

Mātauranga Raranga

Long COVID Registry

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Long Covid Support

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Funding from

- Ministry of Health via the COVID-19 and National Immunisation Programme Research Programme
- The EuroQol Foundation

Project team

- Professor Paula Lorgelly, Principal Investigator
- Jenene Crossan (Ngāi Tahu), Co-Investigator lived experience of long COVID
- Andrew McCullough, Research Assistant
- Associate Professor Daniel Exeter, Named Investigator

Acknowledgments

Te Rōpū Kaitiaki | Advisory Board

- Witi Ashby (Ngāti Hine, Ngāti Kawa)
- Iris Pahau (Te Aupouri, Te Rarawa, Ngāti Kuri, Ngāti Awa)
- Ngapera Riley (Te Arawa, Ngāti Uenukukopako, Ngāti Roroaterangi, Ngāti Whakaue, Tūhourangi)
- Mona Jeffreys
- Marianna Churchward (Lotofaga, Faleasiu, Samoa)
- Jenene Crossan (Ngāi Tahu)
- Andrew McCullough
- Paula Lorgelly



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Long COVID Registry

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- Project's gifted te reo Māori name
- Refers to
 - knowledge sharing
 - thoughts weaving
 - spirituality determination
 - focus
 - working together
- Can also reflect the science of creating something beautiful, useful and with purpose

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What is long COVID?

“the term used to describe symptoms that continue or develop after your initial COVID-19 illness and cannot be explained by any other condition. The symptoms of long COVID may last weeks or months after a COVID-19 infection.”



What do we know & what don't we know?

- Q2 2020 many individuals who survived COVID-19 infection weren't recovering from their infection
- Displaying a myriad of symptoms: brain fog, fatigue, breathlessness, cardiovascular, pain
- Post COVID syndrome, now long COVID (as named by patients)
- Diagnosis is difficult, formal clinical diagnosis is uncommon
- Early evidence of 20% of individuals with COVID-19 did not recover, now in the range of 6-10%
- Treatments are being trialled
- Suggestions that there is a link between severity of infection and long COVID and some evidence of repeat infections and long COVID severity
- Described as a “mass-disabling event”
- WHO call for systematic data collection on patients with long COVID



- In the US total economic cost \$3.7 trillion (incl. QALYs, lost earnings, medical spending) (Cutler, 2022)
- In Germany production loss of €3.4 billion; gross value-added loss €5.7 billion; €1.7 billion healthcare and pensions system (Gandjour, 2023)
- Prof Danny Altmann (Imperial College) declared the burden of the post-infection condition *"so large as to be unfathomable"*.



- *Ngā Kawekawe o Mate Korona* Victoria University Wellington (Russell et al, 2023) national wide study of COVID-19 impact, those infected prior to Dec 2021 (pre-omicron)
 - 8,735 individuals tested +ve test approached, 990 completed survey, 58 interviews
 - 22% met WHO classification for long COVID
 - 1/3rd reported not getting a referral to a specialist
 - Reported lack of financial support



- Closed borders no natural COVID immunity but a highly vaccinated population
- Relaxation of mitigation strategies in late 2021/early 2022
- Questions raised whether long COVID would have similar prevalence and/or impact in Aotearoa New Zealand
- Important to understand the distribution of impact given the inequitable burden of COVID-19
- To date there are no publicly funded long COVID clinics, although clinical coding for diagnosis has been available since August 2022

