Mātauranga Raranga

Long COVID Registry

AOTEAROA NEW ZEALAND

The Burden of Long COVID in Aotearoa New Zealand: Establishing a Registry

Final Report to the Ministry of Health

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Mātauranga Raranga

This is the project's gifted te reo name. The kupu was gifted by our kaumātua Witi Ashby. It refers to knowledge sharing, thoughts weaving, spiritual determination, focus and working together. It can also reflect the science of creating something beautiful, useful and with purpose. Our vision is that the Long COVID Registry delivers mātauranga raranga.

Executive Summary

Long COVID is defined as the continuation or development of new symptoms 3 months after an initial COVID-19 infection, with these symptoms lasting for at least 2 months with no other explanation. Long COVID has been described as one of the most enduring impacts of the COVID-19 pandemic. It presents as a significant and escalating challenge, profoundly affecting the health, wellbeing, and socioeconomic stability of countless individuals. COVID-19 continues to circulate in the community, thus individuals remain at risk of long COVID.

This report highlights the burden of long COVID – the wide-ranging impacts on individuals, whānau, employment, the healthcare system and welfare state – and underscores the urgent need for comprehensive strategies to manage the condition. The findings emphasise the critical need for targeted policies, ongoing research, and public health initiatives to support long COVID sufferers and address the long-term consequences of the pandemic.

What is the lived experience of long COVID sufferers?

Getting a diagnosis: 58% of Māori and 64% of non-Māori long COVID sufferers have received a clinical diagnosis. At six months follow-up the proportion was similar (63%).

Inclusion in the registry only required individuals to self-report long COVID symptoms; 36-42% of individuals had not received a clinical diagnosis. This may be due to a lack of established clinical pathways, the absence of specific biomarkers, limited GP education on long COVID, and inadequate access to healthcare for chronic conditions.

A myriad of persistent symptoms: Fatigue, brain-fog and sleep issues are commonly reported symptoms, many of these symptoms had not improved in the 3 months before joining the registry and they still persist at 6 month follow-up. Other symptoms are also present including breathlessness, muscle and joint pain, headaches, chest pain, and an irregular heartbeat. Respondents reported the full range of symptoms.

These symptoms cause significant clinical impairment. More than half of Māori respondents and a third of non-Māori respondents report a shortness of breath/dyspnoea; there are high rates of moderate or severe depression and anxiety and high or very high levels of psychological distress, as measured using validated clinical screening tools. Reported levels of severe fatigue (~70% of Māori, 50% of non-Māori respondents) are much higher than those reported in international studies of long COVID.

This is evidence of a population with considerable unmet clinical need.

Health and quality of life is worse than before COVID: The self-reported health of sufferers is poor; prior to COVID-19 individuals with long COVID were healthy (not dissimilar to the average New Zealander), with long COVID 51% of Māori and 44% of non-Māori self-rate their health as poor. At 6 month follow-up 28% of respondents still report poor health. This pattern of poor health is replicated for self-reported mental health and health-related quality of life (HRQoL).

Pre-COVID 53% of Māori and 57% of non-Māori respondents reported they were in very good or excellent health, post-COVID with long COVID symptoms 27% of Māori and 21% of non-Māori report poor mental health. Long COVID has intensified mental health struggles.

HRQoL is measured using the EQ-5D-5L, a widely used generic measure. The reduction in EQ-5D-5L values is stark; long COVID sufferers in Aotearoa – who previously were similar to population norms – now have EQ-5D-5L values (0.488 for Māori and 0.529 for non-Māori) that are similar to individuals with MS and cancer. Long COVID substantially impacts individuals' quality of life – a finding that is supported in the international literature. The dimension impacted the most is usual activities, with 88% of Māori and 90% of non-Māori reporting a worsening in this dimension. Rich monthly follow-up data shows that the impact on quality of life endures.

Sufferers feel stigmatised: A significant portion of respondents reported facing stigma related to their long COVID symptoms, impacting their social interactions and mental wellbeing.

Increased healthcare needs: Long COVID sufferers reported substantially higher utilisation of healthcare services, with frequent visits to GPs and specialists being common among respondents.

This high utilisation is likely an underutilisation of appropriate services as many sufferers are unable to access referrals. This will cause distress, perpetuating poor quality of life and perceptions of stigma.

The symptom scales showing unmet clinical need, confirm that long COVID patients require significantly more care and support. Informal care has increased to meet this need: 1 in 4 Māori and 1 in 5 non-Māori respondents reported receiving informal care.

Impacts on employment and household finances: Most respondents reported that their work or study had changed because of their COVID-19 infection, in particularly there was a significant reduction in hours worked/studied (7 hr/week less for Māori, 9 hr/week less for non-Māori). Those that were working reported they had taken sick leave, used up their sick leave and consequently taken leave without pay. Presenteeism was very common – 71% of Māori and 61% of non-Māori respondents reported that they went to work despite being unwell. This results in lost productivity but may also be detrimental to long term health and wellbeing.

Changes in employment have impacted sufferers' income, a significant number of individuals reported that their income had declined. 28% reported a further decline at 6 months. There is some respite for those individuals who started to receive a new benefit (17% of Māori and 14% of non-Māori), but an increased reliance on government support is not a long-term solution.

Recovery: At 6 months registry participants were asked to complete a follow-up survey irrespective of their long COVID status. Only 4% of respondents reported that they were recovered after six months. Some respondents (at baseline and follow-up) reported receiving an alternative diagnosis, which can make tracking long COVID and understanding its full implications challenging.

Without specific biomarkers and with declining testing rates, tracking increases in associated symptoms and diseases will be crucial for public health. Patients often become confused about whether they are still considered to have long COVID when they receive additional diagnoses.

Future Implications

Increased Burden on Healthcare System: COVID-19 continues to infect and reinfect New Zealanders. With a large and possibly growing number of individuals experiencing long-term symptoms, the demand for healthcare services will continue to rise. This could further strain the healthcare system, requiring more resources and specialised care for long COVID patients.

Economic Impact: Prolonged illness among a significant portion of the population could lead to decreased rates of productivity and an increased burden on social support systems. Employers may face challenges with workforce shortages and reduced productivity.

Social and Mental Health Consequences: Long-term health issues and associated stigma can lead to increased social isolation and mental health problems, requiring more comprehensive mental health support services.

Policy and Support Needs: There will be a need for policies that provide financial and social support for long COVID sufferers, as well as public health strategies to manage the long-term impacts of the pandemic.

Research and Development

Ongoing research will be critical to understand long COVID better and to develop effective treatments. Investment in research could lead to improved management and care for long COVID patients in the future. It is imperative to develop integrated healthcare pathways and enhance support mechanisms to prevent worsening health outcomes for those affected by long COVID.

The Long COVID Registry will continue to recruit individuals who self-report long COVID and follow participants over time. The register will continue to be promoted as a research tool, a resource where long COVID projects can recruit participants. There is still much to understand and interrogation of the data (and linked data once uploaded to the Statistics NZ IDI) will continue.

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The project was overseen by a Rōpū Kaitiaki | Advisory Board led by Matua Witeria (Witi) Ashby (Ngāti Hine, Ngāti Kawa), with additional guidance from Whaea Iris Pahau (Te Aupouri, Te Rarawa, Ngāti Kuri, Ngāti Awa). The rōpū also included Ngapera Riley (Te Arawa, Ngāti Uenukukopako, Ngāti Rorooterangi, Ngāti Whakaue, Tūhourangi), Mona Jeffreys, Marianna Churchward (Lotofaga, Faleasiu, Samoa), Jenene Crossan (Ngāi Tahu), Andrew McCullough and Paula Lorgelly. Te Rōpū Kaitiaki consisted of tāngata whenua and tāngata tiriti replicating a partnership model of practice based on Te Tiriti o Waitangi. The purpose of the rōpū was to provide kaitiaki, manaaki and guidance for participants and researchers. We are indebted to the rōpū; their mahi and support has been invaluable.

It was important that this project was patient-led, reflecting the lived experiences of those with long COVID. Long Covid Support Aotearoa (LSCA) has been instrumental in this kaupapa. Run by a group of volunteers they have championed the registry and actively engaged with the project while managing and navigating their own health/wellbeing/life events. LCSA members have suggested research topics, provided feedback on the questionnaire design and online hosting, and offered interpretations of the data and results. Much of the promotion of the registry has been via the LCSA website and their social media presence. They also supported a small team to help with telephone interviews for those participants who could not complete the survey modules online. Ngā mihi nui ki a koe!

Finally, we are indebted to the participants in the Registry and those who have shared their stories. This report is for you and your whānau.

Whakataukī

Whāia te mātauranga hei oranga mō koutou.

Seek wisdom for the sake of your wellbeing.

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Acronyms

ACC	Accident Compensation Corporation
BPI-SF	Brief Pain Inventory – Short Form
CAMs	Complementary and Alternative Medicines/Therapies
CT scan	Computed Tomography scan
ED	Emergency Department
FAS	Fatigue Assessment Scale
GAD-7	General Anxiety Disorder-7
GP	General Practitioner
HRQoL	Health-Related Quality of Life
IDI	Integrated Data Infrastructure (Statistics NZ)
IMD18	Index of Multiple Deprivation (2018)
HIV	Human Immunodeficiency Virus
K10	Kessler Psychological Distress Scale
LCSA	Long Covid Support Aotearoa
LCSS	Long COVID Stigma Scale
MBIE	Ministry of Business, Innovation and Employment
MCID	Minimal Clinically Important Difference
ME/CFS	Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
mMRC	Modified Medical Research Council Dyspnoea Scale
MSD	Ministry of Social Development
MS	Multiple Sclerosis
NHI	National Health Index
PACS	Post-Acute COVID Syndrome
PASC	Post-Acute Sequelae of COVID-19
PHO	Primary Healthcare Organisation
PHQ-9	Patient Health Questionnaire-9
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2, also known as COVID-19
WHO	World Health Organisation
WINZ	Work and Income New Zealand
WSAS	Work and Social Adjustment Scale

Background

In the (Northern Hemisphere) spring of 2020, it became apparent that many individuals who had survived SARS-CoV-2 (COVID-19) were not recovering from their infection. Both hospitalised and community-managed cases were presenting with ongoing symptoms of breathlessness, fatigue, headaches, mental health problems and muscle and joint pains, as well as new symptoms of impaired cognitive function and brain fog [1]. Clinically described as post-COVID syndrome (or post-acute COVID syndrome, PACS, or post-acute sequelae of COVID-19, PASC), and subsequently owned by patients as long COVID [2], it has become apparent that long COVID may be one of the most enduring impacts of the pandemic [3,4].

The World Health Organisation (WHO) defines long COVID "as the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation" [5]. More recently the National Academies of Sciences, Engineering, and Medicine have developed a new consensus definition "Long COVID is an infection-associated chronic condition (IACC) that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems" [6]. Noting that long COVID manifests in multiple ways, and patients may present with single or multiple symptoms, including single or multiple diagnosable conditions. The National Academies note some important features of long COVID, and explicitly state that while long COVID occurs after a COVID-19 infection, this infection does not require laboratory confirmation, emphasising that long COVID can follow infections of any severity, including asymptomatic infections, whether they were initially recognized or not.

Long COVID is not a single condition, but an umbrella term for a myriad of symptoms including brain fog, fatigue, breathlessness, cardiovascular problems, pain, and mental health problems. More than 200 symptoms have been identified that impact multiple organ systems [7]. There is currently no diagnostic test to identify long COVID, and clinical diagnosis is by way of exclusion [8].

The lack of formal diagnosis can make estimates of prevalence difficult. Early evidence suggested that 10-20% of individuals with COVID-19 did not recover [9], now with vaccination, other variants, antivirals and recovery by some, prevalence is thought to be in the range of 4-14% [10–14]. Treatments are being trialled [15,16], but there is still much that is unknown [17]. Vaccination appears to lower the risk and symptom burden of long COVID [18], and antivirals are also effective [19]. It remains that the best way to avoid long COVID is by preventing infection with COVID-19 [20].

The burden of long COVID has been described as "so large as to be unfathomable," [21, p.632] however, researchers have provided estimates, beyond mere case numbers in an attempt to put a value on the impact of symptoms [22]. In the United States, Cutler [23] estimated the total economic cost of long COVID to be $3.7 trillion which included valuing the loss of quality of life, lost earnings, and medical spending; while in Germany, Gandjour [24] estimated that long COVID has resulted in production losses of €3.4 billion; gross value-added losses of €5.7 billion; €1.7 billion cost to the healthcare and pensions system.

The evidence-base with respect to long COVID in Aotearoa New Zealand is limited. The Ministry of Health funded *Ngā Kawekawe o Mate Korona* followed up with all individuals who had tested positive for COVID-19 prior to December 2021 [25,26]. The authors estimated a 22% prevalence of long COVID (with a lowest possible prevalence estimate of 2.7% under assumptions of selection bias). One third of participants reported not getting a referral to a specialist, and some specialist referrals not being accepted. There was also a reported lack of financial support [26].

One further New Zealand study has estimated the prevalence of ongoing symptoms a median of 1.7 years following infection in the first wave of infection, i.e. those infected with alpha/beta SARS-CoV-2 variants [27]. The small observational study (N=42) involved participants completing a number of patient-reported symptom questionnaires and laboratory testing of blood samples. The majority of participants felt that their health was worse now than before they contracted COVID-19. 90% of participants reported at least two ongoing symptoms since their first illness, and many participants were found to have anxiety, depression, breathlessness, pain and sleep issues when assessing symptom scales.

A limitation of both studies is that individuals who were infected in the early waves were recruited. From March 2020 until late 2021, Aotearoa New Zealand was pursuing an elimination strategy [28], and closed borders meant there had been few infections relative to the rest of the world. The arrival of the more transmissible omnicron variant resulted in a rapid increase in cases, from 1,226 cases at the end of December 2021 to a peak of 209,867 daily cases on the 11th of March 2022 [29]. It is thought that at least half of New Zealanders have now had a COVID-19 infection. Many of these individuals would have been vaccinated due to Aotearoa New Zealand's high rates of vaccination, although vaccine uptake was variable, particularly for Māori and Pasifika in part due to the national roll-out [30] which has led to an inequitable distribution of the burden of COVID-19.

Aotearoa New Zealand's pandemic response (delayed mass infection in a highly vaccinated population) and existing health inequities raises questions whether long COVID has a similar prevalence and/or impact as seen in other countries. Possible differences are further accentuated as while there is a Ministry of Health long COVID programme (an expert advisory group existed during 2022, diagnostic codes were introduced in August 2022, and management guidelines were released in September 2022), there were few (and now none) publicly-funded long COVID clinics, unlike in the United States and United Kingdom [31,32].

In late 2022 the Director-General of the WHO, Tedros Adhanom Ghebreyesus, called for immediate and sustained action to address the impact of long COVID [33]. Ghebreyesus laid out a five-point plan for urgent action. This included: listening to patient groups; ensuring equitable access and appropriate use of tests, therapeutics and vaccines; collecting systematic data from individuals with long COVID; sustained investment to progress scientific understanding of treatments; and integrating multi-disciplinary care into healthcare systems. On the need for systematic data collection Ghebreyesus said, "Not knowing the scale of the challenge or if the condition presents differently around the world or in certain patient populations, undermines the overarching response and delays the scientific community from understanding the nature of long Covid and how best to treat it." This project seeks to address this for Aotearoa New Zealand.

A long COVID disease registry will make an important contribution to both understanding how long COVID is presenting in Aotearoa New Zealand, including the distribution of the burden, as well as providing an opportunity to undertake further research in the future.

Objective

The objective of this project is to establish a long COVID registry and with that estimate the clinical, quality of life and economic impacts of long COVID in Aotearoa New Zealand, while providing a mechanism to continually monitor health outcomes and inequities.

Research questions

In addition to setting up the registry, the project sought to answer the following research questions.

1. What is the prevalence of long COVID symptoms in a cohort of individuals with self-reported long COVID?
2. What is the health-related quality of life (HRQoL) of individuals with self-reported long COVID? How does HRQoL change over time?
3. How are individuals who self-report long COVID accessing health care, what diagnosis and treatment have they received and what other treatment and management approaches are individuals utilising?
4. What impact has long COVID had on individuals' ability to work and undertake caring responsibilities?
5. What costs and expenses have individuals who self-report long COVID faced, including lost earnings?
6. How do the impacts listed above vary across severity of COVID-19 infection, time since infection, and socioeconomic and demographic characteristics?
7. Do any of the impacts listed above improve or worsen over time?
8. How does deprivation affect the burden of long COVID?

Establishing a Registry

To answer these research questions the project employs a registry-based cohort study design to collect data from individuals aged 18 years and older who self-report long COVID. A focus on self-reported long COVID (and explicitly not requiring a clinical diagnosis) was important given the current challenges individuals are facing accessing services and getting a diagnosis (as evidenced in international studies [34] and also *Ngā Kawekawe o Mate Korona* [25]).

The registry and data collection tools were co-designed in consultation with individuals with lived experience of long COVID. The registry needed to be more than the collection of clinical data, given the broad impact of the condition. At the time of design there were some early indications of what a core outcome set might look like [35,36]. There was a need for comprehensive data collection, but not a questionnaire that was so long that it exacerbates one of the most common long COVID symptoms of fatigue. Individuals with lived experience and members of the Kaitiaki Rōpū were key to ensuring that data collection was both specific and realistic, addressing the needs of the research project and the needs of individuals with long COVID. It was important that the registry was designed with this collaborative approach, ensuring there is a minimum dataset to support future research, without overburdening participants.

The questionnaire that forms the basis of the registry was split into different survey modules, which allowed for participants to stop, rest or leave, and return to the registry, answering questions at their own pace and discretion. The registry was built on the Qualtrics survey platform and hosted on a University of Auckland webpage https://www.lcregistry.auckland.ac.nz/. Interested participants were directed to read the participant information and then join the registry using Google authentication. Using Google sign-in was both a means to secure the data and improved the functionality of the registry, avoiding the need for additional logins when individuals stop and come back to the registry. After signing in via Google, participants are requested to consent to: take part, receive follow-up surveys, receive information on other research studies they may be eligible for, and/or have their registry data linked to information held by Statistics New Zealand in the Integrated Data Infrastructure (IDI). After consenting the participants are directed back to the dashboard to begin the modules. Participants can review their consent preferences and withdraw on the registry dashboard.

It is important to document that there were some challenges with the Qualtrics software, including some participants getting an error message when logging in (after signing up): "Sorry, an unexpected error occurred". This error was escalated to Qualtrics and unfortunately their engineers could not find a solution. Within the research team two workarounds were developed and conveyed to those individuals who reached out to the project team. It is acknowledged that for a small proportion of those who experienced the error may have been lost to at this point not continuing or completing the survey modules. The workarounds included using a private browser as it was thought the login issues were due to cookies, and sending out individual links to survey modules which were subsequently linked together when the registry data was downloaded. Telephone interviews were offered to those individuals who were not able to complete the survey modules online or did not have a Google account.

The registry was promoted to individuals via the Long Covid Support Aotearoa website https://longcovidsupport.co.nz/ and newsletters, social media platforms, and received coverage in the traditional media (RNZ, The Herald, Stuff, Newsroom, The Listener).

