65 years or over. The majority lived in a main centre and in the upper North Island. Thirty-six percent were students and 27% worked full-time. More than half lived in households of five or more people, and 55% lived in overcrowded conditions. There were two disabled Pasifika participants who were interviewed for the study.

Seventeen percent of non-Pacific Tāngata Tiriti survey participants also reported living with a disability; 62% were female. The majority were in the 45-64 years age group with 30% aged 25-44 years. The majority also lived in a main centre, and in the upper North Island. Thirty-nine percent were in full-time employment. Less than one-fifth lived in households of five or more people, and 7% lived in overcrowded conditions. Ten interviews with disabled non-Pacific Tāngata Tiriti were also conducted; the majority of these (n=8) were with women.

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## NGĀ KITENGA – NGĀ TĀNGATA WHAIKAHA STUDY FINDINGS – PEOPLE WITH LIVED EXPERIENCE OF DISABILITY

Most of the tāngata whaikaha Māori survey participants (69%) reported that they had their disability prior to contracting COVID-19, inferring many or all of the remaining tāngata whaikaha Māori experienced disability as a result of COVID-19. An extensive range of pre-existing health conditions were reported by Tāngata Whenua interviewees. The association of these conditions with pre-existing disability though, was rare. A third of the interviewees identified having a disability (n=6), and only two of these tāngata whaikaha Māori reported this as a pre-existing disability. Typically, tāngata whaikaha Māori interviewees dismissed significant pre-existing health issues, including cancer, cardiac issues and chronic pain, as disabling. Neither did they identify long-term conditions such as chronic asthma, high cholesterol, sleep apnoea and depression, as disabilities.

Four disabled Pasifika survey participants reported that they had their disability prior to contracting COVID-19. Many, if not all, of the remaining disabled Pasifika survey participants experienced disability because of COVID-19.



Similar to the proportion of tāngata whaikaha Māori survey participants, 69% of disabled non-Pacific Tāngata Tiriti survey participants said they had a disability before contracting COVID-19. A number also had pre-existing health conditions.

One-fifth of the tāngata whaikaha Māori survey participants expressed difficulty with mobility and 21% with cognition. Whilst one did report that their disability was improved by having COVID-19, over one third of tāngata whaikaha Māori survey participants reported that their disability stayed the same and half reported that it got worse due to contracting COVID-19.

The prevalence of anxiety among tāngata whaikaha Māori survey participants (53%), depression (59%) and both combined (59%) were significantly higher than among non-disabled Tāngata Whenua ( $P=0.014$ ,  $P=0.005$  and  $P=0.029$ ), indicating significant mental health needs among tāngata whaikaha Māori; yet despite the higher need, receipt of mental health support was significantly less than among their non-disabled counterparts.

One tangata whaikaha Māori interviewee with serious pre-existing conditions who was confined to a wheelchair following a spinal injury and was an amputee described significant barriers to care during his stay in MIQ. There was inappropriate clinical care during an extended stay in MIQ, even though he had a number of serious medical issues that required close monitoring and support, and the wraparound services he was promised on his discharge from MIQ did not eventuate.

While the overall health response for Te Tangata Whenua was insufficient, the unmet need in health services was even higher for tāngata whaikaha Māori. Three out of every five tāngata whaikaha Māori survey participants (60%) reported facing at least one barrier to seeing a GP and almost all (90%) reported a barrier to getting a COVID-19 test. These proportions were significantly higher than among their non-disabled counterparts. This inequity highlights the importance of specifically tailored approaches that are needed for tāngata whaikaha Māori if equitable outcomes are to be achieved.

Among disabled Tāngata Tiriti survey participants, 30% expressed difficulty with cognition and 21% with mobility. Twelve percent reported that their disability was improved by having COVID-19, though no further details were given; of the others, half reported it stayed the same and half reported that it got worse due to contracting COVID-19.

The response from health services for disabled non-Pacific Tāngata Tiriti people did not reach expected levels of care as described by interviewees and survey participants. Among disabled Tāngata Tiriti survey participants, 44% reported facing at least one barrier to seeing a GP, significantly higher than their non-disabled counterparts ( $P=0.010$ ). Seventy one percent also reported facing a barrier to getting a COVID-19 test. The prevalence of anxiety (41%), depression (43%) and both combined (54%) were also significantly higher among disabled compared to non-disabled Tāngata Tiriti survey participants ( $P<0.001$  for each condition), indicating significant levels of mental distress among those with lived experience of disability.