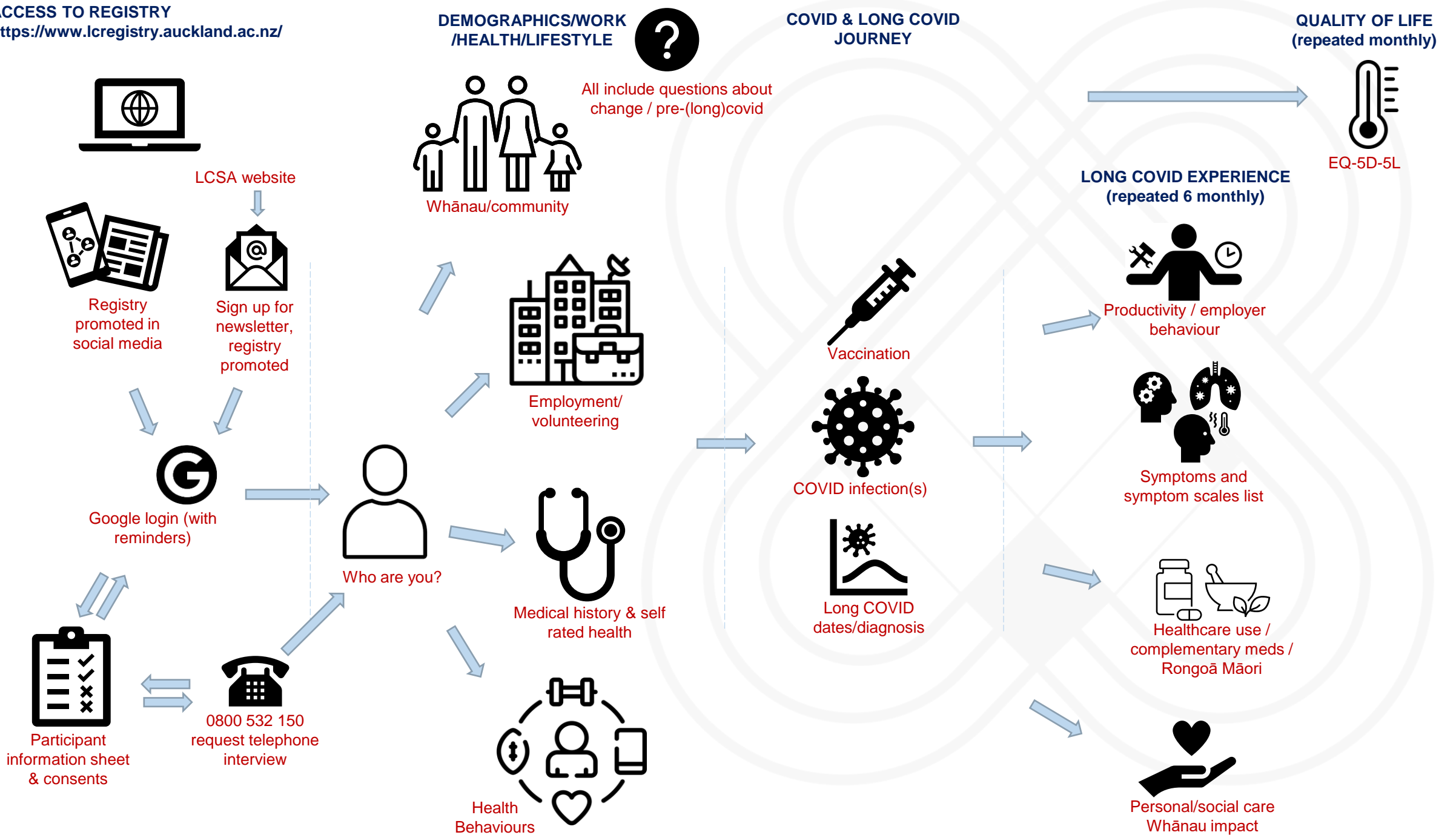


Objective is to establish a **long COVID registry** and with that estimate the clinical, quality of life and economic impacts of long COVID in Aotearoa New Zealand, plus provide a means to continually monitor health outcomes and inequities



1. What is the prevalence of long COVID symptoms in a cohort of individuals with *self-reported long COVID*?
2. What is the 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 burden of long COVID?



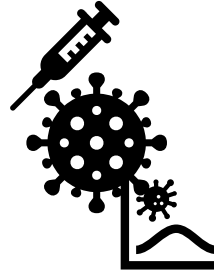


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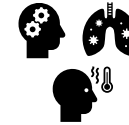
Questions about you