Figure 1 offers a depiction of the registry, from the initial promotion on the LCSA website and via social media, through the sign up and login features and then the various modules. The ‘Who are you?’ module asks several demographic questions including participants National Health Index (NHI) number for subsequent linking to the IDI. In this module participants are also asked to provide their address within an imbedded IMD Qualtrics

Survey Module [37] which converts a New Zealand street address into a data zone and attaches an IMD18 deprivation score and domain ranks to the response [38].

Instruments and questionnaires

This section provides further details on the various instruments and scales used in the survey modules.

To assess the degree of disability that breathlessness poses on day-to-day activities the modified Medical Research Council (mMRC) dyspnoea scale is used [39]. It is a self-rating tool that measures on a scale of 0 to 4: no breathlessness except with strenuous exercise (0); shortness of breath when hurrying on the level or walking up a slight hill (1); walking slower than people of same age on the level because of breathlessness or having to stop to catch one's breath when walking at their own pace on the level (2); stopping for breath after walking ~100 metres or after a few minutes on the level (3); and too breathless to leave the house, or breathless when dressing or undressing (4). The scale does not measure breathlessness directly, but the degree of activity at which a person gets breathlessness or limits what a person can do. It was originally developed as an epidemiology tool but is frequently applied at an individual patient level. The scale has been validated in several patient populations [2,3]. Key for its inclusion in the registry was that it allows self-completion and other long COVID studies are using it.

The Patient Health Questionnaire (PHQ-9) is used to screen for the presence and severity of depression [42]. While widely used in healthcare and community settings [43], it is often included in surveys of the general population [44]. Nine questions ask respondents to report how bothered they are (not at all to nearly every day) by various problems. Each item is scored 0 to 3 and aggregated together to give a PHQ-9 score. Scores are categorised to represent non-minimal depression (<5), mild depression (5-9), moderate depression (10-14), moderately severe depression (15-19) and severe depression (≥20). Estimates of the minimum clinically important difference (MCID), the smallest reduction in depressive symptoms that matter to patients, suggests a reduction of 21% on the PHQ-9 [45] or 5 points [46].

The Generalised Anxiety Disorder Questionnaire (GAD-7) has been shown to be an efficient and valid tool for screening for generalised anxiety disorder and assessing its severity in clinical practice and research [47]. There are seven items scored 0-3 for the frequency of different problems: not at all, several days, more than half the days, or nearly every day. The items are summed to give a GAD-7 total score ranging from 0 to 21. Scores of 5, 10, and 15 are taken as the cut-off points for mild, moderate and severe anxiety, respectively. When used as a screening tool, guidelines suggest further evaluation is recommended when the score is 10 or greater [47]. Research has shown that as a tool it is sensitive to detect change, and that the MCID is 4 points, that is any difference greater than 4 is significant and clinically meaningful [48].

The Kessler Psychological Distress Scale (K10) was developed to provide a global measure of psychosocial distress, based on questions about people's level of nervousness, agitation, psychological fatigue and depression in the past four weeks. It was developed as a short dimensional measure of non-specific psychological distress in the anxiety-depression

spectrum. There are ten items with five-level response scale to reflect the amount of time an individual experienced a particular feeling (none, a little, some, most, all the time). The items are scored 1 to 5 and summed to give a minimum score of 10 and a maximum score of 50. Low scores (<15) indicate little or no psychological distress, scores of 16-21 reflect moderate distress, scores 22-29 reflect high distress, and scores >30 suggest very high levels of psychological distress, and research has shown that these individuals may need professional help.

Fatigue was assessed in the registry using the Fatigue Assessment Scale (FAS) [49]. The FAS is a self-completion questionnaire consisting of 10 items which give a summary score between 10 and 50. Half the items reflect physical fatigue and the other half mental fatigue. Scores below 24 indicate no fatigue. Individuals scoring between 24 and 35 can be classified as having moderate fatigue, while scores above 35 show a high level of fatigue [50]. It has been shown to be a reliable and valid questionnaire [49], and researchers have estimated minimally important differences for the summary score of 4 – 4.86 [51,52] .

Pain, its severity and impact, is measured using the Brief Pain Inventory (Short form) (BPI-SF) [53]. The BPI-SF is a reliable and valid tool [54]. Pain severity is assessed using four items inquiring about pain intensity, while the impact of pain is assessed using seven items querying pain interference. Individuals self-report pain intensity from no pain (0) to worst pain (10), and pain interference from no interference (0) to total interference (10). Items are aggregated and averaged, a higher score reflects greater pain intensity and interference. Respondents are also asked to record where on their body they feel pain, including the area that hurts the most. These areas are summarised to quantifying the location of pain and the frequency, in the form of pain drawings [55].

Two commonly used global self-assessed health questions were included as generic measures of health status. One question asked about general health and the other mental health, both used a 5-point Likert scale, ranging from excellent to poor. To understand the impact of long COVID, one set of questions asked for a self-assessment before respondents had COVID-19, thus offers an estimate of recalled (mental) health, and the other set enquired about their assessment today.

The EQ-5D-5L is a self-completing instrument to assess health-related quality of life [56,57]. It has five dimensions – mobility, self-care, usual activities, pain & discomfort, anxiety/depression – each with five levels (no problems to extreme problems/unable to). Respondents report their health status today captured as a 5-digit descriptive profile ranging from 11111 (no problems in any dimension) to 55555 (the most severe problem in every dimension). There are 3125 health states which have been valued using the New Zealand general public to give an index [58]. The index values range from 1 (full health) to 0 (dead); negative values are possible, and these reflect health states considered to be worse than dead by the general public. Also included in the EQ-5D-5L is a visual analogue scale – the EQ-VAS – where respondents are invited to provide a global assessment of their health on a scale where 100 is the best imaginable health and 0 is the worst imaginable health. As with self-assessed health questions, the instrument was amended (with EuroQol permission) with past tense wording to allow respondents to recall their health before they had COVID, as well as respond for today with long COVID. The EQ-5D-5L has been validated in numerous chronic conditions [59–61] , and it has been included in a number of long COVID studies. del Corral et al [62] recently estimated that the

minimal clinically important difference for individuals with long COVID is a change of at least 0.265 for the EQ-5D-5L index and 7.5 for the EQ-VAS in a Spanish population.

The extent to which individuals with long COVID feel stigmatised is measured using a newly developed Long Covid Stigma Scale (LCSS) [63]. Thirteen questions explore the extent to which individuals never, rarely, sometimes, often, or always (coded 0–4) feel, expect or experience stigma. Similar to the Health Stigma and Discrimination Framework [64] the LCSS captures three dimensions of stigma: enacted (5 items), internalised (4 items), and anticipated (4 items). The items are used to quantify the prevalence of stigma at least sometimes and, separately, often or always. An overall summary LCSS score can be estimated by aggregating the individual item scores.

The Work and Social Adjustment Scale (WSAS) measures impairment in functioning [65]. It has five items that evaluate the impact that an individual's condition or problem has on their ability to function in terms of work, home management, social leisure, private leisure and personal or family relationships. The scale is from 0 not at all to 8 very severely. Item scores are aggregated, giving a WSAS score of between 0 and 40. Higher scores indicate more significant functional impairment, scores above 20 indicate moderately severe or worse impairment, scores between 10 and 20 represent significant functional impairment, and scores below 10 are considered subclinical. It has been applied in a numerous patient groups including those with chronic fatigue [66] and found to be a valid measure with an MCID of 8 points [67].

Other questions were informed by general population surveys in New Zealand – including the 2018 Census and the New Zealand Health Survey – and from international long COVID research [36,68–70].

Ethical approval

Ethical approval was received from the Health and Disability Ethics Committee on 7th June 2023 (ref 2023 EXP 15097).

Analytical Framework

Kaupapa Māori

The registry operates under Te Tiriti o Waitangi relationship framework, which incorporates the following principles:

- Recognises that Te Tiriti o Waitangi | Treaty of Waitangi was signed between Tāngata Whenua and the Crown.
- Accepts that the grievances that Tāngata Whenua have suffered as indigenous people of Aotearoa need to be addressed structurally and culturally beyond the Treaty settlement process using a different approach to current and future relationship development.
- Acknowledges that Tāngata Whenua have the right and the responsibility to manaaki all Tāngata Tiriti who come to Aotearoa in a manner that expresses Tikanga Māori and acknowledges cultural worldview difference.

This relationship framework is fundamental to positive research outcomes. Additionally, a Kaupapa Māori approach was employed that uses a Māori/non-Māori analytical frame [71,72]; that presents separate analyses rather than including ethnicity as a covariate. Such an analytical framework recognises "the fundamental nature of our [Māori] relationship with the Crown affirmed in te Tiriti o Waitangi and our expectations of good governance and for equity" [71, p.193]. It is acknowledged that the non-Māori group includes Pacific people who have similar health and socioeconomic experiences to Māori and therefore it may underestimate inequities. Should the registry sample sizes allow the analysis could be extended to a Pasifika group and a comparison non-Māori/non-Pasifika group (as in *Ngā Kawekawe o Mate Korona* [25]). For now, a Māori/non-Māori analysis is more practical in the context of data quality and statistical power limitations and provides a non-overlapping comparison group.

Concerns have been raised that in epidemiological research the quality of ethnicity data may misclassify Māori incorrectly as non-Māori, but as ethnicity is self-reported in the registry this misclassification should not occur [72]. This Kaupapa Māori approach seeks to avoid deficit framing, where research invisibilises the historical and institutional drivers of inequities for marginalised groups, therefore placing blame for inequitable outcomes on marginalised individuals and collectives [73].

Statistical analysis

The statistical analysis is largely descriptive; categorical data are summarised as proportions expressed as percentages and continuous data is summarised as means and standard deviations or medians and interquartile ranges. These descriptive statistics attempt to quantify the lived experience of Māori and non-Māori individuals with long COVID. Following Statistics NZ guidelines, cells with fewer than six people have been suppressed in tables and figures and rounding is employed to support secondary suppression [74]. For the questions that are asked with reference to pre-COVID and now with long COVID, chi-squared tests for proportions or t tests for equality of means are used to assess whether any differences are significant. This statistical analytical approach is also employed when comparing impacts between groups as categorised by disease and sociodemographics or when comparing baseline and 6 month follow up responses.

Data were downloaded from the Qualtrics server, and survey modules and follow-up surveys were merged using R 4.4.0 [75]. Analysis was undertaken in Stata 18.0 [76].

Findings

The registry remains open to enrolments, and the results presented are for those enrolled as of the 31st March 2024, reflecting 8½ months of recruitment.

Sample

As of the 31st March 2024 there were 1,348 unique individuals in the registry. With respect to ethnicity 1,157 (85.8%) respondents identified as New Zealand European, 116 (8.6%) as

Māori, 21 (1.6%) as Pasifika, 15 (1.1%) as Chinese, 15 (1.1%) as Indian and 192 (14.2%) as another ethnicity, 6 participants preferred not to report an ethnicity. An analysis of prioritised ethnicity (where people are allocated to a single ethnic group in an order of priority, even if they identified with more than one ethnicity) finds that there are 116 Māori participants, 15 Pasifika participants, 46 Asian participants, and 1,165 New Zealand European or other ethnicity participants.

In keeping with the analysis framework and a desire to avoid deficit framing, separate analyses are conducted for Māori (tāngata whenua) N=116 and non-Māori (tāngata tiriti) N=1,232 respondents, where suppression rules allow. Some analyses, including that with the smaller follow-up sample (see below), do not allow for separation by ethnicity without suppressing a large number of Māori findings, so in these instances the sample is not separated, so should be considered indictive for Māori rather than definitive.

Consent

All participants consented to take part in the registry. With respect to the other consent requests: 100% of Māori participants and 99.1% of non-Māori participants consented to receive email reminders to complete follow-up surveys; 100% and 97.1% of Māori and non-Māori participants respectively consented to be sent information on other research studies they may be eligible to take part in; and 100% and 93.6% of Māori and non-Māori participants respectively consented to have their registry data linked with other person-centred data held by Statistics NZ in the IDI. Note some of these percentages have been rounded to support suppression.

The high level of consent and subsequent engagement in follow-up surveys (see below) has resulted in a database that will be invaluable for future research; both primary research which recruits participants for future studies, and also secondary research using the rich data collected on individuals with long COVID, the majority of which will be linked to the IDI.

Module responses

The number of Māori and non-Māori respondents completing each survey module of the registry is presented in Figure 2. The latter survey modules have a lower completion rate, as expected despite designing the survey to allow for respondents to come and go.

Also presented are the number of participants who responded to the monthly EQ-5D-5L follow-up surveys and 6 monthly follow-up survey. The number of responses for the monthly EQ-5D-5L follow-up surveys are increasing as more individuals join the registry each month. Engagement in these follow-up surveys remains strong, the response rate varies from 40.9% to 54.1%.

The 6 monthly follow-up survey began in late January 2024. It was sent to those participants who had joined the registry six months prior. In order to maximise the data available for this report the 6 month follow-up survey data was downloaded on the 15th April 2024. The sample of respondents for the 6 month follow-up survey is 224; this is equivalent to a response rate of 35.8%.

Participant characteristics – Who has long COVID?

The sample characteristics are presented in Table 1. The average age of Māori (non-Māori) respondents is 45 (49) years old, and 75.2% (73.5%) of respondents are female. This aligns with the international literature that the long COVID patient population is predominantly female [77], although notably nearly a quarter of registry respondents are male.

Respondents are more highly educated than the New Zealand population [78] and correspondingly have higher household income [79]. 41.4% (45.2%) of Māori (non-Māori) respondents have private health insurance, this is a higher proportion than the general population as reported in the 2022/23 New Zealand Health Survey [80]. These dissimilarities are likely due to the method of data collection, not directly linked to long COVID as a condition.

The IMD18 deprivation quintiles suggest that non-Māori respondents reside in less deprived areas, 23.8% in Quintile 1 and 23.7% in Quintile 2, compared with 20% of the New Zealand population in each of those quintiles. The pattern of deprivation for Māori respondents is variable, there are fewer respondents in Quintile 1 (15.2%), compare to the population (20%), and more in Quintile 5 (25%), but there are also more in Quintile 2 (25%) than present in the New Zealand population.

The Ministry of Business, Innovation and Employment (MBIE) [81] estimated that during level 4 restrictions there were 529,000 essential workers who were going work, of 2.645m total employees, that is 20% of all workers were considered essential. 150,000 of these were in the health care and social assistance sector, that is 28% of essential workers were healthcare workers. 37.9% (32%) of Māori (non-Māori) respondents in the registry reported they were considered an essential worker during COVID-10 lockdowns, and 36.4% (40%) of these were healthcare professionals. Therefore the registry is over representative of these workers, although there is evidence to suggest that essential workers are at greater risk of COVID-19 exposure and therefore long COVID [20].

Nearly all respondents are vaccinated, and the mean number of vaccines is 3.26 (3.44) for Māori (non-Māori) respondents.

COVID-19 experience

The majority of individuals in the registry were first infected with COVID-19 in 2022 (Table 2), this aligns with the relaxation of mitigation measures and the arrival of the Omicron variant of SARS-CoV-2. The mean of COVID-19 infections is 1.69 (1.46) for Māori (non-Māori) and the majority of respondents noticed long COVID symptoms after their first infection, although a third noticed it after their second infection.

Most respondents were unwell for 10 or more days with the COVID-19 infection that they believed gave them long COVID (Table 2). When asked to self-report the severity of their COVID-19 symptoms (listed as cough, sneezing, runny nose, fever, loss of smell, altered sense of taste, sore throat, short of breath, fatigue or feeling of tiredness), the mean number of severe symptoms was greater than 2. The most common severe COVID-19 symptom was fatigue, then shortness of breath and then a sore throat (see Figures 3 and

4). Hospitalisation was rare, only 9.2% and 7.5% of Māori and non-Māori respondents reported a hospital admission for any COVID infection (Table 2). Just over a quarter of Māori respondents reported being prescribed antivirals; this reflects the prescribing criteria that prioritises Māori and Pasifika people aged over 50 years old.

Long COVID diagnosis

There is considerable variation in the registry with respect to the number of days that respondents have had long COVID symptoms. Table 3 shows that the average Māori respondent in the registry has had symptoms for 376 days, while the average non-Māori respondent has had symptoms for 343 days. Some respondents joined the day they recognised symptoms, possibly due to searching for information to understanding their symptoms, discovering the LCSA website and being directed to the registry. Others in the registry have had long COVID since 2020.

The majority of respondents in the registry have received a clinical diagnosis (diagnosed by a GP or specialist), 57.8% of Māori respondents and 64.3% of non-Māori respondents. A small number of respondents considered themselves recovered (9.3% and 5.6% of Māori and non-Māori) but this includes at least 11 individuals who noted they had recovered but then related with reinfection. Some respondents have received an alternative diagnosis for their symptoms, including 8 who have received a diagnosis of ME/CFS.

Long COVID symptoms

Registry participants were asked what long COVID symptoms they have experienced (using the list of common symptoms as source on the Ministry of Health in June 2023). Figures 5 and 6 present the symptoms that respondents reported experiencing, whether as a current symptom, a previous symptom or they have not experienced it.

Fatigue, brain fog (loss of concentration), sleep issues, sleep disturbance, and breathlessness are the top 5 most common symptoms ever experienced by Māori respondents; for non-Māori respondents the top 5 symptoms ever experienced are fatigue, brain fog, headache, sleep disturbance, and sleep issues. Many of these symptoms have not improved over the previous 3 months (see Figures 7 and 8).

The lived experience of these long COVID symptoms are explored further using various symptom scales (see Table 4). The modified MRC Breathlessness scale suggests more than half of Māori respondents and more than a third of non-Māori respondents have dyspnoea or a shortness of breath (Grade 2 or higher). These proportions are higher than that reported in a Danish post-COVID cohort with long COVID [82], and similar to a systematic review and meta-analysis that used a lower criteria (Grade 1 and above) [83], these imply that the registry participants have more shortness of breath compared with other long COVID studies.

Depression, anxiety and psychological stress, measured using the PHQ-9, GAD-7 and K10 respectively are more prevalent in the registry participants than in the general New Zealand public. Table 4 shows that 36.4% and 29.1% of Māori and non-Māori respondents have moderately severe or severe depression, while 41.1% and 25.4% of Māori and non-

Māori respondents have moderate or severe anxiety. In a cohort study exploring the impact of the pandemic in the early days (May-June 2020) reported mean PHQ-9 and GAD-7 scores of 7.88 and 6.26 respectively [84]. Gasteiger and colleagues went on to show that these were significantly greater than published population norms (2.91 and 2.95 respectively). The mean PHQ-9 and GAD-7 reported in Table 4 are similar or higher to those reported by Gasteiger et al [84], thus it can be concluded that long COVID symptoms have a significant impact on depression and anxiety. Similarly for psychological distress; the New Zealand Health Survey [80] reported that in 2022/23, 1 in 8 adults (11.9%) reported high or very high levels of psychological distress. Table 4 shows that 53.4% of Māori respondents and 36.2% of non-Māori had high or very high levels of psychological distress.