## **RECOMMENDATIONS – PEOPLE WITH LIVED EXPERIENCE OF DISABILITY**

1. Recognise that those already disadvantaged are likely to face greater challenges in a pandemic. Support and resources should therefore be prioritised for those with greatest need. Having disabled people involved at the start in design and decision-making will ensure their needs are visible and solutions are appropriate.
2. Ensure there are easy-to-use, accessible options for disabled people so they can report adverse reactions or unmet health needs and the system responds in a timely manner.
3. Lockdowns and changes to the way health services have operated since the pandemic continue to make access more difficult for some disabled people. Supports such as transport or home services are needed to ensure equity of access.
4. Disabled people are knowledgeable about their own health and their lived experience should be valued. At the same time, health providers need to recognise health issues will not all be related to a disability; new issues need holistic assessment and treatment.
5. Ensure that when advice, public health messaging and COVID-19 support information of any kind is being communicated, that messaging reaches tāngata whaikaha Māori and disabled Tāngata Tiriti at the same time as non-disabled people, with no delay.

## TE WHAKARĀPOPOTOTANGA – KOWHEORI MAUROA

### EXECUTIVE SUMMARY – LONG COVID

Long COVID is a term that is used to describe ongoing or new symptoms following COVID-19 illness, which persist for at least three months following COVID-19 infection and are not explained by an alternative diagnosis (World Health Organization, 2021). In this Executive Summary, we report on the lived experiences of those with long COVID. We thank the survey participants and interviewees who shared their intimate stories with our researchers.

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## NGĀ KITENGA – KOWHEORI MAUROA

### STUDY FINDINGS – LONG COVID

Of the survey participants, 22% (n=217) met the WHO criteria for long COVID, including 33 Tāngata Whenua, four Pasifika peoples, and 181 non-Pacific Tāngata Tiriti, reporting at least one symptom lasting three months or more. Tāngata Whenua and Tāngata Tiriti were equally likely to report symptoms lasting more than three months. Pasifika peoples were less likely to do so. Neither age group nor gender predicted the risk of getting long COVID. A higher risk of long COVID was seen in people who had pre-existing heart disease or high BMI ( $\geq 25\text{kg/m}^2$ ). A higher risk of long COVID was also seen among people who, in the first month of having COVID-19, reported difficulty breathing, muscle aches, a change in taste or smell, chest pain, dizziness or brain fog. There was no association between attending hospital due to COVID-19 and developing long COVID.

The most frequently reported symptoms were fatigue, brain fog, shortness of breath, muscle aches, joint pain and anxiety, all of which were experienced by over 50% of either Tāngata Whenua, Tāngata Tiriti, or both. This range of symptoms was reflected in the stories of interviewees: many referred to experiencing extreme fatigue, something they had never experienced before. Some likened the physical effects of long COVID to “ageing”, reporting that they felt like they now had the conditions that older people often get.

There was a lack of understanding by health professionals reported by survey participants, including not feeling listened to or understood and noting that doctors seemed to have a lack of information or be misinformed. This confusion by health professionals contributed to the burden carried by people with long COVID. About a third of Tāngata Whenua and Tāngata Tiriti reported not being referred to a specialist, and some specialist referrals not being accepted. Interviewees recognised that much is new and unknown, but they wanted their doctors to be proactive about finding out more about long COVID. Overwhelmingly, people wanted an acknowledgement that we do not know enough about long COVID or how to treat it. Overall, the lack of good information on where to get help or on what to do to support themselves was a concern for many study participants. In the absence of professional support, some Tāngata Whenua interviewees resorted to spending a lot of money and energy doing their own research and seeking out their own solutions. Many interviewees turned to peer support, including through on-line groups, which some found useful, while others did not. The lack of knowledge or awareness of long COVID varied among interviewees and had some people doubting whether their symptoms were COVID-19-related, or just general poor health.

Survey participants reported sources from where they had received help for long COVID. Most reported informal help from their whānau, families, friends and neighbours. About half reported getting help or support from their GP, public health units and a smaller proportion from a nurse. Employers were also a reported source of help and support. The use of health services by people with long COVID was significant, with about one in six people with long COVID seeing their GP four or more times because of COVID-19 symptoms or ongoing impacts. Twelve percent of people with long COVID (Tāngata Whenua, n=4 (22%); Tāngata Tiriti, n=11 (10%)) reported experiencing a time they needed to see a doctor because of COVID-19 or long COVID but did not because they couldn't afford it.