Questions about your COVID experience



Questions about your post COVID experience

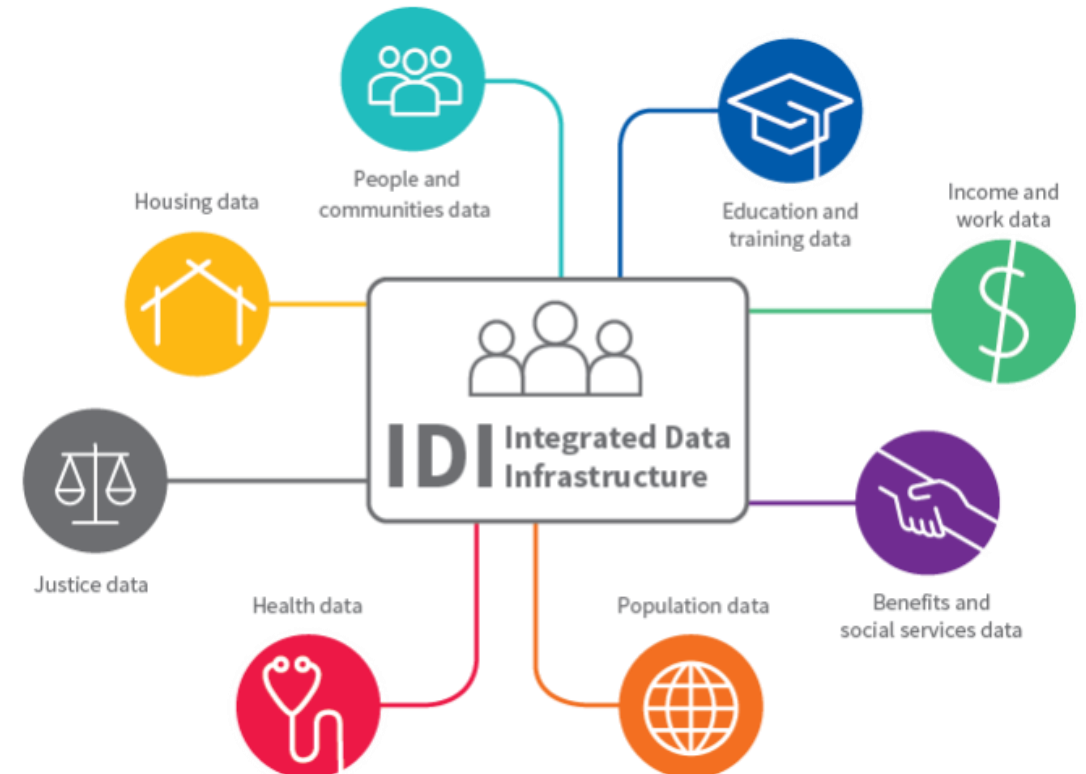
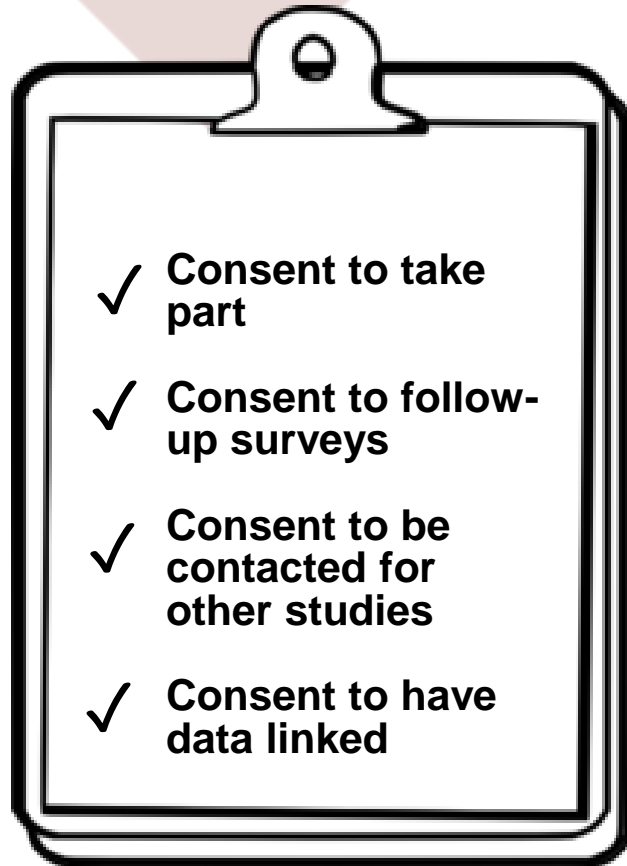


Reminder
Emails

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Research Oversight / Data Governance



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Thank you, this is the end of this survey module.

Are you sure you want to submit?



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* Required

Yes, I'm

ATTENTION: THIS IS ONLY INTENDED FOR SUBMITTING FINAL RESPONSE.

You will NOT be able to access the Registry Portal after final submission to make changes or start/complete unfinished surveys.

Are you sure you want to submit your final responses?

Please confirm you are happy to submit your information to the registry.