The Fatigue Assessment Scale (FAS) findings in Table 4 show that only 1 in 10 respondents reported experiencing normal levels of fatigue. Nearly 70% of Māori respondents and more than half of non-Māori respondents reported experiencing severe fatigue. Māori respondents have a mean FAS score of 36.53 and non-Māori respondents a mean FAS score of 34.03. These registry estimates are much higher than the international literature on fatigue in individuals with long COVID: Kircheberger et al [85] reports a mean FAS of 22.96 in non-hospitalised individuals with post-COVID syndrome compared with a mean FAS of 15.56 in individuals without long COVID, while O'Sullivan et al [86] reports a mean FAS of 23 in hospitalised patients, 26 in patients managed in the community but with ongoing symptoms (e.g. long COVID), 17 in patients with community illness now recovered, and 15 in a comparison population.

The Brief Pain Inventory (BPI-SF) explored the presence, intensity and interference of pain. 68.4% (58.9%) of Māori (non-Māori) respondents reported experiencing pain today (see Table 4). The presence of bodily pain in specific areas is depicted in Figures 9 and 10. The existence of pain, its severity and interference is similar to those in a Spanish study [55], which found much higher pain values in those with long COVID (69.5%) compared to individuals who had recovered from COVID-19 (26.3% in pain) and a healthy control group (23.3% in pain).

Impact on health

Participants in the registry were asked to self-report their health prior to their COVID-19 infection. The distribution of self-assessed health is given in Table 5. Pre-COVID 60.6% of Māori respondents said they were in very good or excellent health, for non-Māori this was 62.3% of respondents. In the 2022/23 New Zealand Health Survey, the general population reported 41.4% of Māori and 55.1% of non-Māori were in very good or excellent health [80]. After COVID and with long COVID symptoms 51.1% of Māori respondents and 44.4% of non-Māori respondents were in poor health. This difference was statistically significant for non-Māori.

With respect to self-assessed mental health, a similar pattern is apparent (see Table 5). Before COVID-19 the majority of respondents reported they had very good or excellent mental health (52.5% of Māori, 56.6% of non-Māori respondents), whereas today on joining the registry their mental health had declined (26.6% of Māori and 20.6% of non-

Māori respondents reported poor mental health). The difference pre-COVID and today with long COVID symptoms is statistically significant for both Māori and non-Māori.

Other health impacts that are evident include the number of reported comorbidities; pre-COVID the average number of comorbidities respondents self-reported was 3.02 (2.64) for Māori (non-Māori), with long COVID symptoms respondents reported on average 4.29 (3.71) comorbidities for Māori (non-Māori). This is a statistically significant increase.

Respondents were also asked to consider whether they had/have a disability, impairment or a long-term condition (with reference to the Ministry of Health's definition). In 2013 (the most current population data available) 24% of New Zealanders identified as having a disability [87]. In the Long COVID Registry, 31.3% (28.8%) of Māori (non-Māori) respondents said they considered themselves to have a disability, impairment or long-term condition pre-COVID. whilst now with long COVID 86.6% (84.4%) of Māori (non-Māori) respondents consider themselves to have a disability, impairment or long-term condition. These differences are statistically significant for both Māori and non-Māori samples.

Impact on quality of life

Participants in the registry were asked to complete the EQ-5D-5L reflecting on a time before they had COVID-19, and today with long COVID. The EQ-5D-5L index pre-COVID is 0.856 (0.887) for Māori (non-Māori) respondents. Applying New Zealand population norms to the registry sample for Māori [88] and non-Māori [89], given the age and gender distribution, suggests that the EQ-5D-5L would be 0.822 for Māori and 0.847 for non-Māori for this sample – thus the reported EQ-5D-5L pre-COVID are not too dissimilar to those of the general population. This is also true for the EQ-VAS. Applying population norms to the sample would suggest an EQ-VAS of 71.5 (74.6), slightly lower than the self-reported recalled pre-COVID EQ-VAS scores of 80.4 and 81.3 for Māori and non-Māori respondents.

Significant differences are apparent when comparing the pre-COVID responses with 'today' when joining the registry. EQ-5D-5L values today with long COVID are 0.488 for Māori and 0.529 for non-Māori. Whilst EQ-VAS scores are 44.7 and 48.6 for Māori and non-Māori respectively. These are statistically significant declines compared with pre-COVID levels. The decrement in health-related quality of life (HRQoL) due to long COVID is similar to that reported in the international literature [90–92]. Notably these long COVID EQ-5D-5L values are lower than has been reported for a cohort of New Zealanders with multiple sclerosis (MS) [93].

Figures 11 and 12 explore the specific dimensions of the EQ-5D-5L and the change pre-COVID to today with long COVID. The dimension that is impacted the most is usual activities. 87.9% of Māori respondents and 90.1% of non-respondents reported a worsening in this dimension. Usual activities is described in the EQ-5D-5L questionnaire as work, study, housework, family or leisure activities.

Participants who consented to be followed up received monthly EQ-5D-5L surveys. Analysis of these in Figure 13 shows that the decrement in EQ-5D-5L values from baseline continues. There is a slight increase, but not back to the initial pre-COVID or population norm levels. It is evident in the boxplot for non-Māori respondents that there are several

outliers (the lower dots), these individuals report poor HRQoL, using the lowest levels on the EQ-5D-5L instrument (unable to walk about/wash or dress/do usual activities, in extreme pain or discomfort, and/or extremely anxious or depressed.

Impacts on health behaviours, life satisfaction, whānau and caregiving

Table 6 shows the wider impact on individuals in terms of changes in their health behaviours and lifestyle. 38.9% and 36.9% of Māori and non-Māori respondents now drink less alcohol than before they have COVID-19, and the majority of respondents who smoked or vaped before COVID-19 have quit or reduced their consumption. All Māori respondents and 94.2% of non-Māori respondents are, however, less physical active now with long COVID, and 76.1% (70.2%) of Māori (non-Māori) respondents report worse quality of sleep (this aligns with the reported long COVID symptoms of sleep issues and sleep disturbance).

Nearly half of respondents report low overall life satisfaction, whereby 48.8% of Māori respondents and 50.3% of non-Māori respondents are somewhat or completely dissatisfied with life (see Table 7). All Māori respondents and 91.4% of non-Māori respondents report that life is worse now compared to before long COVID.

Respondents report impacts on their whānau | family: 58.3% (38.4%) of Māori (non-Māori) respondents think their family is coping worse than before they had long COVID, and 32.6% (28.3%) of Māori (non-Māori) respondents feel that their family needs more support.

The further effects on whānau can be seen in Table 8; 28.8% (16.7%) of Māori (non-Māori) respondents were informal caregivers prior to COVID-19 (defined as care, support or assistance, generally unpaid, to a friend or whānau | family member who has a health problem or disability), this has significantly reduced now that respondents have long COVID. Very few respondents were receiving informal care prior to COVID-19, now 1 in 4 of Māori respondents and 1 in 5 non-Māori respondents are receiving care from friends or whānau.

Stigmatisation

Table 7 shows that most respondents have been open with friends and family with respect to their long COVID, although 20% of Māori and 16.1% of non-Māori respondents have told as few people as possible.

Further exploring the stigma individuals with long COVID experience finds that a large proportion of respondents feeling stigmatised at least some of the time and many often or always feel stigmatised (Table 9). The Long Covid Stigma Scale (LCSS) for Māori respondents has a mean value of 24.03, for non-Māori respondents it is 20.29. These responses are similar to the stigma reported in a group of individuals in the United Kingdom with long COVID (mean=20.4) [63].

Healthcare use

It is interesting to understand how these symptoms, self-reports of poor health and wellbeing manifest with respect to access to healthcare services. Registry participants were asked about their use of the health care system, medicines, treatments and diagnostics. There was considerable heterogeneity in the respondents' resource use. Some respondents reported limited use of healthcare, while others were high users, hence Table 10 reports medians (and the interquartile range).

The New Zealand Health Survey 2022/23 reports that 73.2% of New Zealanders visited a GP in the last 12 months, and the mean number of visits was 2.4 [80]. 83.3% and 84.4% of Māori and non-Māori respondents in the registry reported visiting a GP for their long COVID symptoms in the last 6 months, the median number of GP visits for respondents' long COVID symptoms was 3 for Māori and 2 for non-Māori over the previous 6 months (see Table 10). This suggests individuals with long COVID are more likely to attend a GP and have higher attendance.

The pattern is somewhat dissimilar for visits to the practice nurse. The New Zealand Health Survey reports 31.6% of New Zealanders attend a practice nurse, 0.7 times in the last 12 months [80]. In the registry 27.1% (28.5%) of Māori and non-Māori respondents have consulted a practice nurse in the last six months. With respect to emergency department (ED) visits 22.9% (13.7%) of Māori (non-Māori) respondents attended in the last 6 months, compared with 17.9% of New Zealanders in the previous 12 months [80]. Many respondents (37.5% of Māori; 47.6% non-Māori) reported consulting with other healthcare providers in the previous 6 months. Analysis of the job titles of these providers is presented in Figure 14. Physiotherapists, cardiologists and respiratory specialists were mostly commonly consulted.

Many respondents reported having diagnostic tests to better understand their long COVID symptoms (56.3% of Māori, 51.6% non-Māori). Blood tests and ECGs were most common (Table 10). Other specific diagnostic tests reported included CT scans, ultrasounds, gastroscopy, colonoscopy and blood pressure assessment (Table 11).

A large number of respondents were taking medications, and 55.3% and 49.6% of Māori and non-Māori respondents reported being prescribed medications for their long COVID symptoms. Details of these are listed in Table 13, and include Symbicort (budesonide/ formoterol), vitamin D/B12, and low dose naltrexone.

Table 14 reports that more than 70% of respondents are taking vitamins or supplements, including vitamin D and vitamin B12. Practice of complementary and/or alternative therapies is common – 46.8% of Māori and 36.1% of non-Māori respondents report this – including the practice of mediation, massage and herbal therapies.

Registry participants were asked to report how much they paid for each healthcare consult (using a range of values). Applying these costs (lower and upper bounds of the range) to the number of consultations in the previous 6 months and adding to this how much respondents reported paying out-of-pocket for any diagnostic tests provides an estimate of the personal total cost of seeking care for long COVID symptoms in the last 6 months. Conservative estimates (using the lower bound) suggest Māori and non-Māori respondents have paid a median value of $160 in the 6 months prior to joining the registry (see Table

15). Using the upper bound this median cost is between $220 (for non-Māori) and $245 for (for Māori). Many respondents were able to receive care at no cost via the public health system including free GP care, while others paid upwards of $1,000 to consult with specialists.

Impacts on employment

While the majority of respondents were employed (full time, part time or self-employed) (see Table 16), 76.0% of Māori and 68.3% of non-Māori respondents reported that their work or study situation had changed because they had had COVID-19. Comments provided by respondents as to how their situation had changed referred to losing their job due to ill health or having to leave their job, working less hours, changing to a less demanding role, moving to part time employment, and taking early retirement. This changing situation is supported by analyses of the of labour market in the United Kingdom [94,95]. Ayoubkhani et al [94] found that, compared with pre-infection periods, inactivity (individuals not working and not looking for work) was higher in participants with long COVID 30-40 weeks post-infection. The authors estimated in that July 2022 27,000 working age adults were inactive in the United Kingdom because of long COVID.

The registry respondents changes in employment is reflected in mean hours worked or studied: pre-COVID this was similar to a 40-hour week (39 hours for Māori, 38 hours for non-Māori) and now with long COVID symptoms Māori (non-Māori) respondents reported working/studying for 32 hours (29 hours) a week. This reduction (7.3 hours for Māori, 9.4 hours for non-Māori) is a statistically significant amount.

Registry participants were asked to select statements as to how their work/study had changed. Respondents reported significant amounts of absenteeism: 59.5% (53.4%) of Māori (non-Māori) respondents had taken time off; 39.2% (29%) of Māori (non-Māori) respondents had used up their sick leave; 31.6% (24.6%) of Māori (non-Māori) respondents had taken leave without pay. Presenteeism was also evident: 70.9% of Māori respondents and 61.3% of non-Māori respondents had worked despite being unwell. This is also reflected in the findings on days unwell in the past 4 weeks with long COVID symptoms (16.6 and 15.7 Māori and non-Māori respectively), and the days absent from work in the past 4 weeks (4.8 and 6.3 Māori and non-Māori respectively). Presenteeism is often regarded as an indicator of the economic burden of disease, as it results in lost productivity to the employer when an employee is not fully functioning, but it is also detrimental to long-term health and wellbeing [96].

The impact that long COVID symptoms can have on impairment of functions was assessed using the Work and Social Adjustment Scale (WSAS). The scale asked participants to report how impaired they are with respect to work, home management, social and private leisure activities and close relationships. Table 16 reports the mean WSAS for Māori respondents as 25.15 and for non-Māori respondents the mean WSAS is 23.82. These are both in the severe impairment range. These values are similar to those reported in a cohort of long COVID patients who presented at specialist post-COVID clinics in the United Kingdom [90].

The registry also explored the impact of long COVID beyond employment. Table 17 reports that 81.3% of Māori and 77.5% of non-Māori respondents reduced or stopped domestic tasks at home, 41.3% and 37.7% of Māori and non-Māori respondents respectively reduced or stopped volunteering. Few respondents stopped or reduced their involvement in childcare, as would be expected parenting still continues irrespective of an individual's ill health.

Impacts on finances

Respondents reported that these changes in employment impacted their income (Table 18). 52.7% (43.3%) of Māori (non-Māori) respondents reported that their income had decreased since their COVID-19 infection. Some respondents have been able to access additional support, including financial support from government agencies (18.2% and 12.7% of Māori and non-Māori respondents), over a quarter of respondents have paid out-of-pocket for this additional support. On average Māori (non-Māori) respondents paid $2,344 ($1,790) for additional support in the past 6 months. Some respondents have started to receive new benefits (17.2% and 14% of Māori and non-Māori respectively), including the unemployment benefit, disability allowance and accommodation supplement.

Variability of impacts

The heterogeneity of these impacts is explored by categorising COVID-19 infection severity (two or more severe symptoms), time with long COVID symptoms (a year or more), area deprivation (IMD quintiles 4/5), age (50 or over) and essential worker status (yes). As summary of the numerous impacts is presented in Table 19, these include symptom scales, HRQoL scores, stigmatisation, healthcare out-of-pocket cost, employment impacts and financial impacts.

Table 19 shows that more severe infection significantly increases all the symptom scales, suggesting a more severe COVID infection subsequently presents as more severe long COVID. Those who had a more severe infection also have a greater decline in EQ-5D-5L (so worse HRQoL impact). Those with more severe infection also report experiencing more stigma (LCSS) and greater impacts in terms of the functional impairment (WSAS).

Respondents who have experienced long COVID for longer, report worse HRQoL impact from baseline (EQ-5D-5L and EQ-VAS) and more disability than those who have had long COVID for less than a year. Long COVID "long-hauler's" also experience more stigma and are more likely to report a decrease in income.

Respondents who reside in more deprived areas (IMD18 Quintiles 4 & 5) have significantly higher symptoms scores (except for the prevalence of pain) than those who reside in the least deprived neighbourhoods. These respondents also report higher stigmatisation and are more likely to have used up their sick leave entitlements.

Younger respondents (those aged under 50 years old) report greater scores for depression, anxiety and psychological distress and fatigue than older respondents. They also report significantly worse HRQoL via the EQ-5D-5L and EQ-VAS, more stigma (via LCSS), higher

healthcare costs (more than double $1733 vs $722), are more likely to have used up their sick leave and worked despite being unwell. Younger respondents report significantly worse functional impairment and are more likely to have experienced a decrease in income.

Essential workers report similar symptom scores as non-essential workers, and similar HRQoL although they have a higher EQ-VAS difference with baseline (suggesting a greater decrement). Respondents who are essential workers were more likely than non-essential workers to have used up their sick leave, worked despite being unwell and subsequently experienced a decline in their income.

Impact at six months

As of 15th April 2024, 224 participants have completed the 6 month follow-up survey (response rate 36%). Table 20 presents the descriptive statistics of these respondents and analyses were undertaken to compare them to the full sample, in order to understand if these early enrolees into the registry are different from those who have not yet had the opportunity to respond or did not take up the opportunity. Due to the small sample size analysis is combined for Māori and non-Māori; Figure 2 shows that when the data were downloaded only 14 Māori respondents have completed the 6 month follow-up. This 6 month follow-up subsample is very similar to the full sample, the only significant difference is that the proportion of healthcare professionals is higher in the 6 month follow-up subsample (bottom of Table 20).

Only a small proportion of respondents considered themselves recovered (3.6%), 87.4% of respondents reported still experiencing long COVID symptoms. Table 21 shows that 63% of respondents have received a clinical diagnosis, this is similar to the proportion who had received a clinical diagnosis at baseline (when joining the registry) (Table 3). Some respondents reported a diagnosis of new conditions in the last 6 months, including ME/CFS (29.6%), chronic sleeping problems (13.6%) and chronic pain (10.6%). Re-infections in the previous 6 months were not uncommon (19.7%), and most individuals reported that these were less severe (77.3%) (see Table 22). 22.7% of respondents reported that they had been prescribed antivirals. Just over a quarter of respondents had received had a COVID vaccination/booster in the previous 6 months.

A summary of respondents long COVID experience and its impacts and (where available) change in impacts is reported in Figures 15 and 16, and Tables 23, 24 and 25.

Figure 15 shows that fatigue remains as the most common long COVID symptom respondents experience. Brain fog and sleep issues (sleeplessness and sleep disturbance) still continue to be experienced 6 months on. Sleeplessness and sleep disturbance have not changed or have worsened for 70% or more respondents. The proportion reporting improvements over the previous 6 months (Figure 16) is much larger than the reported improvements over the previous 3 months at baseline (Figures 7 and 8).

This possible improvement in symptoms is also evident in Table 23. All the symptom scores, except the GAD-7, are lower (which is indicative of an improvement), and statistical tests shows these are significant. It is important to also consider if they are clinically

significant (in addition to being statistically significant), and for those instruments which have reported minimal clinically important differences (MCID), the mean decline in PHQ-9 (1.2 points) and the mean decline in the FAS (2.0 points) over 6 months are less than the MCID [45,46,51,52], so the average improvement in fatigue may not be clinically meaningful. Individual respondents may perceive improvements, but not for the subsample as a whole. Note that at 6 months, the GAD-7 mean score is similar, implying that the average respondent still has anxiety issues.

HRQoL appears to have improved over the last 6 months, but no indicator shows that it is back to pre-COVID levels. For example, Table 24 reports that self-assessed mental health is improving compared to an assessment at baseline, but it is still significantly different and poorer relative to pre-COVID mental health assessment. This is also true for EQ-5D-5L, and the EQ-VAS – notably these mean values are still very different from reported population norms [89]. While the proportion who identify as having a disability, impairment of long-term condition as similar to baseline (85.8%, Table 24 vs 86.6% & 84.4%, Table 5), there is a statistically significant association, implying that group membership changes (i.e. some individuals no longer identify, while others now do identify as having a disability).