Over half of survey participants with long COVID did not agree that they had received adequate health (56% for Tāngata Whenua and 53% for Tāngata Tiriti) or social care (47% for Tāngata Whenua and 33% for Tāngata Tiriti) for ongoing COVID-19 symptoms or long COVID. Interviewees encountered varying responses to their long COVID symptoms from health practitioners, from active investigation of symptoms to symptomatic treatment only, to dismissal of symptoms. People with long COVID had to fight to be seen and heard; this required a step up into self-advocacy, and was difficult for people already reduced in capacity. This was unsurprising for Tāngata Whenua, given their previous experiences of the health system. Others were told there was not much that could be done for them.

Survey participants reported that their usual activities were most affected by having had COVID-19, with over 40% reporting such effects. Both physical and mental activity had a detrimental effect on the symptoms of people with long COVID. For both Tāngata Whenua and Tāngata Tiriti, about three quarters reported that physical activity made their symptoms worse and around two thirds reported that mental activity affected their symptoms. Interviewees spoke of the difficulty of coping with the fatigue associated with previously normal activities, or mild forms of exercise such as walking or playing golf as well as more energetic sports. Interviewees also described the impact of long COVID on their social wellbeing, with emotional effects from socialising and cultural impacts from no longer being able to smell and taste food, so important to many aspects of tikanga Māori.

Around one third of survey participants reported moderate, extreme, or severe impacts of ongoing COVID-19 symptoms. Brain fog was a major ongoing symptom, and for many a major cause for concern, with some worried they might be experiencing the onset of dementia, and others struggling with daily tasks such as safely driving a car or remembering to shower. This was painful for whānau and family members to see. For others, there were significant impacts on their ability to work, and hence to earn sufficient income to support themselves, their whānau and their families. These impacts resulted in high reported levels of anxiety or depression; some participants experienced symptoms of post-traumatic stress disorder. People with long COVID talked about how the illness had challenged their sense of identity: how they see themselves now, when who they once were is there no more, having to slow down and no longer being able to participate in community activities of importance to them. Some also talked about a sense of loss and grief in having to make major changes in their lives and losing their sense of purpose. They reported having to try hard to look forward, and to be resilient.

A lack of available financial support through ACC or WINZ for those who lost their jobs or had to reduce their hours was identified as a major issue in Aotearoa, of significant concern to those with long COVID, who also lived with the uncertainty of how long the condition might last for.

Survey participants had constructive ideas about what matters to people with long COVID, and how care for people with long COVID could be delivered in the future. In particular, people need clear clinical pathways (including access to specialists), a long COVID clinic, better communication on what to do next and better-informed doctors who can help with a path to improvement. Interviewees with ongoing symptoms of COVID-19 desperately wanted to know what was happening to them and what could be done to help them. They spoke of being scared of the unknown. They want to be heard. And they want to be believed.

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## NGĀ TAUNAKI – KOWHEORI MAUROA

### STUDY RECOMMENDATIONS – LONG COVID

1. Include people with lived experience of long COVID in each change that is under consideration for the benefit of people with long COVID.
2. Ensure that all relevant policies, resource development, service commissioning etc, is pro-equity.
3. Establish a national long COVID centre to support local long COVID clinics. The national centre would be consumer-led and would develop evidence-based guidelines for wraparound services to support not just health but wider wellbeing, and resources to better support those with long COVID, including in culturally accessible forms and for those with lower health literacy. Local clinics would include case managers/navigators to work with people with long COVID to develop consumer-led local pathways for wraparound services to support both health and wellbeing. Such clinics should be widely available, free for the service-users, and available via telehealth, in order to ensure accessibility. Ideally, clinics should be located in the community, closely linked with primary health care and community-based Iwi, Māori providers, and Pasifika providers to foster integration with existing care. Specialist referrals should be included as needed.
4. Regularly review criteria for a diagnosis of long COVID and ensure these are communicated to health professionals.
5. Recognise that long COVID is multi-faceted, fluctuating and varied. Empower primary health care providers by acknowledging that it can be difficult to diagnose, developing an evidence-based symptom check list, and develop transparent and equitable referral criteria for specialist care.
6. Ensure that long COVID is recognised as a disability, to allow access to financial and practical support.
7. Recognise the value of peer support, and fund this as a key service, bearing in mind that peer supporters may themselves be struggling with the impacts of long COVID.
8. Plan for and develop policies and guidelines regarding the long-term care and support of long COVID consumers including but not limited to: work-safe policies, extended leave of absence for COVID-19 related illness, workplace accommodations, income support, and physical in-home care.
9. Develop a transparent and equitable policy around accessing financial support for people with long COVID. This must encompass the MSD/WINZ benefits system and ACC and should include an emergency long COVID fund for people with long COVID who are unable to access job seekers' allowances or other benefits.

Note: References for citations in this document are available in the accompanying full report.