* Required

Yes, I'm sure *

Interim Analysis

Registry opened 7th July 2023

Data download as of
23:59 30th September 2023

Qualtrics > R > Stata

10 modules, average number of modules
completed is 7

N=355 fully submitted to the registry

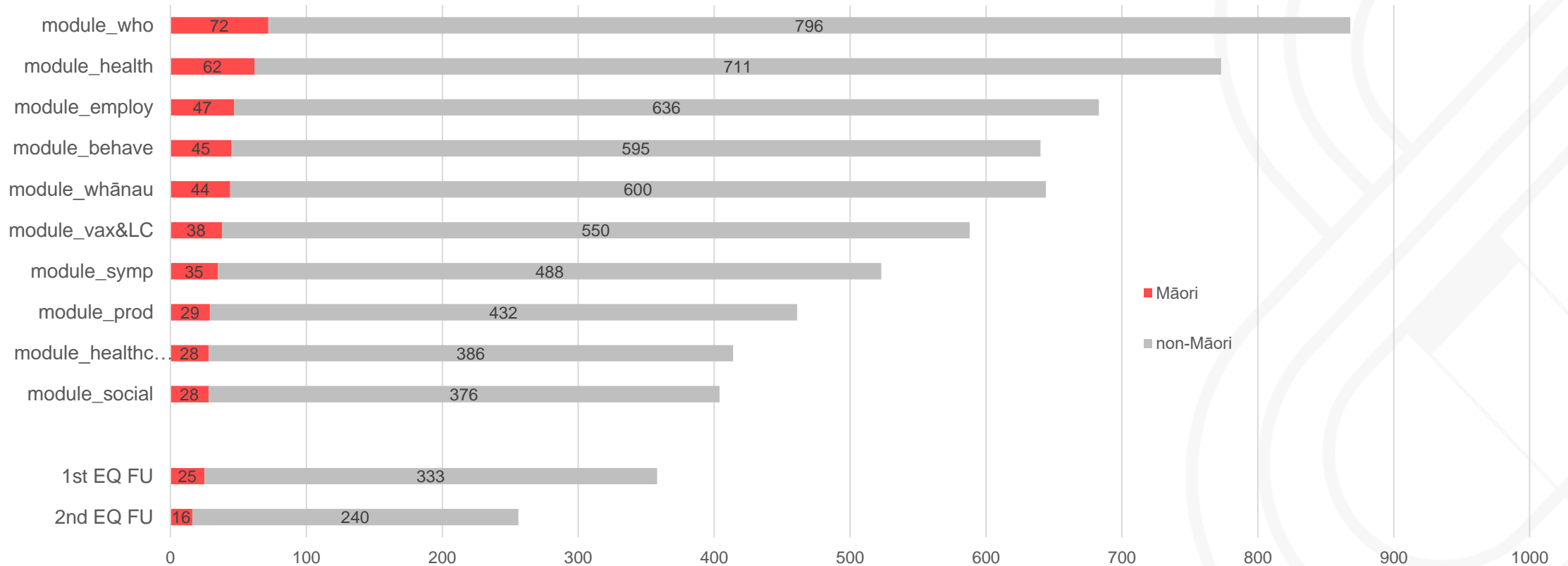
- Study is underpinned by a Tiriti o Waitangi Framework
 - Te Rōpū Kaitiaki consisting of tangata whenua and tāngata tiriti replicating a partnership model of practice
- Recognise relationship as fundamental to positive research outcomes
 - Avoid deficit framing; research invisibilises the historical and institutional drivers of inequities for marginalised groups, therefore placing blame for inequitable outcomes on marginalised individuals and collectives (Reid and Robson, 2007)
- Māori data sovereignty 'inherent rights and interests that Māori have in relation to the collection, ownership and application of Māori data'
- Interim sample, prioritised ethnicity: Māori 72, Pacific 10, Asian 30, Other 752
- Analysis framework separate analyses for Tangata Whenua 8.29%; Tāngata Tiriti 91.71%



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Number of Responses



	Māori (%)	non-Māori (%)
Sex		
Female	74.00	72.86
Male	22.50	24.50
Non-binary / third gender	†	2.39
Age (mean)	44.52	49.49
Current household income		
\$0 - \$30,000	15.22	11.76
\$30,001 - \$50,000	17.39	7.21
\$50,001 - \$100,000	19.57	28.68
> \$100,000	43.48	41.85
IMD Quintile		
1	14.29	24.97
2	28.57	22.86
3	11.43	20.11
4	21.43	20.37
5	24.29	11.70