At 6 months follow-up there are variable impacts to respondents' financial situation and employment. The proportion in full time employment (30.9%) is significantly lower (Table 25). The average hours respondents are working or studying is similar to baseline reports and remains significantly lower than pre-COVID times. Fewer respondents are reporting absenteeism and presenteeism, and the functional impairment (as measured by the WSAS) is improving (lower mean score). This may reflect some adaption within workplaces and study institutions and a recognition of long COVID as a chronic condition. The proportion of respondents receiving financial support from government agencies is significantly higher.

Discussion

This project validates that it is possible to design and implement a lived experience led long COVID disease registry. While there are some technical issues with the survey software, the registry continues its active role in recruiting participants and following their lived experience over time to understand the impact of long COVID. There are high levels of sustained engagement and anecdotal evidence from emails and personal communication that sufferers of long COVID feel heard now there is a registry.

> *"Thank you for the work you are doing in this area. As someone from the ME/CFS community, I really appreciate you shining a light on these struggles"*

> *"It's really good you are doing this survey … any long term changes in understanding that come out of the survey for people are great."*

Despite considerable efforts to ensure that the registry is representative of Aotearoa New Zealand's population, it is disappointing that only 8.6% of participants are Māori (19.6% of Aotearoa's population in 2023 was Māori [97]). The project team actively engaged with

Māori, speaking and meeting with Māori groups and iwi, and following the advice of the Kaitiaki Rōpū, many of whom reached out to their networks. Māori are an important-to-reach group (purposely avoiding the phrase hard-to-reach) and the project to date has not delivered. This is also true for Pasifika people who are under-represented in the registry. Further work is needed to ensure that the registry is representative and any analysis informative for all tiriti partners, therefore engagement with Māori continues. There are ongoing qualitative studies that seek to understand the lived experience of Māori and Pasifika, these will address some of this evidence gap [98–100].

One of the challenges of recruiting to a registry outside of a clinical setting is that individuals need to have an awareness of or diagnosis of long COVID. Long Covid Support Aotearoa has run social media campaigns to increase knowledge and awareness of long COVID, however this can only go so far if individuals are not able to get help and support. There is evidence of gaslighting in the international literature [34], personal experience of this in the project team, and this challenge is real for individuals with long COVID symptoms. In part this appears to be because of a lack of knowledge of long COVID amongst health professionals, and an overstretched healthcare system.

> *"Do I need to get a diagnosis from my Dr before I can participate in your study? I got fobbed off a while ago as it wasn't 3 months after covid that I saw her."*
>
> *"I have not been able to find a doctor. There is a 3-6 month waiting list, so I haven't had any follow up talks with a GP"*
>
> *"GP is amazing but little she can do. Occupational health expert also couldn't really add anything. Presently seeing an exercise physiologist (not doing exercise at present just diet stuff etc) - this is getting quite expensive."*

Recruitment challenges aside, analyses have confirmed that the lived experience of long COVID in Aotearoa New Zealand concurs with the international evidence on clinical presentation [7]. It appears that irrespective of the variant or the vaccination status (the two defining features of Aotearoa's COVID-19 experience relative to other countries) there is still a considerable burden of long COVID. It impacts health, quality of life, wellbeing and the economic stability of sufferers and their whānau.

Registry respondents report similar symptoms and symptom burden as evidenced in the long COVID literature [70,90,91,101–103]. Fatigue and brain fog are the most prevalent symptoms for both Māori and non-Māori respondents. While sleep disturbance and sleep issues are the symptoms that respondents report as less likely to have improved in the 3 months prior to joining the registry. Fatigue and brain fog remain the most common symptoms reported by respondents at the 6-month follow-up.

The impact of these symptoms is evident in the self-reported symptom scales:

- a large majority of respondents report breathlessness, in line with some estimates in the international literature [82,83,104];
- approximately a third of respondents have moderately severe or severe depression, similar to some estimates in the international literature [86,102];

- over a quarter of respondents have moderate or severe anxiety, also reflected in the international literature [86,102];
- 90% of respondents reported experiencing fatigue;
- pain is common, and its severity and interference is similar to another cohort of long COVID sufferers [55].

This symptom burden has an impact on the HRQoL of Māori and non-Māori with self-reported long COVID. The use of a recall questions to understand health and HRQoL has been shown to be valid [105,106], and this is confirmed as respondents reported pre-COVID EQ-5D-5L scores that were similar to New Zealand population norms [88,89]. Now with long COVID, HRQoL is significantly lower than it was pre-COVID and is comparable with self-reports from individuals with MS in Aotearoa [93], but lower than those with cancer [107] and other chronic conditions (see [91]). A cohort study with follow-up in the United Kingdom also confirmed this impact, estimating that self-reported long COVID was associated with a loss of 0.37 quality adjusted life months [91].

The Long COVID Registry also finds that the significant decrement in HRQoL endures over time. These self-reports were captured using monthly EQ-5D-5L surveys. While this was designed as a simple touchpoint many respondents contacted the registry to explain their response or suggest that more data should be collected. These comments provide additional rich information on the lived experience of individuals with long COVID and show how actively engaged participants are as research subjects. For example, some of them had had a subsequent infection and relapsed *"I thought that I should let you know that I had a second Covid infection. This has caused my Long Covid to get significantly worse over the last month"*; others have adapted to their condition *"I am now 'well' from long-covid in the sense that I can do everything I need to in a day (hence all answers to the questions are 'great'). However, my life has changed drastically to accommodate this"* and *"I also feel I have gotten so used to being like this that I'm not even aware of my limitations"*; while some respondents have experienced other health events *"My pain and struggle are due to a fall on the weekend"*.

Correspondence was received from registry participants who thought that the EQ-5D-5L does not adequately capture their quality of life: *"I've just completed my first survey update re my quality of life and I was intrigued that most of the questions were about mobility and one on anxiety and depression, but none covered cognitive issues"* and *"The Quality of Life survey is very superficial and I know it has been validated for NZ, however it in no way captures my quality of life with more specific things such as pacing and breathlessness"*. Other researchers have identified this challenge with using the generic EQ-5D-5L in long COVID research [108].

Respondents have also contacted the registry to share possible response bias issues with the survey design: *"I just filled in the April quality of life survey. It wanted to know how I was feeling today. It strikes me that this introduces some bias into the survey as on a shitty crash day I am not going to be on my emails so the only time I answer the questions is when I'm having a good day with the capacity to open said survey. I'm pretty sure there have been times I didn't fill out the survey at all as I was not well enough..."*

This rich feedback helps with the interpretation of results, can inform future survey designs and stimulate further research to better understand HRQoL and how and why it fluctuates over time.

The reported symptom burden, health and HRQoL impacts has resulted in greater use of the healthcare system than the average New Zealander. Māori and non-Māori respondents reported greater attendance at the GP and more visits, and Māori respondents reported higher ED attendance. Respondents reported consulting with a range of healthcare professionals, including physiotherapists, cardiologist and respiratory specialists. Many reported undergoing diagnostic tests and being prescribed medications for their long COVID symptoms. The estimated out-of-pocket cost of healthcare consultations in the previous 6 months was between $160 and $245 for Māori respondents, and between $160 and $220 for non-Māori respondents. Increased utilisation of health services is confirmed in the international literature [109]. This literature also quantifies the total health care expenditure, the public and patient cost [110–112]. Further work will estimate the total expenditure on long COVID care and explore the determinants of costs.

A unique feature of the Long COVID Registry is the inclusion of questions beyond the clinical and health impacts of long COVID. This element was promoted by those with lived experience involved in the design, as while some were able to manage their health and symptoms, they found the broader environment including returning to work post-COVID and post-pandemic challenging. Analysis of the registry has found respondents have significantly reduced the hours they work, experienced a reduction in income, and have high levels of absenteeism and presenteeism (working despite being unwell). More than 70% of respondents also report severe impairment of functioning on the WSAS scale, a level of impairment that is worse than that reported by patients with inflammatory conditions, breast cancer and HIV [113].

Changing employment status and hours of employment has impacted income, 52.7% of Māori and 43.3% of non-Māori respondents reported a reduction in their income since they had COVID-19. At follow-up 27.8% of respondents reported a decrease in their income in the previous 6 months. The financial impact is challenging. Many respondents have received government support including benefits, although this needs to be more systematic. Long COVID sufferers with partners face additional barriers accessing income support. Nga Kawekawe o Mate Korona called for long COVID to be recognised as a disability in order of allow access to financial and practical support [26], evidence from the registry add further support to this recommendation.

The heterogeneity of the impacts were explored and there is evidence to suggest that there are differences in terms of the severity of the index infection, the length of time someone has had long COVID, the deprivation of the area where respondents live, respondents age and essential worker status. Differences were also evident between Māori and non-Māori, many of these will likely be due to historical and institutional drivers of inequities and therefore warrant further considered analysis to avoid deficit framing.

While high levels of consent, engagement and participation make this an invaluable research resource to understand the long-term consequences of the pandemic, continued follow-up is at risk. Many who recover will be lost to follow-up, although they are encouraged to complete the 6 month follow-up survey to document their recovery. One

participant has already requested withdrawal as they are fed-up that their involvement in the registry has not resulted in them receiving any help or support. There is a risk that the registry becomes research for research-sake when evidence and recommendations are not implemented into the health and care system.

A next natural step for the registry is to understand how the findings align with other data collected within Aotearoa New Zealand. Linkage with the Statistics NZ's IDI will allow for the analysis to be extended to hospital episodes and pharmaceuticals, however understanding primary care presentations will not be possible within the IDI as these data are not included. Accessing and interrogating Primary Healthcare Organisation (PHO) data will be key. Such an analysis may need to go beyond standard clinical codes as one PHO has already noted that classification is poor and is likely giving a false picture [114]. Limitations in using clinical coding alone to understand long COVID has been noted elsewhere [115]. Further research is needed to understand why coding is not used and if this impacts the care delivered.

Limitations

It is important to acknowledge that this is an uncontrolled cohort study; that is, it is a registry of only those who self-report long COVID symptoms. While long COVID and these symptoms may be correlated, the results should be interpreted with caution because without a control group it is not possible to directly attribute the symptoms to long COVID.

This lack of an appropriate control group has been highlighted in the literature [116]. Some of the international studies referenced in this report may or may not suffer from this, and it should be noted that comparisons are not like for like. There is, however, a growing body of controlled studies which control for infection status and hospitalisation experience, and systematic reviews and meta-analyses of these confirm that fatigue, brain fog, and breathlessness have higher prevalence in those infected compared to control groups [117–119].

The registry recruited individuals who self-reported long COVID, which may result in an overestimation of symptoms prevalence compared with other infected individuals who do not identify as having long COVID.

While the prospective repeated collection of monthly quality of life data is a strength of the registry, to understand the initial impact participants were asked to retrospectively self-report their health and HRQoL prior to their COVID-19 infection. This is unavoidable due to the nature of the pandemic and the study design, however it may introduce recall bias, although other researchers have found no evidence of this [120,121].

Recommendations from Patients' Lived Experiences

Access

Consistent & Continuous Medical Assessment: Patients need ongoing and regular medical evaluations to monitor their condition and adapt treatments as necessary.

Specialised Long COVID Clinics: Access to specialised long COVID clinics and specialists is essential. Currently, patients are triaged alongside the general public, often missing out on necessary care due to resource shortages.

Access to Antivirals: Patients should have access to antivirals for re-infections to help manage and mitigate symptoms effectively.

Vaccinations: Ensuring access to COVID-19 vaccines for all patients, especially those with long COVID, is crucial for preventing further complications.

Belief

Validation of Symptoms: Patients need to be believed and supported. It's important to acknowledge that no one is fabricating their symptoms. Feeling supported is vital for their recovery.

Higher Diagnosis Rates: There should be an increase in the rate of diagnoses to ensure patients receive the necessary care.

Support Pathways: Establish clear support pathways for long COVID patients to navigate their healthcare journey.

Symptom Mapping: Implement systematic symptom mapping to better understand and track patients' conditions.

Clinical Check-ins: Regular clinical check-ins to monitor progress and adjust treatments as needed.

Global Best Practices: Adopt a globally educated approach to ensure best-practice treatments and management strategies are utilised.

Public Education: Enhance public education about long COVID through GPs and public health messaging to reduce stigma and improve understanding.

Support

Space to Recover: Patients need the freedom to focus on their recovery without the added stress of working while being ill.

Financial Support Pathways: Establish clear financial support pathways. Currently, issues arise due to GPs not understanding or diagnosing long COVID, requiring repeat assessments and wasting resources.

Home Aid & Mobility Devices: Increase the availability of home aid and mobility devices to meet the growing demand as more patients require support.

Care

Employer Assistance: Provide employers with resources to support employees with

long COVID, ensuring they can offer necessary time off or adjust employment status without bearing the full financial burden.

Regular GP and Assigned Support: Ensure every patient has a regular GP and assigned support to manage their chronic condition.

GP Capacity: Address the lack of time and bandwidth GPs have to support chronic condition patients effectively.

Mental Health Services: Enhance mental health services and provide support for patients experiencing significant changes in their quality of life.

Hope

Future Prospects: Patients need to know that there is hope and a future for them. With proper support and space, they can see improvements and regain a sense of normalcy (and quality of life improvements).

Funding Research: Invest in research, patient monitoring and wrap-around support. Communicate these initiatives regularly to instil hope in patients.

Strategic Planning: Incorporate chronic conditions into strategic health pathway planning and co-design these pathways with lived experience to ensure patients' voices are heard and their burden is not increased.

Future Proofing: Minimise reinfections by supporting access to antivirals, free tests and vaccines, advocating mask-wearing when sick, and providing government support for sick leave.

These recommendations aim to provide comprehensive support for long COVID sufferers, addressing their medical, emotional, and practical needs to ensure better outcomes and a higher quality of life.

Challenges in Writing This Report

Writing this report presented significant challenges, as one of the authors and co-investigators was sick with long COVID, facing numerous medical procedures and enduring weeks without being able to even open a computer. Additionally, another co-investigator was hospitalised with COVID related complications.

Collecting data from individuals also proved difficult, as many participants were too unwell to engage consistently, taking months to contribute due to their severe symptoms. Support group members often withdrew their involvement, either unable to complete tasks due to cognitive dysfunction or finding the process too stressful to participate.

These obstacles highlight the profound impact long COVID has on both patients and researchers alike.

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Technical Appendices

Figures and tables to support the written report.

Figure 1: Schematic of the Registry – promotion, recruitment, modules and follow-up