	Māori (%)	non-Māori (%)
Highest educational attainment		
No formal qualifications	†	†
Primary school	†	†
High school/secondary	19.44	10.68
Post-school education	22.22	19.85
Bachelor's degree	30.56	31.16
Bachelor Honours degree	8.33	14.2
Master's degree	11.11	16.33
Doctoral degree	†	5.65
Prefer not to say	†	1.51
Essential Worker		
Yes	37.50	30.00
of which healthcare worker	30.00	45.00
No	62.50	70.00

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

Before COVID	Māori (%)	non-Māori (%)	Today	Māori (%)	non-Māori (%)
Self-Assessed Health			Self-Assessed Health		
Excellent	21.00	26.11	Excellent	‡	‡
Very Good	41.00	38.47	Very Good	‡	3.50
Good	27.50	22.64	Good	11.29	15.50
Fair	11.00	10.28	Fair	30.65	34.50
Poor	‡	2.36	Poor	53.23	46.00**
Self-Assessed Mental Health			Self-Assessed Mental Health		
Excellent	26.00	22.64	Excellent	‡	2.66
Very Good	29.00	36.67	Very Good	13.00	13.46
Good	24.00	24.03	Good	27.50	24.54
Fair	16.00	12.78	Fair	24.00	40.25
Poor	‡	3.61	Poor	29.00	19.07**
EQ-5D-5L (mean)	0.853	0.892	EQ-5D-5L	0.484**	0.533**
EQ-VAS (mean)	81.08	81.80	EQ-VAS	44.04**	48.42**

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

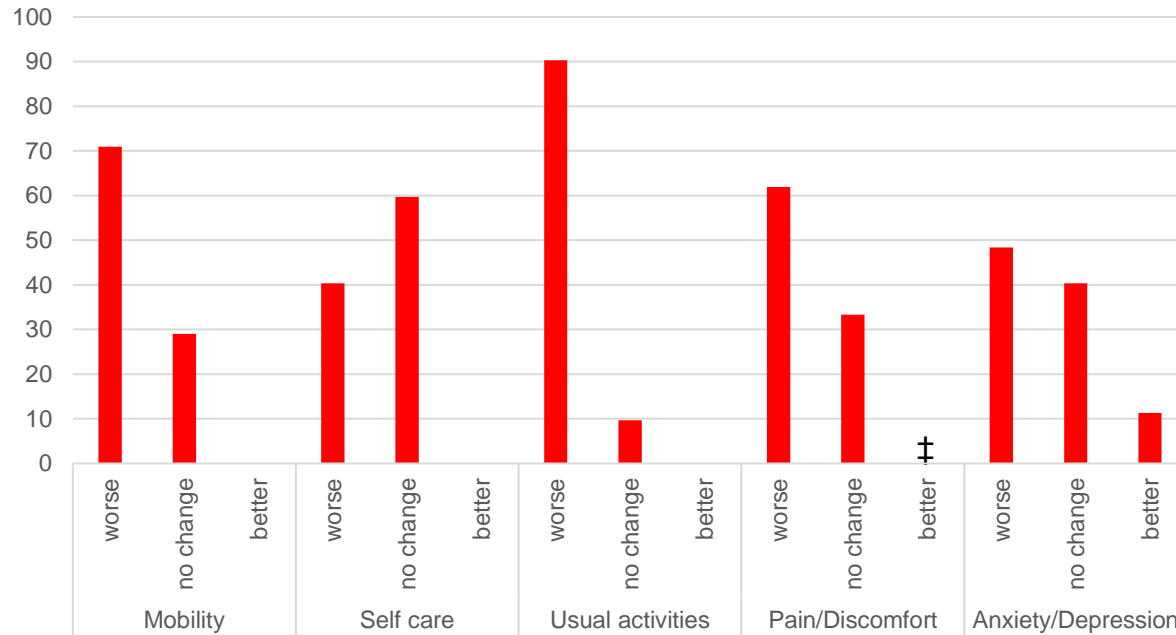
**significant difference between before & today

Evidence on HRQoL – norms, other conditions & long COVID

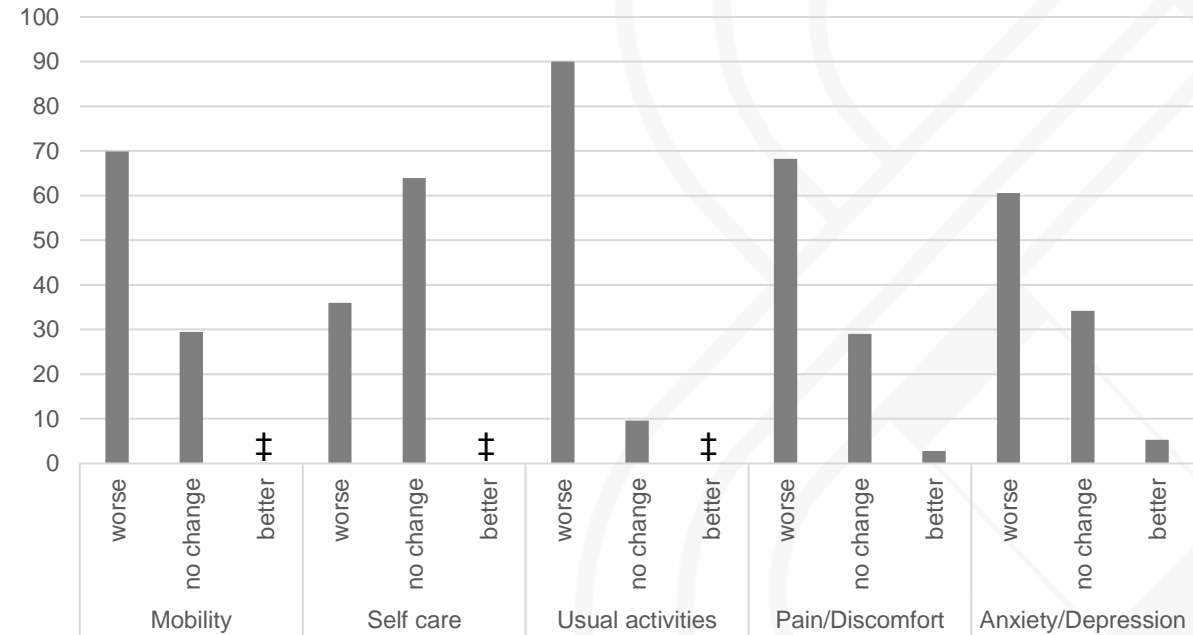
- Sullivan et al (2021) report population norms for Aotearoa of 0.847 on EQ-5D-5L and EQ-VAS score of 74.8
- Clafin et al (2023) report an EQ-5D-5L health state utility of 0.58 people with multiple sclerosis (MS) in NZ, and similar values for individuals with cancer
- Tak (2023), 82 individuals with self-reported long COVID from 13 countries, reported a mean EQ-5D-5L utility score of 0.51 and the EQ-VAS of 41.6
- Walker et al (2023), sample 3000+ individuals from 31 post-COVID (long COVID) clinics in the UK reported a mean EQ-5D-5L of 0.54



Māori - EQ-5D-5L domain change before/today (%)



non-Māori - EQ-5D-5L domain change before/today (%)



Cells with fewer than 6 people have been suppressed.

- Usual activities is much worse for both Māori and non-Māori respondents

	Māori (%)	non-Māori (%)		Māori	non-Māori
Current employment			Hours (mean)		
Full time	40.38	38.10	Before COVID-19	38.86	38.68
Part time	15.38	20.58	Current	31.2	28.76
Self employed	13.46	12.29	Difference	7.66**	9.92**
Benefit	13.46	11.98			
Unemployed	13.46	7.83	Has there been a change in work/study? (%)		
Homemaker	‡	2.92	Yes	76.00	70.00
Student	11.54	3.23	No	24.00	30.00
Retired	‡	12.14	Prefer not to say	‡	‡
Other	‡	3.69			

‡ cells with fewer than 6 people have been suppressed with rounding for secondary suppression.