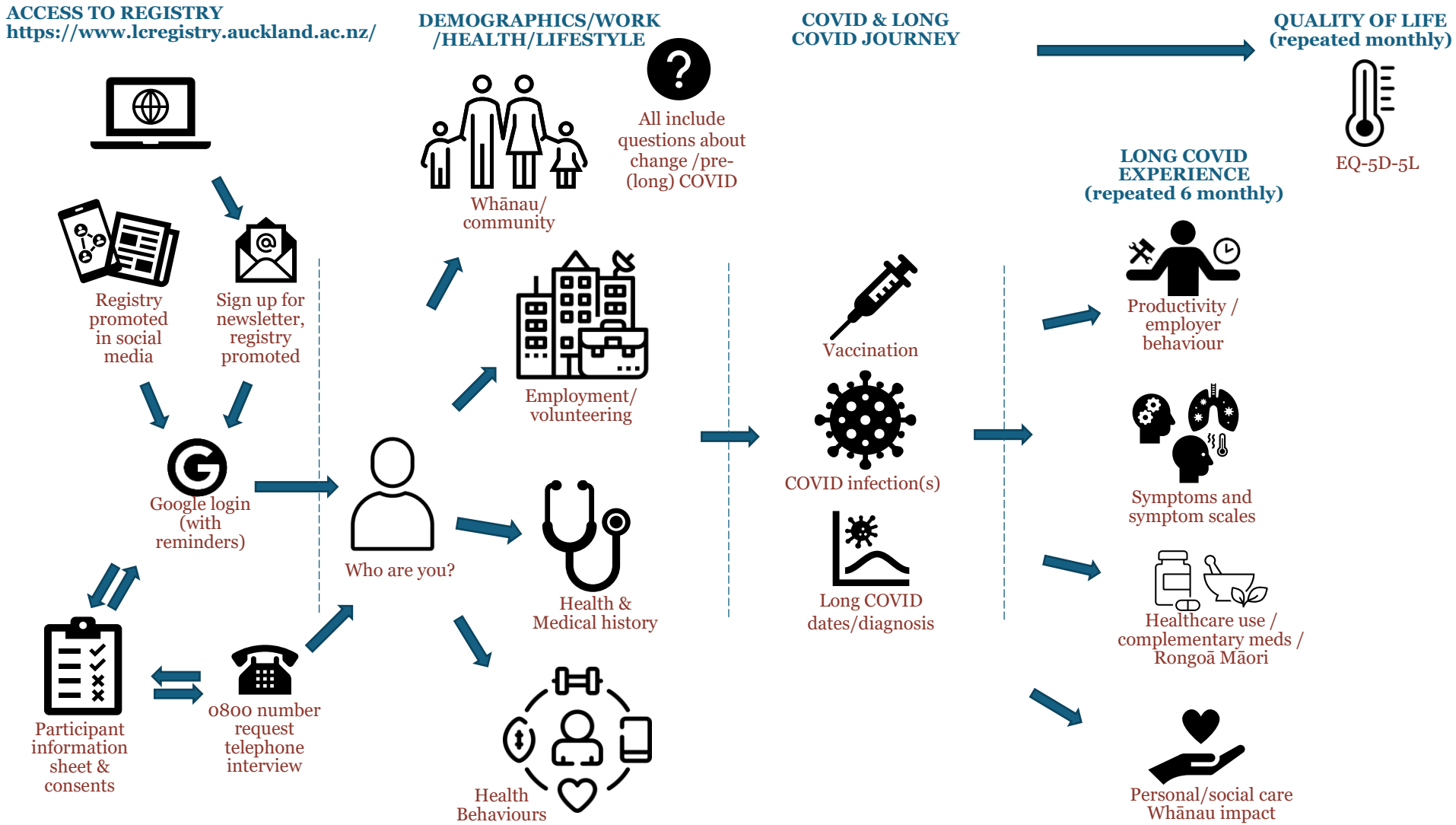
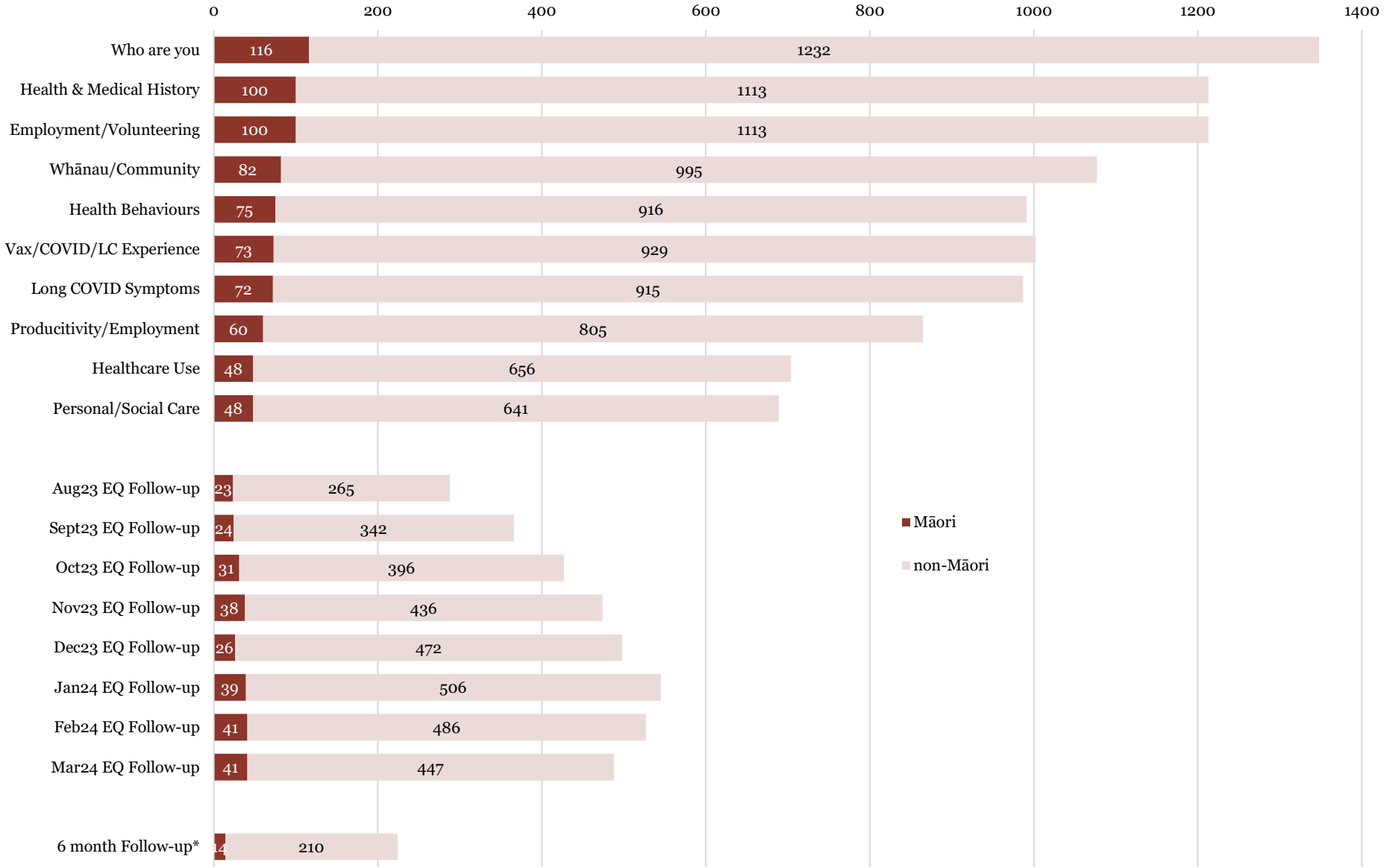
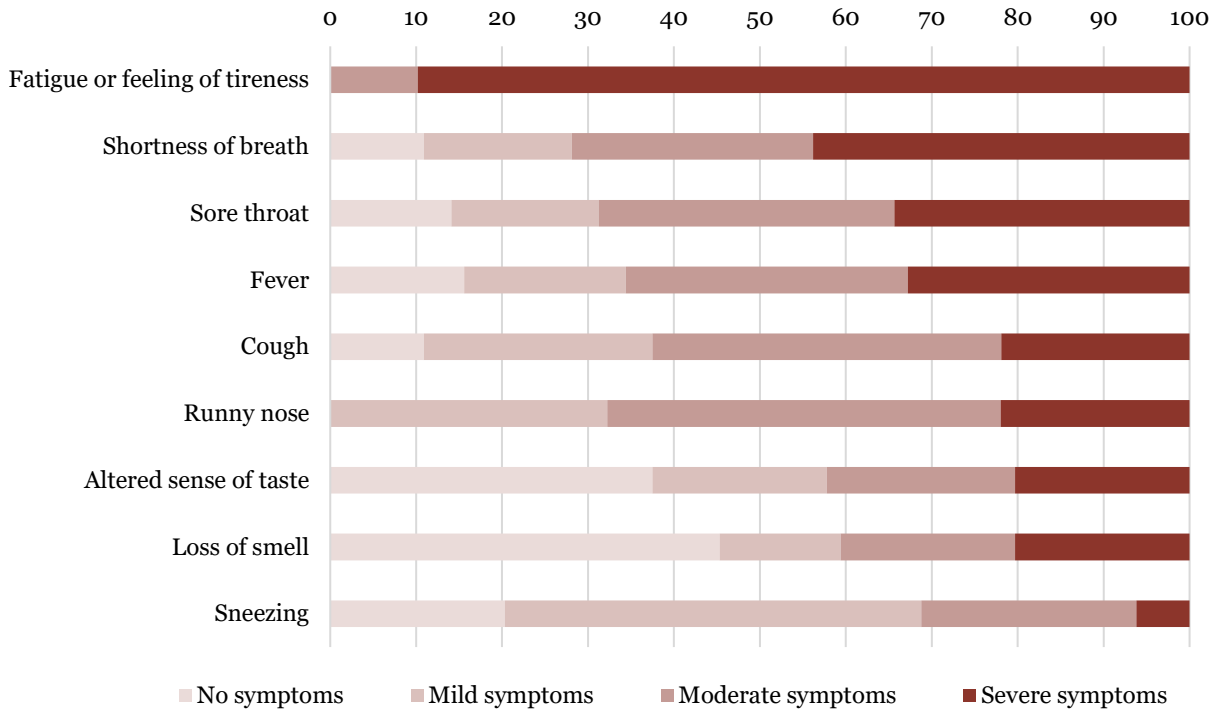


Figure 2: Number responding to each survey module as of 31st March 2024



* Responses for 6 month follow-up as of 15th April 2024

Figure 3: Severity of symptoms for the COVID-19 infection thought to result in long COVID, Māori respondents, %



Note: Frequencies with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Figure 4: Severity of symptoms for the COVID-19 infection thought to result in long COVID, non-Māori respondents, %

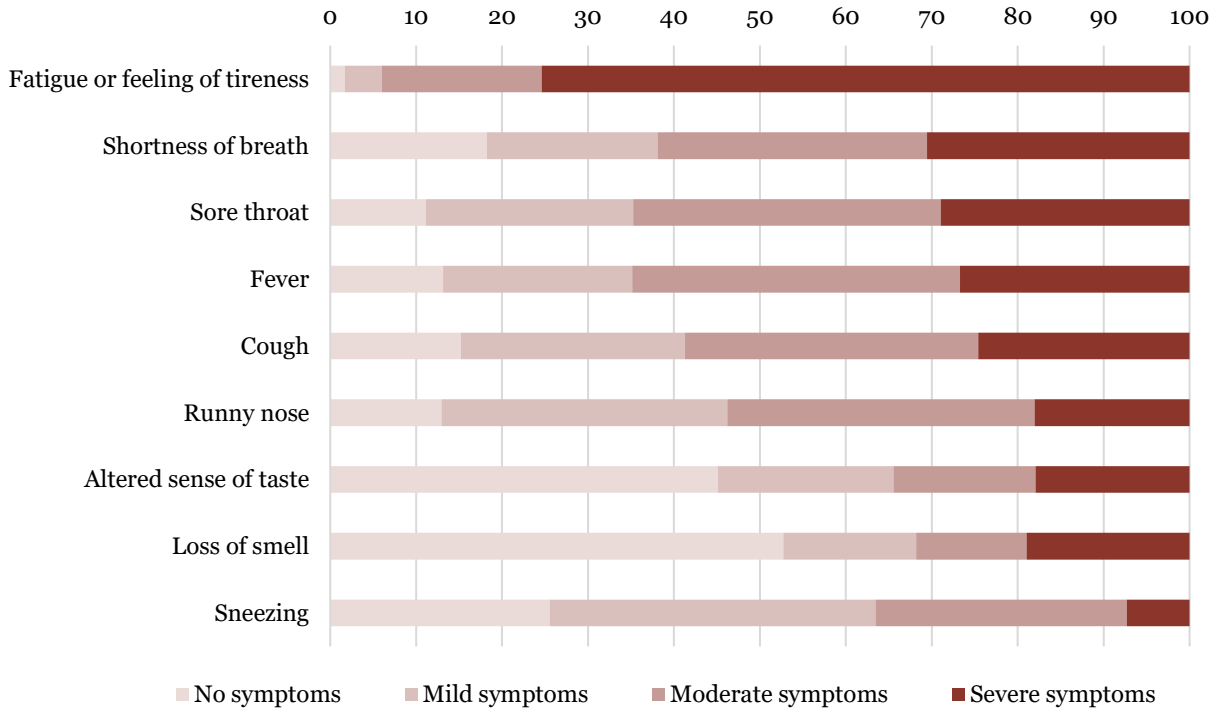
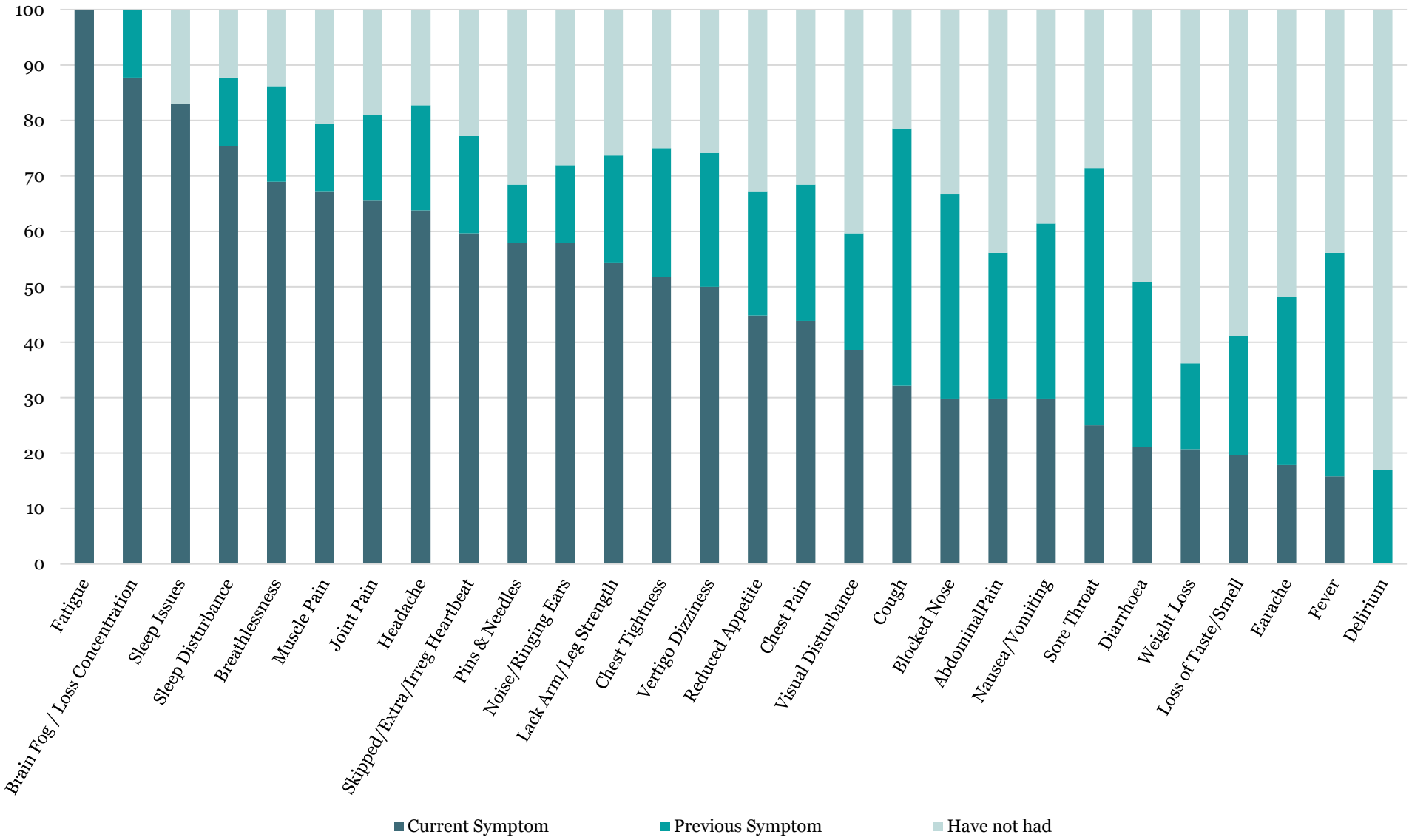


Figure 5: Percentage of self-reported long COVID symptoms, Māori respondents



Note: Frequencies with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Figure 6: Percentage of self-reported long COVID symptoms, non-Māori respondents

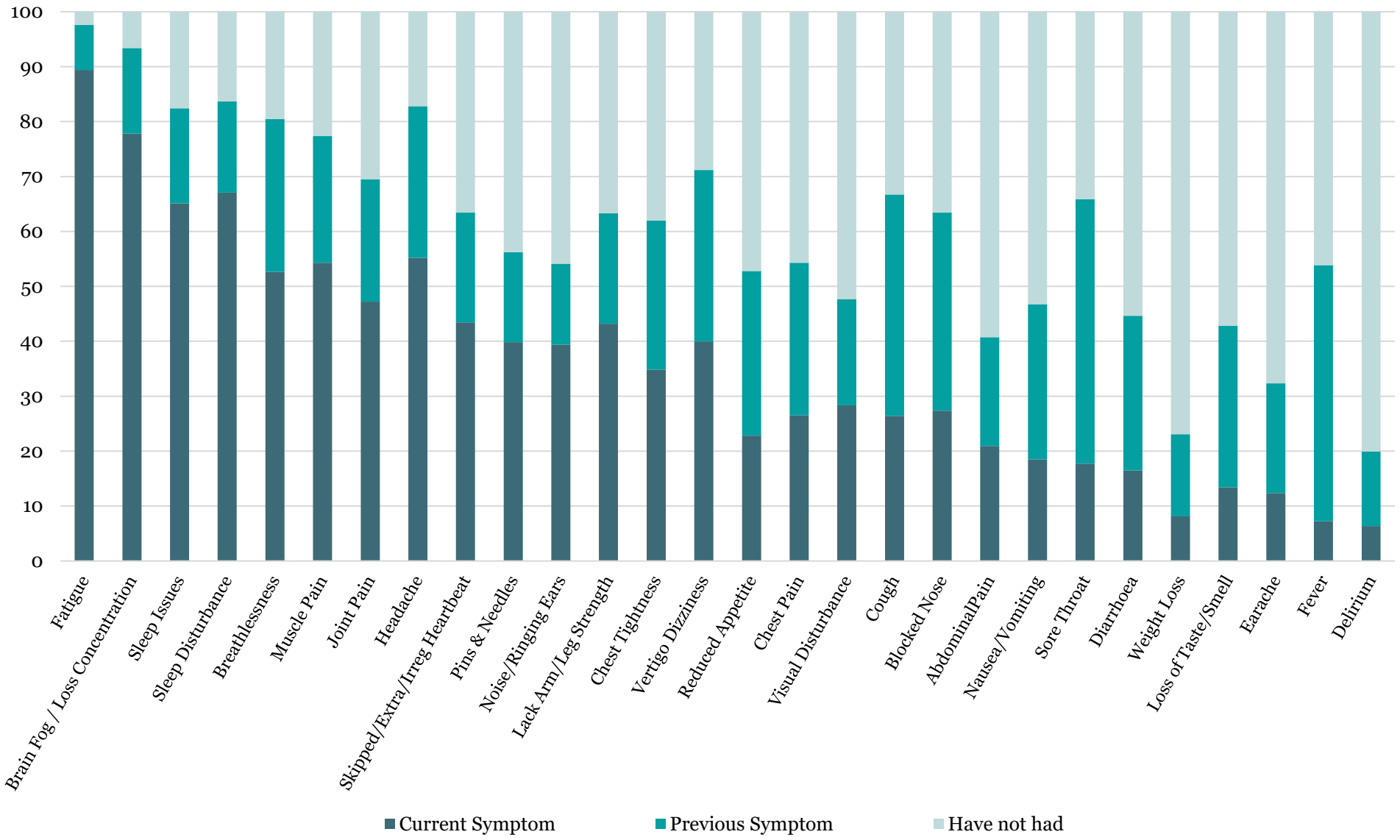
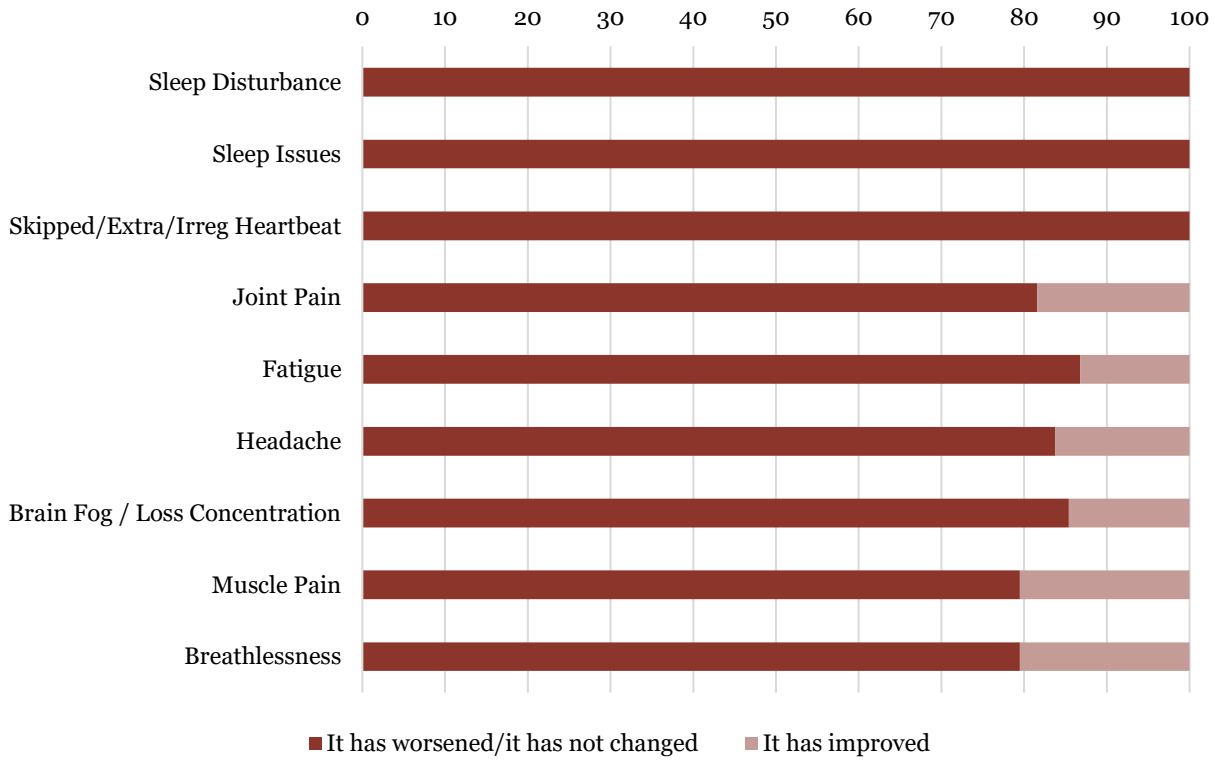