**significant difference before & current

	Māori (%)	non-Māori (%)		Māori (mean)	non-Māori (mean)
Reduced work hours	47.73	53.45	Days off work study (paid/unpaid) due to LC	93.41	78.15
Taken time off	65.91	65.92	Days off without pay due to LC	95.75	72.70
Used up sick leave	43.18	33.33	Days family friends took off to care	37.8	25.16
Taken leave without pay	36.36	27.93			
Worked despite being unwell	77.27	71.88	Days absent from work in past 4 weeks	4.77	6.21
Family/friends took time off	22.73	16.95	Days unwell with LC symptoms in past 4 weeks	16.54	16.10
			WSAS – Work and Social Functioning Impairment (low: 0-9, moderate 10-19; severe 20-40)	24.48	24.26

Absenteeism and Presenteeism

- Reported reducing working hours, confirms earlier estimate of 7.66-9.92 hrs a week
- 66% of Māori and non-Māori respondents have taken time off, including 36% of Māori and 28% of non-Māori who have taken leave without pay
- 77% of Māori and 72% of non-Māori have worked despite being unwell (presenteeism)
- Average WSAS scores are in the severe range
 - Similar to the UK long COVID study (Walker et al 2023) implying severe impairment of daily functioning



Impacts beyond employment

- 46% Māori and 36% non-Māori have reduced or stopped volunteering
- 78% Māori and 68% non-Māori have reduced domestic tasks at home
- 28% of Māori and 20% of non-Māori have reduced or stopped caregiving for others
- 9% of non-Māori have reduced or stopped providing childcare



Volunteering and unpaid tasks

	Māori (%)	non-Māori (%)		Māori (%)	non-Māori (%)
Volunteering			Caregiving		
More unpaid voluntary work now	‡	2.06	Provided more unpaid caregiving	‡	1.28
Less unpaid voluntary work	19.57	15.4	Provided less unpaid caregiving	13.04	11.84
Stopped doing unpaid voluntary work	26.09	20.79	Stopped providing unpaid caregiving	15.22	8.32
Started doing unpaid voluntary work	‡	2.7	Started providing unpaid caregiving	‡	1.44
Unpaid voluntary work not changed	‡	7.3	It has not changed	‡	5.92
Did not do voluntary work	50.00	50.48	Did not provide caregiving	56.52	70.24
Domestic Work at Home			Child care		
More unpaid domestic work	‡	2.04	Look after a child or children more	‡	‡
Less unpaid domestic work	78.26	67.77	Look after a child or children less	‡	7.00
Stopped doing unpaid domestic work	‡	8.96	Stopped looking after a child/children	‡	3.00
Unpaid domestic work not changed	13.04	19.65	Started looking after a child/children	‡	1.00
Did not do domestic work	‡	1.57	It has not changed	‡	2.50
			Did not provide childcare	84.44	86.00

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

- 53% of Māori and 44% of non-Māori experienced a decline in income since COVID-19 infection (9% of both Māori and non-Māori report increased income)
- 13/47 Māori reported receiving benefits pre COVID infection, 11/47 Māori reported getting a new benefits since their COVID infection
- 142/639 non-Māori reported receiving benefits pre COVID infection, 109/633 non-Māori reported getting a new benefits since their COVID infection



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COVID experience

- 100% Māori respondents and 99% of non-Māori respondents are vaccinated
- Mean doses of vaccine is 3.14 for Māori, 3.44 for non-Māori
- 92% of Māori respondents and 91% of non-Māori respondents first infected during omicron and later waves (2022 onwards)
- Mean number of infections for Māori 1.48; mean number of infections for non-Māori 1.42
- Mean number of days with long COVID is 367 days for Māori respondents and 335 days for non-Māori respondents (max 3+ years)



Healthcare use & cost of care (last 6 months)

(means)	Māori N _{max} =25	non-Māori N _{max} =346
GP consult	4.21	3.74
Tele/virtual consult	2.44	2.43
Nurse consult	2.50	2.55
A&E consult	‡	1.94
Hospitalisation consult	‡	1.40
Rongoā consult	‡	4.75
Other provider* consult	5.80	5.80
Total cost GP visits	\$154.17	\$143.14
Total cost tele/virtual visits	\$64.44	\$66.36
Total cost nurse visits	\$26.67	\$40.35
Total cost A&E visits	‡	\$84.12
Total cost rongoā visits	‡	\$120.00
Total cost other provider	\$1615.00	\$2388.32
Total out-of-pocket costs	\$863.60	\$1457.66

‡ cells with fewer than 6 people have been suppressed.



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Symptoms

- Most respondents experienced symptoms of fatigue at some point (92% Māori respondents, 91% non-Māori respondents)
- Loss of concentration / brain fog also common long COVID symptom
- Top symptoms include
 - Fatigue
 - Muscle pain
 - Brain fog / Loss of concentration
 - Irregular heartbeat
 - Sleep disturbance
 - Chest pain
 - Sleep issues
 - Breathlessness
- 50% of Māori and 50% of non-Māori respondents report no change in their symptoms in the last 3 mths, 35% of Māori respondents and 27% of non-Māori report worsening symptoms



Presence of symptoms (%)

	Fatigue	Fever	Abdominal Pain	Joint Pain	Muscle Pain	Nausea/ Vomiting	Diarrhoea	Weight Loss	Reduced Appetit	Sleep Issues	Chest Tightness	Chest Pain	Skipped/ Extra/Irreg Heartbeat	Breathlessness	Cough	Brain Fog	Headache	Sleep Disturbance	Pins & Needles	Delirium	Lack Arm/Leg Strength	Visual Disturbance	Noise/Ringing Ears	Earache	Sore Throat	Vertigo Dizziness	Loss Taste/Smell	Blocked Nose	
Current																													
Māori (N=36)	92	17	34	67	72	34	‡	22	47	72	65	49	71	78	32	83	58	69	51	‡	51	40	54	18	18	47	18	26	
non-Māori (N=496)	91	7	20	47	53	20	16	9	21	66	36	28	45	54	28	77	56	67	40	6	45	28	40	11	16	39	13	30	
Previous																													
Māori (N=36)	‡	49	26	19	‡	29	34	22	31	‡	21	23	‡	‡	47	‡	28	17	‡	21	29	17	14	38	50	33	18	34	
non-Māori (N=496)	7	48	20	23	24	26	27	16	31	17	27	27	20	27	38	17	27	17	17	14	20	18	13	19	49	30	30	33	

- Measured using new validated Long COVID Stigma Scale (Pantelic et al, 2022) *13 questions scored 0-never 4-always*
- Mean score for Māori respondents 23.4; mean score non-Māori respondents 20.45
 - Means similar to the stigma reported by Pantelic et al (2022) in a group of UK individuals with long COVID (mean=20.4)
- 49% of Māori respondents and 52% of non-Māori respondents felt stigmatised at least some of the time



- Highly engaged participants

Consent ...	Māori (%)	non-Māori (%)
... to be followed up	98.61	99.75
... to be approached for further research	98.61	97.60
... to have data linked to IDI	98.61	94.20



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- Long COVID has a detrimental impact on the HRQoL of Māori and non-Māori with self-reported long COVID
 - Pre-COVID similar to population norms, with long COVID symptoms EQ-5D-5L is like that of individuals with MS and cancer
- Individuals with self-reported long COVID have significantly reduced the hours they work, experienced a reduction in income, and have high levels of absenteeism and presenteeism (working despite being unwell)
- Fatigue and brain fog are most common symptoms for both Māori and non-Māori respondents, this could explain why functioning (scored using WSAS) is in the severe range
- Symptoms have not improved for the majority of individuals with self-reported long COVID
- Respondents reported experiencing stigma due to their long COVID
- High levels of consent make this an invaluable research resource to understand the long-term consequences of the pandemic



Term	Description
EQ-5D	A standardised measure of health-related quality of life using five dimensions, produces index score and EQ-VAS
QALY	Quality-adjusted life year is a measure of disease burden which combines quality of life and length of life.
IMD	Index of Multiple Deprivation used to measure deprivation within neighbourhoods. Quintiles, 1 is least deprived - 5 is most deprived.
NHI	National Health Index is a unique number assigned to every individual who uses healthcare in Aotearoa New Zealand.
Modified Medical Research Council Dyspnoea Scale (mMRC)	A 1-5 scale of breathlessness related to activity.
Patient Health Questionnaire-9 (PHQ-9)	A 9-item measure of severity for current depressive disorders.
General Anxiety Disorder-7 (GAD-7)	A 7-item measure of severity for anxiety.
Kessler Psychological Distress Scale (K10)	A 10-item measure of severity for psychological distress.
Fatigue Assessment Scale (FAS)	A 10-item measure of chronic fatigue symptoms.
Brief Pain Inventory (BPI)	A tool used to measure the intensity of pain and how pain interferes with daily activities.
Work and Social Adjustment Scale (WSAS)	A widely used measure of functional impairment related to general life.

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Sullivan T, Turner RM, Derrett S, Hansen P. New Zealand Population Norms for the EQ-5D-5L Constructed From the Personal Value Sets of Participants in a National Survey. *Value Health*. 2021 Sep;24(9):1308-1318. doi: 10.1016/j.jval.2021.04.1280. Epub 2021 Jun 26. PMID: 34452711.

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