Figure 7: How have symptoms changed in the last three months? Top nine most common self-reported symptoms, Māori respondents, %



Note: Frequencies with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Figure 8: How have symptoms changed in the last three months? Top nine most common self-reported symptoms, non-Māori respondents, %

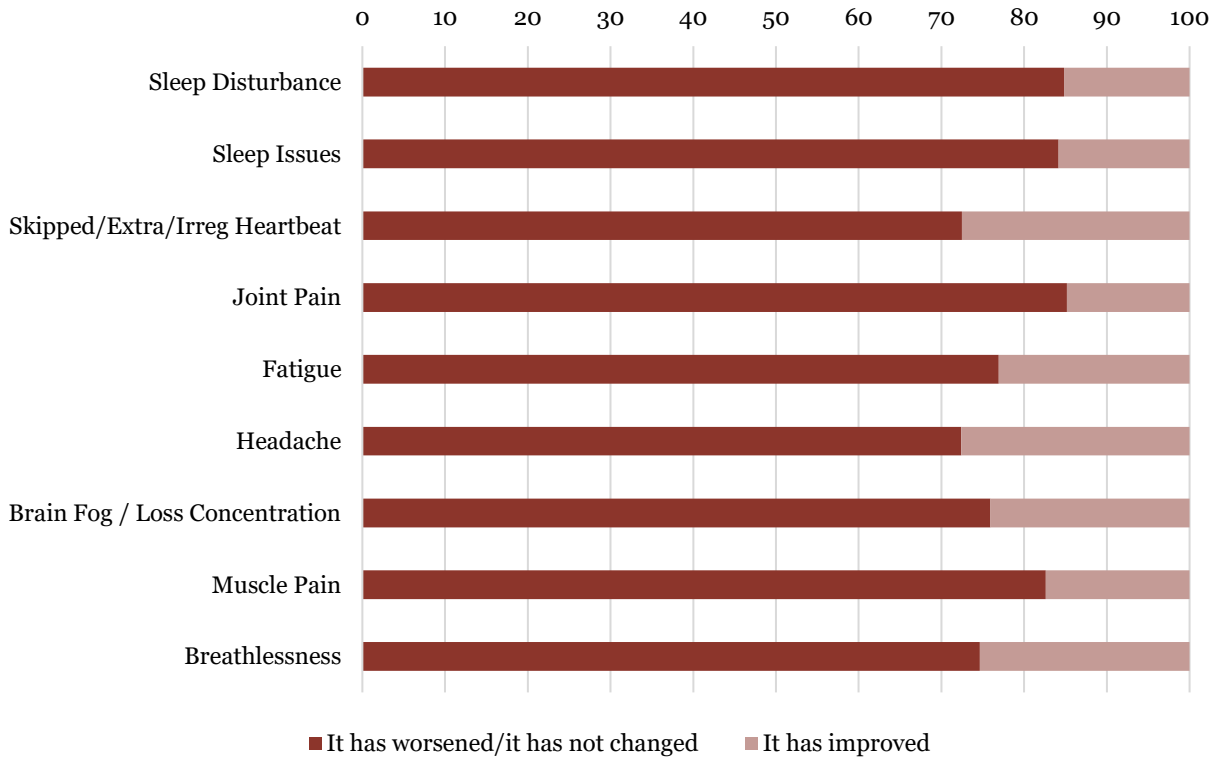


Figure 9: Areas where Māori respondents felt pain today (Brief Pain Inventory – Short Form, BPI-SF), %

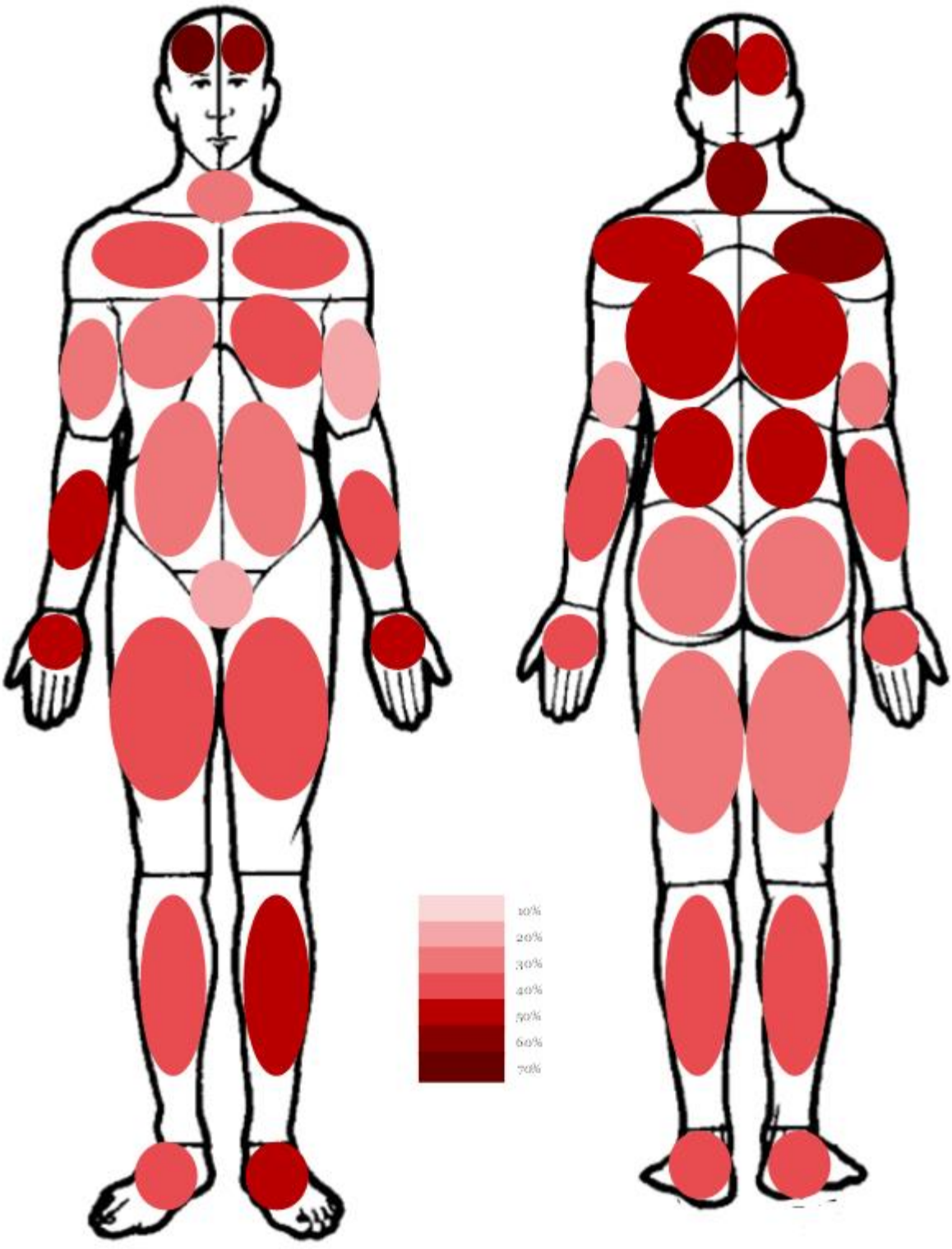


Figure 10: Areas where non-Māori respondents felt pain today (Brief Pain Inventory – Short Form, BPI-SF), %

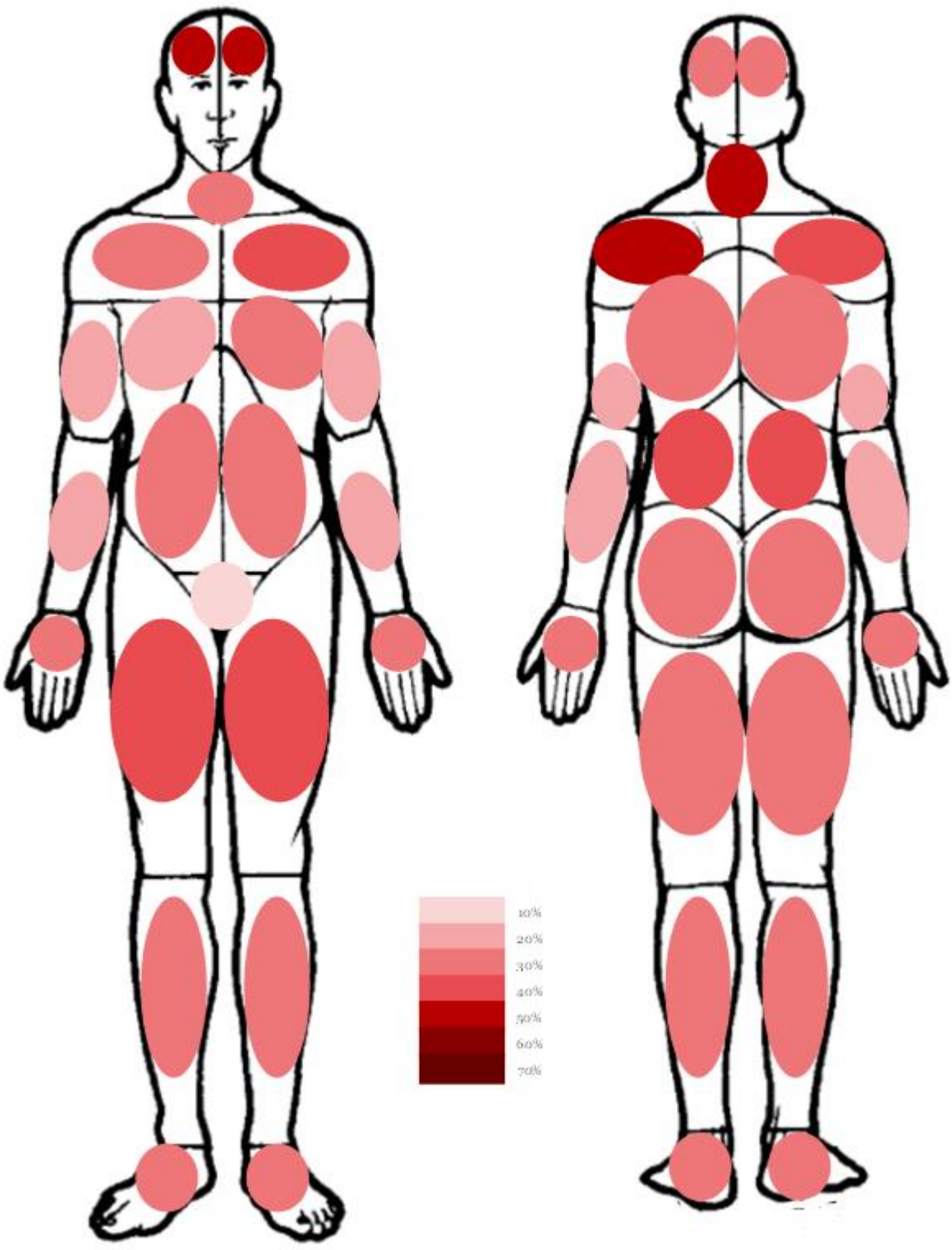
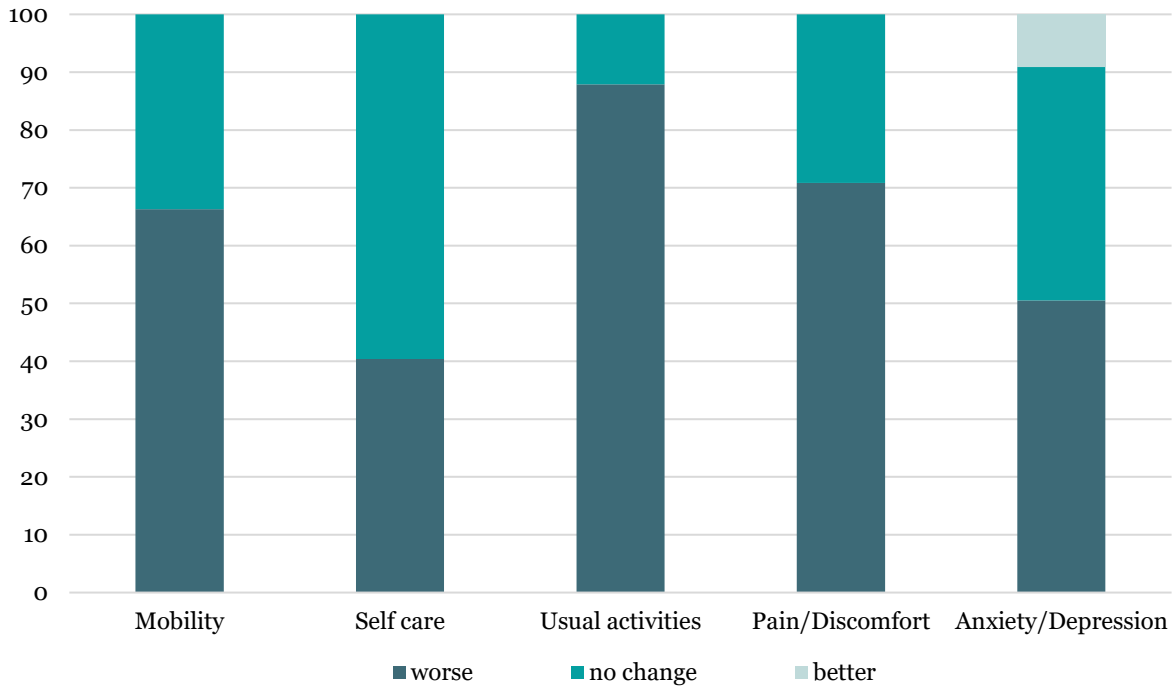
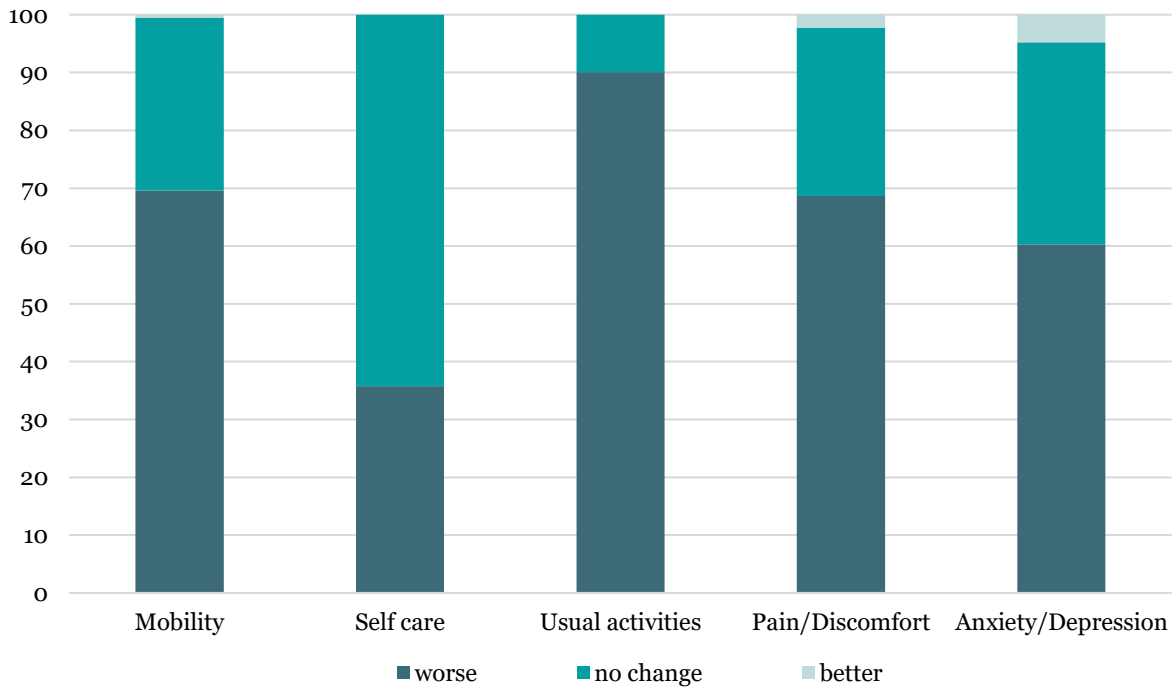


Figure 11: EQ-5D-5L domains where Māori respondents reported change between pre-COVID and today with long COVID symptoms



Note: Frequences with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Figure 12: EQ-5D-5L domains where non-Māori respondents reported change between pre-COVID and today with long COVID symptoms



Note: Frequencies with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Figure 13: Box plot of EQ-5D-5L utility scores over time (monthly follow-up)

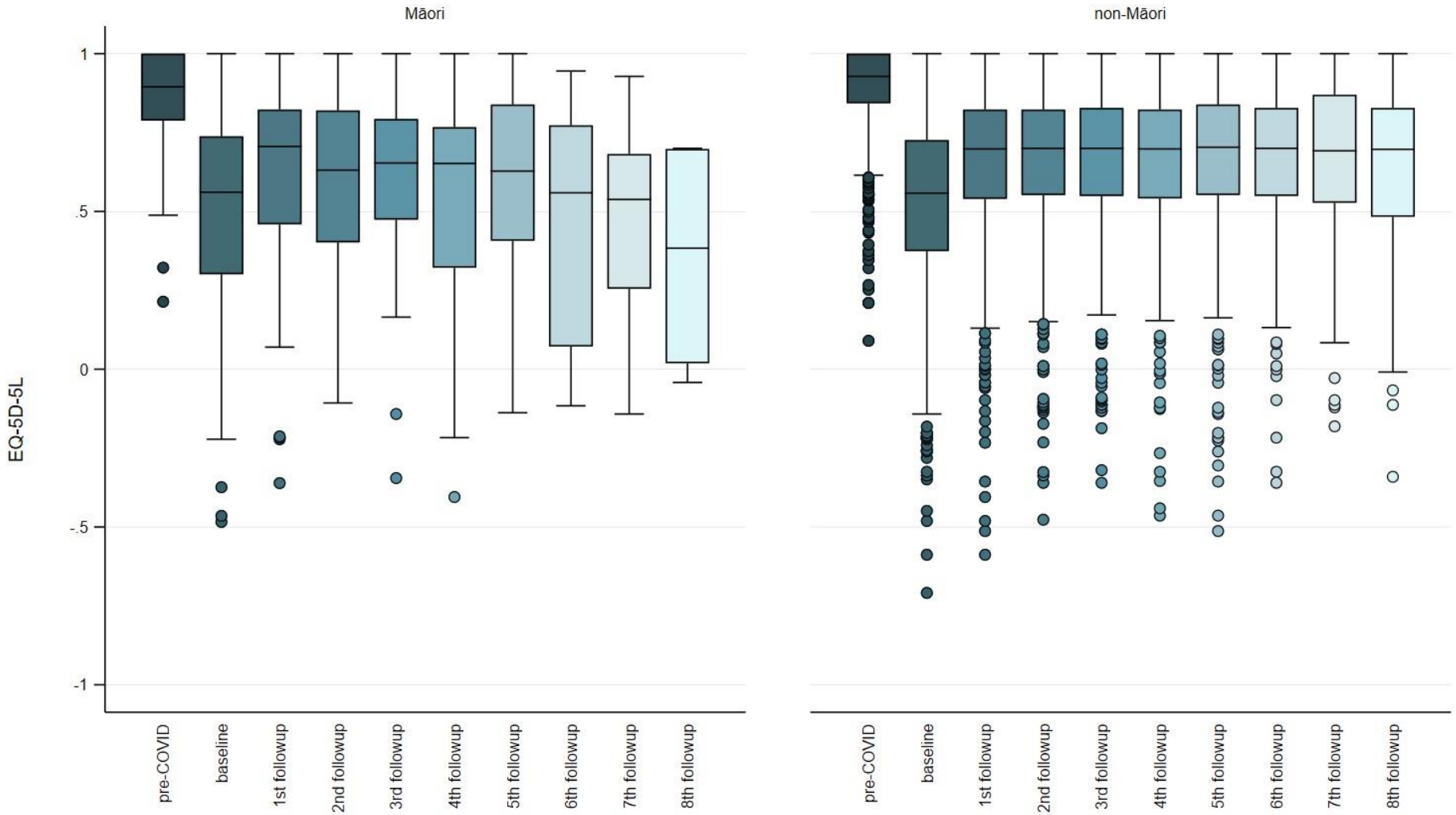


Figure 14: Word cloud of the 20 most common other healthcare providers consulted by respondents in the previous 6 months for long COVID symptoms

Figure 15: Long COVID symptoms experienced over the last six months (% respondents at 6 month follow-up)

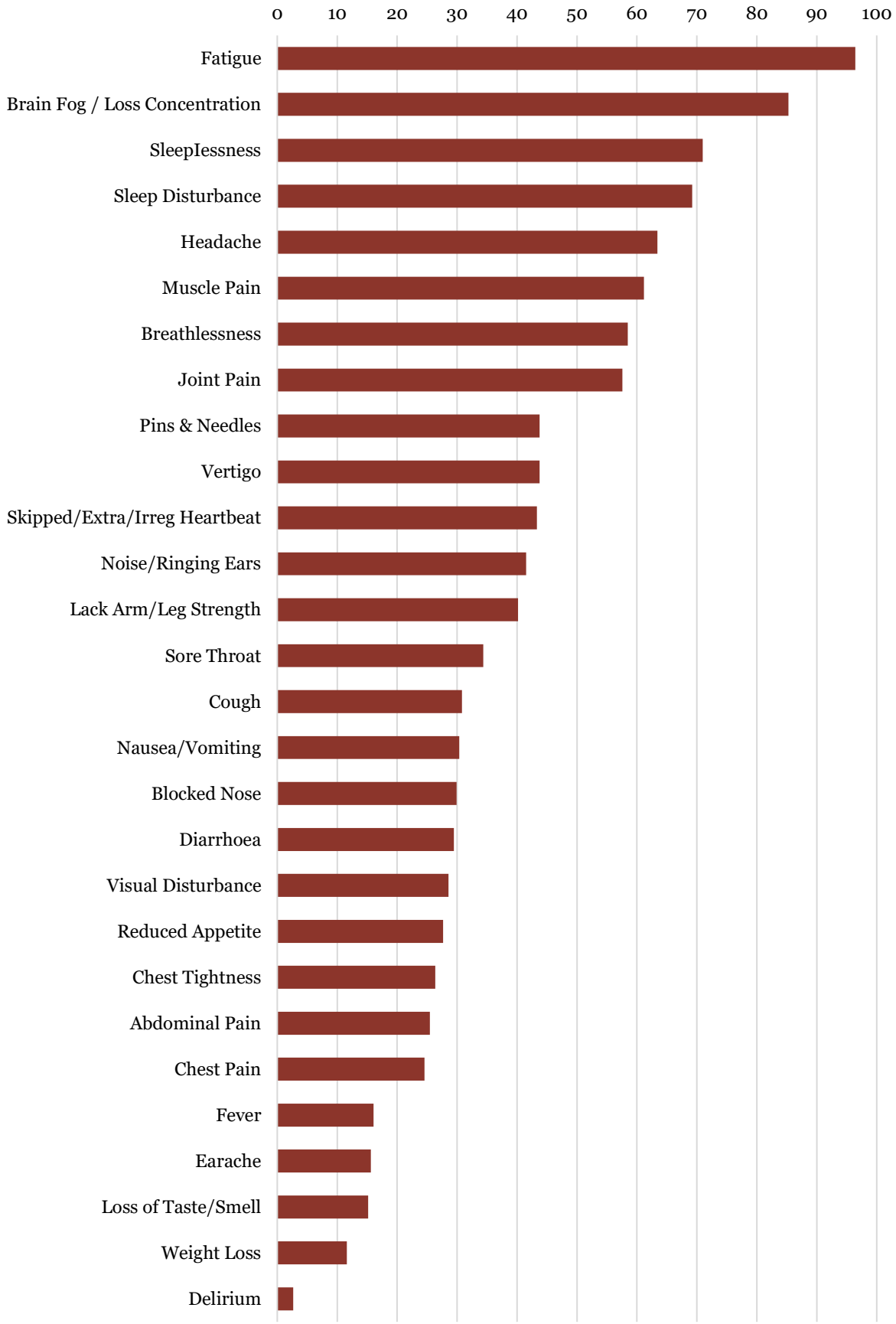
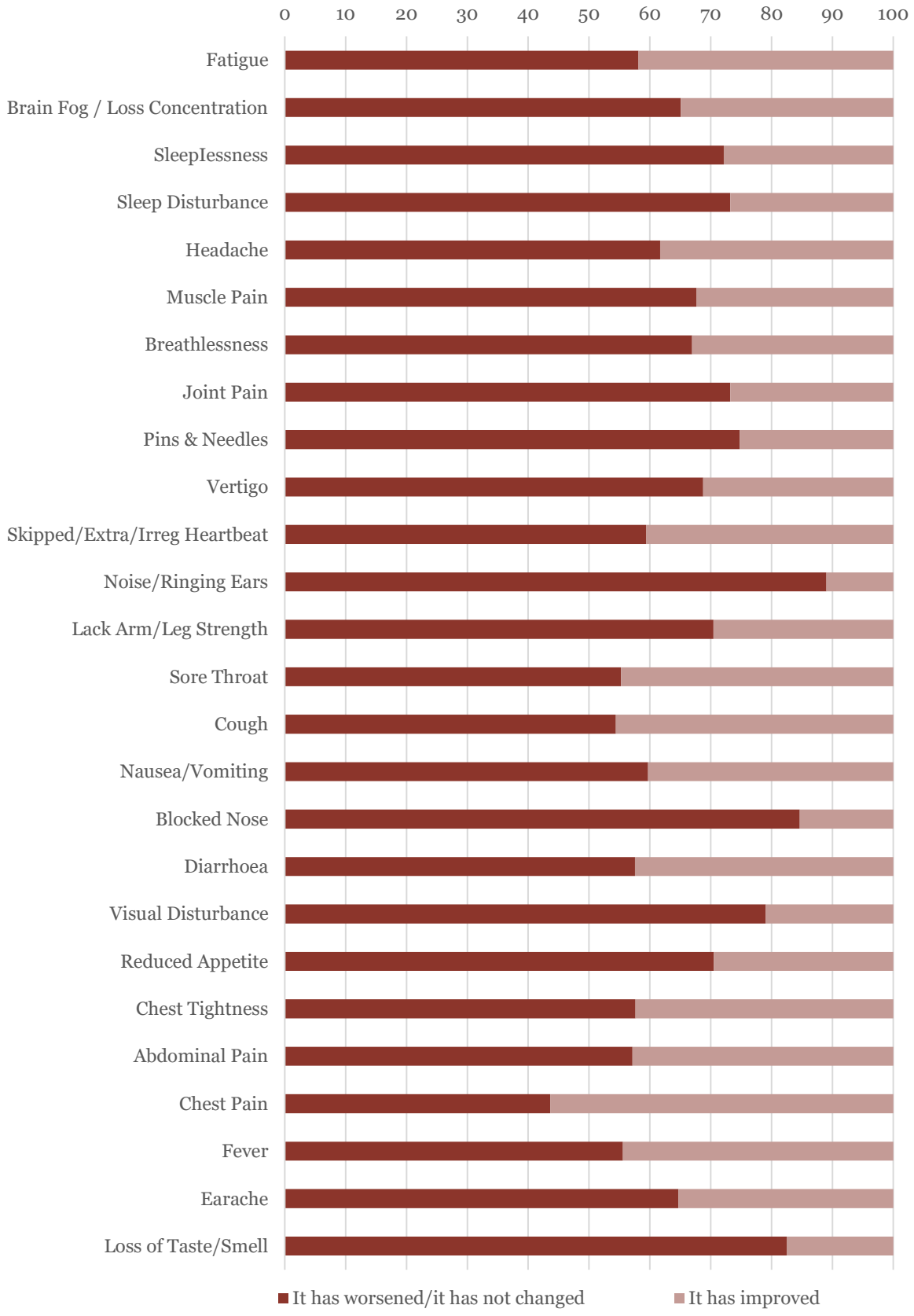


Figure 16: How have symptoms changed in the last six months? (% respondents at 6 month follow-up)



Note: Frequencies with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Table 1: Sample characteristics of the Long COVID Registry participants as of 31st March 2024; percentage and mean (standard deviation) as appropriate

	Māori	non-Māori
N*	116	1,232
Age on joining registry (mean)	44.69 (13.49)	48.80 (14.15)
Gender (%)		
Female	75.2	73.5
Male	24.8	23.3
Non-binary / third gender	‡	2.7
Prefer not to say	‡	0.5
Highest qualification (%)		
No schooling or Primary only	‡	0.6
High school/secondary school/college	23.1	12.0
Post-school education or workplace qualification	24.1	19.5
Bachelor's degree or equivalent	34.3	31.1
Bachelor Honours degree or equivalent	9.3	13.8
Master's degree	9.3	15.6
Doctoral degree	‡	5.9
Prefer not to say	‡	1.5
Household income (%)		
$0 - $30,000	15.3	12.7
$30,001 - $50,000	16.7	7.8
$50,001 - $100,000	25.0	29.0
> $100,000	43.1	39.5
prefer not to say	‡	11.0
Health insurance (%)	41.4	45.2
Type of health insurance (%)		
Comprehensive	39.0	39.6
Hospital only	46.3	37.6
Other	14.6	22.8
Area Deprivation Quintile (IMD18) (%)		
1 – lowest deprivation	15.2	23.8
2	25.0	23.7
3	15.2	21.2
4	19.6	19.7
5 – highest deprivation	25.0	11.6
Essential worker status (%)		
Yes	37.9	32.0
Healthcare professional (% of essential workers)		
Yes	36.4	40.0
Vaccinated against COVID-19 (%)	100.0	98.5
Number of vaccinations (mean)	3.26 (1.11)	3.44 (0.96)

* Maximum sample size, response rates vary depending on the question
‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.
IMD18: Index of Multiple Deprivation 2018

Table 2: COVID-19 infections and long COVID; % respondents or mean (standard deviation) as appropriate

	Māori	non-Māori
Year of first infection (%)		
2020	‡	4.1
2021	‡	5.1
2022	87.7	76.6
2023	12.3	14.2
Number of COVID Infections (mean)	1.69 (0.90)	1.46 (0.69)
When noticed long COVID symptoms (%)		
After the 1st COVID-19 infection	65.4	62.1
After the 2nd COVID-19 infection	34.6	32.6
After the 3rd COVID-19 infection	‡	2.7
Unsure	‡	2.7
Days unwell will COVID infection that caused long COVID (%)		
Asymptomatic/No symptoms	‡	0.9
Less than 4 days	10.8	10.1
Between 4 and 9 days	23.1	29.7
Between 10 and 14 days	29.2	24.1
15 or more days	36.9	35.2
Number of severe symptoms for infection that caused long COVID (mean)	2.83 (2.12)	2.48 (2.01)
Severity of subsequent COVID infections (%)		
More severe	47.6	30.6
No difference	‡	17.1
Less severe	52.4	52.3
Hospital admission for any COVID infection (%)	9.2	7.5
Prescribed antivirals for any COVID infection (%)	26.2	11.1

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Table 3: Long COVID diagnosis; % respondents or mean (standard deviation) as appropriate

	Māori	non-Māori
Days with long COVID symptoms (at registration) (mean)	375.5 (230.0)	342.9 (223.3)
Received a clinical diagnosis of long COVID (%)	57.8	64.3
Previously had long COVID and recovered* (%)	9.3	5.6
Symptoms explained by an alternative diagnosis** (%)	9.2	4.4

* This includes at least 11 respondents who reported recovery, but then relapse with reinfection.
** Note this includes 8 respondents who reported an alternative diagnosis of ME/CFS.

Table 4: Symptoms scales; percentages and means (standard deviations) as appropriate

	Māori	non-Māori
Modified MRC Breathlessness Scale		
Grade 0	13.8	20.1
Grade 1	32.8	41.6
Grade 2	37.9	25.4
Grade 3 & 4*	15.5	12.8
Patient Health Questionnaire (PHQ-9)		
No/minimal depression (%)	‡	13.4
Mild depression (%)	34.5	28.0
Moderate depression (%)	29.1	29.5
Moderately severe depression (%)	21.8	19.1
Severe depression (%)	14.5	10.1
Mean PHQ-9 score (range: 0-27)	12.27 (5.69)	11.30 (6.01)
Generalised Anxiety Disorder (GAD-7)		
Minimal anxiety (%)	31.0	42.3
Mild anxiety (%)	27.6	32.3
Moderate anxiety (%)	27.6	14.1
Severe anxiety (%)	13.8	11.4
Mean GAD-7 score (range: 0-21)	8.17 (5.59)	6.73 (5.31)
Kessler Psychological Distress (K10)		
Low (%)	27.6	38.7
Moderate (%)	19.0	25.1
High (%)	22.4	16.3
Very high (%)	31.0	19.9
Mean K10 score (range: 10-50)	25.33 (8.15)	22.81 (7.75)
Fatigue Assessment Scale (FAS)		
Normal fatigue (%)	‡	11.3
Mild-to-moderate fatigue (%)	30.4	35.1
Severe fatigue (%)	69.6	53.7
Mean FAS physical score (range: 5-25)	20.21 (3.78)	18.93 (4.43)
Mean FAS mental score (range: 5-25)	16.33 (4.72)	15.11 (5.21)
Mean FAS total score (range: 10-50)	36.53 (7.49)	34.03 (8.94)
Brief Pain Inventory (BPI-SF)		
Pain prevalence total (%)	68.4	58.9
Pain Severity (range: 0-10)	4.13 (2.14)	3.06 (2.22)
Pain Interference (range: 0-10)	4.72 (2.99)	3.60 (2.90)
Taking pain medication (%)	58.6	53.9
Number of pain medications (mean)	2.17 (1.17)	2.00 (0.99)

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.
* Combined to support suppression
MRC: Medical Research Council

Table 5: Self-reported health (SRH) and health-related quality of life (HRQoL) before COVID-19 and today with long COVID; percentages, mean (standard deviation)

	Māori		non-Māori	
	Pre-COVID	Today	Pre-COVID	Today
Self-Assessed Health (%)				
Excellent	21.2	‡	24.0	‡
Very Good	39.4	‡	38.3	3.2
Good	23.2	12.8	23.9	15.6
Fair	16.2	36.2	11.7	36.8
Poor	‡	51.1	2.1	44.4
p-value	0.583		<0.001	
Self-Assessed Mental Health (%)				
Excellent	23.2	‡	22.2	3.1
Very Good	29.3	10.6	34.4	13.2
Good	27.3	31.9	26.3	25.3
Fair	13.1	30.9	12.9	37.8
Poor	7.1	26.6	4.2	20.6
p-value	0.005		<0.001	
EQ-5D-5L	0.856 (0.158)	0.488 (0.331)	0.887 (0.125)	0.529 (0.265)
p-value	<0.001		<0.001	
EQ-VAS	80.4 (14.2)	44.7 (22.2)	81.3 (15.1)	48.6 (20.2)
p-value	<0.001		<0.001	
Considered to have a disability, impairment or long-term condition (%)	31.3	86.6	28.8	84.4
p-value	0.008		<0.001	
Number of reported comorbidities	3.02 (2.36)	4.29 (3.04)	2.64 (2.03)	3.71 (2.50)
p-value	<0.001		<0.001	

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Table 6: Health behaviours including changing behaviours as a result of long COVID; % respondents or mean as appropriate

	Māori	non-Māori
Alcohol consumption before COVID-19 (%)		
Regularly	17.8	19.6
Casually	43.8	55.7
Formerly	16.4	7.8
Never	21.9	16.9
How alcohol consumption has changed since COVID (%)		
I drink less than before	38.9	36.9
I drink about the same as before	12.5	14.0
I drink more than before	‡	1.3
I have stopped drinking	11.1	23.1
I have started drinking	‡	0.8
I still do not drink	37.5	24.0
Smoking/vaping before COVID-19 (%)		
Regular user cigarettes	13.7	3.8
Regular user of cannabis	12.3	3.3
Regular user of vapes	17.8	5.7
How smoking/vaping has changed since COVID-19 (%)		
Quit or reduced use of cigarettes	100.0	77.1
Quit or reduced use of cannabis	‡	54.8
Quit or reduced use of vapes	53.8	50.9
Physically active before COVID-19 (%)	100	90.8
How has physical activity changed since COVID-19 (%)		
Less physically active	100	94.2
More or about the same	‡	5.8
How many hours sleep before COVID-19 (mean)	7.22	7.39
How has the amount of sleep changed? (%)		
Less sleep	50.0	42.5
About the same	22.2	25.7
More sleep	27.8	31.9
How has the quality of sleep changed? (%)		
Worse	76.1	70.2
About the same	23.9	27.2
Better	‡	2.6

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Table 7: Life satisfaction and impact on whānau; % respondents or mean as appropriate

	Māori	non-Māori
Satisfaction with life overall (%)		
Completely satisfied	‡	4.5
Somewhat satisfied	37.2	34.9
Neither satisfied, nor dissatisfied	14.0	10.3
Somewhat dissatisfied	27.9	35.8
Completely dissatisfied	20.9	14.5
How does life compare to before long COVID (%)		
Things are better now	‡	2.2
Things are the same as before	‡	6.3
Things are worse now	100.0	91.4
How are the whānau | family coping? (mean) (0 = Extremely badly; 10 = Extremely well)	6.32	6.61
Compared to before long COVID, how are the family coping? (%)		
Doing better	‡	4.4
About the same	41.7	48.6
Doing worse	58.3	38.4
Not sure/Prefer not to say	‡	8.7
Are whānau | family getting enough support? (%)		
Previous had help, now managing without	‡	3.3
Managing without help	41.3	44.8
We need more support now	32.6	28.3
Not sure	26.1	23.6
Worries index (mean) (1 = does not apply; 5 = strongly applies)		
I am nervous when I think about current circumstances	3.79	3.73
I am calm and relaxed [reverse coded]	2.46	2.58
I am worried about the health of my family members	3.54	3.15
I am stressed about leaving my house	3.26	2.89
Who knows about your long COVID? (%)		
I tell as few people as possible	20.0	16.1
Most of my whānau | family know, but not many others	‡	13.4
Most of my whānau | family and close friends know	42.2	40.5
Most people know	37.7	30.0

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Table 8: Informal caring roles before COVID-19 and now with long COVID; % respondents

	Māori		non-Māori	
	Pre-COVID	Today	Pre-COVID	Today
Provided informal care	28.8	16.9	16.7	10.3
p-value	<0.001		<0.001	
Received informal care	‡	25.4	1.43	18.22
p-value	0.014		<0.001	

Table 9: Long COVID Stigma Scale, mean (standard deviation) score and prevalence of stigma (%)

	Māori	non-Māori
LCSS Score	24.03 (11.57)	20.29 (11.23)
Experienced stigma at least 'sometimes' (%)		
Overall Long COVID Stigma Scale	100	94.5
Enacted stigma	57.5	59.0
Internalised stigma	100	88.2
Anticipated stigma	100	87.4
Experienced stigma often/always (%)		
Overall Long COVID Stigma Scale	100	74.4
Enacted stigma	35.0	22.4
Internalised stigma	75.0	62.2
Anticipated stigma	77.5	58.3

Frequencies with fewer than 6 people have been suppressed, with rounding to support secondary suppression.
LCSS: Long Covid Stigma Scale

Table 10: Healthcare resource use in the previous 6 months for long COVID symptoms, median (interquartile range) or percentages as appropriate

	Māori	non-Māori
GP visit	3.0 (1.0; 5.0)	2.0 (1.0; 4.0)
Virtual GP consult	0.0 (0.0; 2.0)	0.0 (0.0; 1.0)
Community/primary care nurse consult	0.0 (0.0; 1.0)	0.0 (0.0; 1.0)
ED visit	0.0 (0.0; 0.0)	0.0 (0.0; 0.0)
Hospitalisation	0.0 (0.0; 0.0)	0.0 (0.0; 0.0)
Rongoā consult	0.0 (0.0; 0.0)	0.0 (0.0; 0.0)
Other healthcare provider	0.0 (0.0; 3.5)	0.0 (0.0; 3.0)
Had a diagnostic test? (%)	56.3	51.6
Specific tests (% of those who had a test)		
Blood	56.2	47.2
Chest x-ray	18.8	16.8
CT scan	‡	4.3
Echo	12.5	8.5
ECG	35.4	20.8
Heart rate monitor	14.6	13.8
MRI – brain	‡	3.1
MRI – heart	‡	0.9
Lung function tests	‡	9.6
Walk tests	‡	7.9
Other tests	18.8	12.6

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.
GP: General Practitioner; ED: Emergency Department; CT: computerised tomography scan; ECG: Electrocardiogram; MRI: Magnetic Resonance Imaging

Table 11: Specific diagnostic tests in the previous 6 months, top 4 (% all responses, N=87)

	%
CT scan	31.0
Ultrasound	10.3
Gastroscopy	9.2
Colonoscopy	8.1
Blood pressure	6.9

CT: computerised tomography scan

Table 12: Medications taken at baseline, including specific medicines & those reporting changes in medications due to their long COVID (%)

	Māori	non-Māori
Taking medications (%)	85.4	81.3
Specific medications (% of those taking medications)		
Anticoagulation	‡	4.9
Aspirin	‡	8.5
Colchicine	‡	1.1
Ivabradine	‡	‡
Beta Blockers	14.6	9.6
Hormone Replacement Therapy	‡	10.5
Oral Contraceptive Pill	‡	7.0
Mirena Coil	‡	6.3
Famotidine	‡	5.3
Antihistamines	41.7	32.0
Anti-Depressants	31.2	24.9
Other medications	60.4	59.0
Medications changed (+/-) with long COVID (%)	65.2	50.8
Prescribed specific medications for long COVID (%)	55.3	49.6

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.

Table 13: Specific medications prescribed for long COVID symptoms, top 15 (% all responses, N=343)

	%
Symbicort	11.95
Vitamin D / B12	9.62
Low Dose Naltrexone (LDN)	8.45
Paracetamol	8.16
Inhaler	7.87
Amitriptyline	7.00
Antihistamine	7.00
Melatonin	6.71
Prednisone	5.54
Ibuprofen	4.66
Omeprazole	3.79
Nortriptyline	3.79
Flixonase	3.79
Propranolol	2.92
Escitalopram	2.62

Table 14: Vitamins/supplements/CAMs use including specifics & those reporting changes in Vitamins/supplements/CAMs due to their long COVID (%)

	Māori	non-Māori
Taking vitamins/supplements (%)	72.3	75.7
Specific vitamins/supplements (% of those taking vitamins)		
Iron	21.3	15.2
Vitamin D	38.3	35.8
Vitamin B12	36.2	29.8
Niacin (Vitamin B3)	‡	11.5
Melatonin	‡	11.2
Other	51.1	60.3
Vitamins/Supplements changed (+/-) with long COVID (%)	64.7	68.3
Practicing complementary/alternative therapies (%)	46.8	36.1
Specific therapies* (%)		
Mediation	21.3	16.2
Massage	19.1	15.4
Herbal therapies	12.8	10.1
Use of CAMs changed (+/-) with long COVID	100	75.0

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.
* Top three listed, due to need to suppress with small cells sizes
CAMs: Complementary and alternative medicines/therapies

Table 15: Healthcare cost (2023/24 NZD) in the previous 6 months for long COVID presentations, median (interquartile range)

	Māori		non-Māori	
	Lower bound cost	Upper bound cost	Lower bound cost	Upper bound cost
GP visit(s)	60 (20; 160)	95 (35; 200)	70 (30; 160)	100 (50; 210)
Virtual GP consult(s)	0 (0; 15)	0 (0; 30)	0 (0; 10)	0 (0; 20)
Community/primary care nurse consult(s)	0 (0; 0)	0 (0; 0)	0 (0; 0)	0 (0; 0)
ED visit(s)	0 (0; 0)	0 (0; 0)	0 (0; 0)	0 (0; 0)
Rongoā consult(s)	0 (0; 0)	0 (0; 0)	0 (0; 0)	0 (0; 0)
Other healthcare provider(s)	0 (0; 75)	0 (0 ;100)	0 (0; 300)	0 (0; 400)
Diagnostic test(s)	0 (0; 0)	0 (0; 0)	0 (0; 0)	0 (0; 0)
Total 6 month cost	160.0 (60.0 500.0)	245.0 (95.0 850.0)	160.0 (50.0 600.0)	220.0 (60.0 800.0)

GP: General Practitioner; ED: Emergency Department

Table 16: Employment, changes and time off work/study given long COVID symptoms, % or mean as appropriate

	Māori	non-Māori
Current employment status (%)		
Full time	45.1	37.2
Part time	14.6	21.0
Self employed	11.0	12.0
Benefit	15.9	12.0
Unemployed	8.5	8.0
Homemaker	‡	2.8
Student	11.0	3.6
Retired	‡	12.4
Other	‡	4.4
Hours worked/studied (mean)		
Before getting COVID-19	39.46	38.01
Currently	32.20	28.64
Difference (hours)	7.25	9.37
p-value	<0.001	<0.001
Has there been a change in work/study? (%)		
Yes	76.0	68.3
No	24.0	30.7
Prefer not to say	‡	1.0
How has work/study changed (%)		
Reduced work hours	40.5	43.3
Taken time off	59.5	53.4
Used up sick leave	39.2	29.0
Taken leave without pay	31.6	24.6
Worked despite being unwell	70.9	61.3
Family/friends took time off	17.7	13.2
No change	7.6	16.7
Days off work study (paid/unpaid) due to long COVID (%)	75.7	77.4
Days off without pay due to long COVID (%)	73.0	72.4
Days family friends took off to care (%)	28.6	28.5
Days absent from work in past 4 weeks (mean)	4.82	6.28
Days unwell with LC symptoms in past 4 weeks (mean)	16.64	15.62
WSAS		
Low impairment (0-9)	‡	8.5
Moderate impairment (10-19)	16.3	21.3
Severe impairment (20-40)	83.7	70.2
WSAS total (mean)	25.15	23.82

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.
WSAS: Work and Social Adjustment Scale

Table 17: Impacts beyond employment, % respondents

	Māori	non-Māori
Reduced or stopped volunteering (%)	41.3	37.7
Reduced or stopped domestic tasks at home (%)	81.3	77.5
Reduced or stopped caregiving for others (%)	27.0	19.6
Reduced or stopped providing childcare (%)	16.2	10.0

Table 18: Financial changes and support; % respondents or mean value (2023/24 NZD) as appropriate

	Māori	non-Māori
How has income changed since COVID-19? (%)		
Decreased	52.7	43.5
No change	36.5	44.3
Increased	10.8	9.2
Prefer not to say	‡	3.1
Additional support accessed (%)		
Financial support (e.g. WINZ, ACC, MSD)	18.2	12.7
Carer support	‡	1.9
Home help	7.8	5.9
Transport	9.1	5.5
Child care	‡	2.6
Other	14.3	7.6
Paid for additional support (%)	30.6	28.6
Amount paid (mean)	$2344	$1790
Receiving benefits before COVID (%)	19.8	18.2
Receiving **new** benefits now with long COVID symptoms (%)	17.2	14.0

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.
WINZ: Work and Income New Zealand; ACC: Accident Compensation Corporation; MSD: Ministry of Social Development

Table 19: Variability of long COVID impacts by severity of infection, time with long COVID, IMD quintile, age and essential worker status

	Severity of COVID infection (symptoms)		Time with long COVID		IMD		Age		Essential worker	
	< 2	≥ 2	< 1 year	≥ 1 year	Quintile 1	Quintile 4/5	< 50	≥ 50	Yes	No
Symptoms										
Modified MRC (mean)	1.20	1.46 *	1.31	1.43	1.25	1.52 *	1.37	1.35	1.39	1.35
PHQ-9 score (mean)	9.92	12.29 *	11.32	11.46	10.59	12.33 *	12.04	10.72 *	11.37	11.45
GAD-7 score (mean)	5.58	7.61 *	6.92	6.73	6.31	7.48 *	7.78	5.87 *	6.87	6.85
K10 score (mean)	21.04	24.22 *	22.93	23.11	22.31	23.92 *	24.28	21.71 *	22.89	23.16
FAS total score (mean)	32.66	35.22 *	33.85	34.67	32.84	35.51 *	35.05	33.38 *	34.06	34.33
Pain prevalence total (%)	51.4	64.7 *	57.2	62.0	57.7	65.0	62.3	56.7	58.2	60.7
HRQoL										
EQ-5D-5L difference (mean)	-0.336	-0.381*	-0.347	-0.386*	-0.351	-0.392	-0.383	-0.334*	-0.367	-0.356
EQ-VAS difference (mean)	-32.5	-34.5	-32.2	-35.6 *	-33.0	-34.3	-34.7	-31.4 *	-35.3	-31.9 *
Disability difference (%)	58.5	54.5	50.8	61.4 *	57.4	52.9	56.2	54.0	55.7	55.2
Stigma										
LCSS score (mean)	18.61	21.71 *	19.26	22.10 *	19.62	22.57 *	23.11	18.06 *	21.11	20.17
Healthcare cost										
Total 6 month cost (mean, $)	1307	1127	1160	1260	1645	1079	1733	722 *	1158	1235
Employment										
Hours worked difference (mean)	-8.45	-9.15	-8.43	-9.36	-9.79	-9.60	-8.79	-9.65	-9.62	-8.74
Used up sick leave (%)	26.8	29.1	27.1	29.2	26.1	36.0 *	38.7	20.4 *	37.5	25.5 *
Worked despite being unwell (%)	60.4	60.6	58.0	63.6	61.1	62.0	74.5	49.0 *	67.7	58.5 *
WSAS (mean)	23.08	24.50 *	23.63	24.35	23.64	24.90	25.38	22.61 *	23.68	24.04
Finances										
Income decreased (%)	43.9	43.9	37.6	51.0 *	40.2	50.7	48.7	39.4 *	46.8	42.4 *
Amount paid for additional support (mean, $)	1893	1784	1551	2166	2323	1601	1740	1962	1593	1980

* statistically significant differences, p-value ≤ 0.05, t test of differences in means or Pearson's χ^2 test for proportions.

PHQ-9: Patient Health Questionnaire; GAD-7: General Anxiety Disorder; K10 Kessler Psychological Distress Scale; FAS: Fatigue Assessment Scale; HRQoL: Health-related quality of life; LCSS: Long Covid Stigma Scale; WSAS: Work and Social Adjustment Scale

Table 20: Sample characteristics of the Long COVID Registry respondents at 6 month follow-up (percentages and means (standard deviations) as appropriate)

	6 month follow-up
N	224
Age on joining registry (mean)	50.03 (14.42)
Gender (%)	
Female	72.8
Male	24.5
Non-binary / third gender	2.7
Highest qualification (%)	
No schooling or Primary only	‡
High school/secondary school/college	10.1
Post-school education or workplace qualification	20.2
Bachelor's degree or equivalent	35.8
Bachelor Honours degree or equivalent	12.4
Master's degree	13.3
Doctoral degree	8.3
Prefer not to say	‡
Household income (%)	
$0 - $30,000	11.5
$30,001 - $50,000	10.1
$50,001 - $100,000	32.1
> $100,000	37.2
prefer not to say	9.2
Health insurance (%)	46.9
Type of health insurance (%)	
Comprehensive	42.7
Hospital only	40.8
Other	16.5
Area Deprivation Quintile (IMD18) (%)	
1 – lowest deprivation	21.6
2	26.6
3	17.0
4	23.4
5 – highest deprivation	11.5
Essential worker status (%)	
Yes	32.6
Healthcare professional (as % of essential workers)	
Yes	52.1*

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression
* statistically significant difference (p-value ≤ 0.05) from the full sample
IMD18: Index of Multiple Deprivation 2018

Table 21: Long COVID experience in the 6 months since joining the registry

	6 month follow-up
Still experiencing symptoms (%)	
Yes	87.4
No	3.6
Unsure	9.0
Consider yourself recovered (%)	3.6
Ever received a clinical long COVID diagnosis (%)	
Yes	63.0
No	25.5
Unsure	11.6
Diagnosis of new conditions in last 6 months (%)	29.6
(previous) ME/CFS	16.7
Chronic sleeping problems	13.6
Long term (chronic) pain	10.6
Allergies (including hay fever)	7.6
High blood pressure	7.6

ME/CFS: Myalgic encephalomyelitis/chronic fatigue syndrome

Table 22: New COVID-19 infections in the 6 months since joining the registry

	6 month follow-up
COVID re-infection (%)	
Yes	19.7
No	74.9
Unsure	5.4
Number of new COVID infections (mean)	1.07 (0.25)
Days unwell with most recent infection (%)	
Less than 4 days	18.4
Between 4 and 9 days	47.4
Between 10 and 14 days	34.2
15 or more days	‡
Number of severe symptoms with most recent infection (mean)	1.30 (1.07)
Severity of most recent infection compared to earlier episodes (%)	
More severe / no difference	22.7
Less severe	77.3
Hospital admission for any COVID infection (%)	-
Prescribed antivirals for any COVID infection (%)	22.7
Vaccination/booster in the last six months (%)	28.6

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression

Table 23: Summary symptom scales, 6 months post registration (percentages and means (standard deviations) as appropriate)

	6 month follow-up	Direction & sign. of change cf. baseline
Modified MRC (mean)	1.31 (0.97)	↓ *
PHQ-9 score (mean)	10.38 (6.53)	↓ *
GAD-7 score (mean)	6.31 (5.58)	nc
K10 score (mean)	21.58 (8.12)	↓ *
FAS total score (mean)	32.77 (8.91)	↓ *
Pain prevalence total (%)	54.5	↓ *
Taking pain medication (%)	50.9	↓ *

* statistically significant differences, p-value ≤ 0.05, t test of differences in means or Pearson's χ^2 test for proportions.
↓ improvement in symptom scale; ↑ deterioration in symptom scale; nc no change
MRC: Medical Research Council; PHQ-9: Patient Health Questionnaire; GAD-7: General Anxiety Disorder; K10 Kessler Psychological Distress Scale; FAS: Fatigue Assessment Scale

Table 24: Self-reported health (SRH) and health-related quality of life (HRQoL), 6 months post registration (percentages and means (standard deviations) as appropriate)

	6 month follow-up	cf. pre-COVID	cf. baseline
Self-Assessed Health (%)			
Excellent	‡		
Very Good	10.3		
Good	26.0		
Fair	35.4		
Poor	28.3		
p-value		0.157	<0.001
Self-Assessed Mental Health (%)			
Excellent	3.6		
Very Good	18.3		
Good	35.3		
Fair	31.3		
Poor	11.6		
p-value		<0.001	<0.001
EQ-5D-5L	0.607 (0.291)		
p-value		<0.001	<0.001
EQ-VAS	56.1 (22.9)		
p-value		<0.001	<0.001
Considered to have a disability, impairment or long-term condition (%)	85.8		
p-value		<0.001	<0.001

Table 25: Employment, work/study and finances, 6 months post registration (percentages and means as appropriate)

	6 month follow-up	Direction & sign. of change cf. baseline
Current employment status (%)		
Full time	30.9	↓ *
Part time	20.6	↑ *
Self employed	10.8	↑ *
Benefit	14.3	↓ *
Unemployed	7.6	↑ *
Homemaker	4.9	↑ *
Student	‡	-
Retired	14.8	↑ *
Other	5.8	↑ *
Hours worked/studied	28.68	
Difference from baseline	-0.82	
Difference from pre-COVID	9.05	↓ *
How work/study has changed (%)		
Reduced work/study hours	27.7	↓ *
Stopped work/study	21.0	±
Started work/study	6.3	±
Used up sick leave	13.4	↓ *
Taken leave without pay	12.9	↓ *
Worked despite being unwell	45.5	↓ *
Family/friends took time off	11.2	↓ *
No change	25.0	↑ *
WSAS (low: 0-9, moderate 10-19; severe 20-40) (mean)	22.06	↓ *
Has income changed (%)		*
Decreased	27.8	↓
No change	56.1	↑
Increased	16.1	↑
Prefer not to say	‡	
Additional support (%)		
Financial support (e.g. WINZ, ACC, MSD)	17.1	↑ *
Carer support	‡	
Home help	5.0	↓ *
Transport	4.5	↓ *
Child care	2.7	↓ *
Other	6.8	↓ *
Paid for additional support (%)	30.5	↑ *
Receipt of benefit (%)	26.3	±
Continued to receive a benefit (% of those in receipt)	81.4	±
Started receiving a new benefit (% of those in receipt)	16.9	±
Stopped receiving a benefit (% of those in receipt)	37.3	±

‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression
± these categories are not comparable between baseline and follow-up questionnaires
* statistically significant differences, p-value ≤ 0.05, t test of differences in means or Pearson's χ^2 test for proportions.
↓ lower value cf. baseline questionnaire; ↑ higher value cf. baseline questionnaire