# Mātauranga Raranga

Long COVID Registry
AOTEAROA NEW ZEALAND

# "This isn't a life": An analysis of EQ-5D in a cohort of individuals with long COVID symptoms

EE422

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# Background

Long COVID – COVID-19 symptoms or sequelae that persist for longer than three months – is a significant public health problem.

Aotearoa New Zealand had closed borders during the acute pandemic phase, but has subsequently had high rates of infection, and therefore there is an expected large number of individuals long COVID symptoms. Little is known about the impact long COVID is having on the health-related quality of life (HRQoL) of individuals over an extended period post-infection and its wider implications.

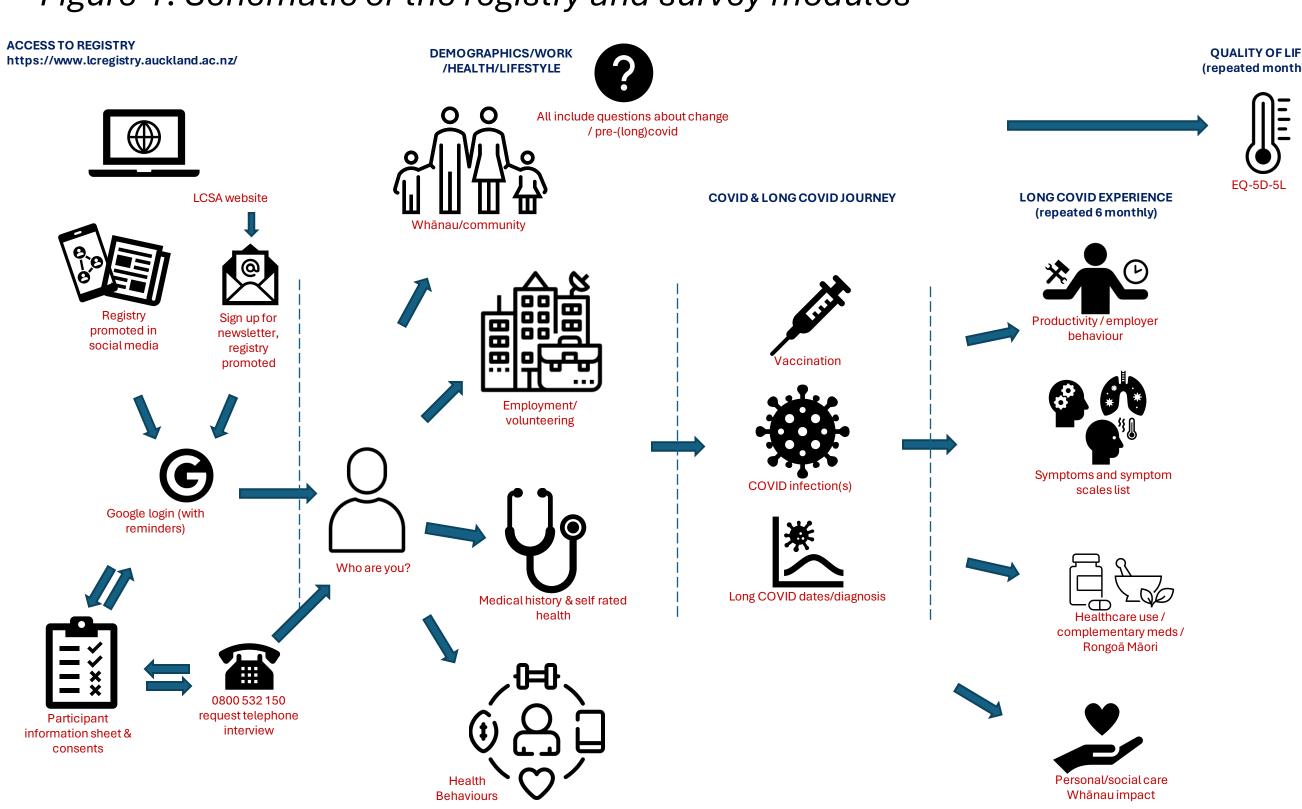
## **Objective**

Long COVID is expected to be the most significant and enduring impact of the COVID-19 pandemic. This study provides evidence of the impact of long COVID symptoms on EQ-5D-5L using the New Zealand value set. It also explores the change over time and possible mediators of this impact.

#### Methods

Mātauranga Raranga | Long COVID Registry Aotearoa consists of ten linked survey modules (Figure 1) designed in partnership with people with lived experience of long COVID.

Figure 1: Schematic of the registry and survey modules



66 Prior to catching Covid I was extremely active in local politics, the community, volunteering, a co-campaign manager, I was on a leadership program, and a busy parent. It felt like I was just reaching the top of my career, with loads of future potential.

After Covid I ended up with inflammation on my spine, extreme extreme fatigue, chronic pain everywhere. I spent a year stuck to the couch. So much pain and not enough energy to walk to the toilet. 16 months in, I take 11-12 pills a day, can now do 3-4 steps (from my chair to the toilet), and can now have conversations with people (as long as I pace myself), I can look at Facebook, and I try to shower every day. The rest of the time, I sleep/rest. This is nooooothing compared to where I used to be.

This isn't a life."

- Female, Samoan/NZ European

The first module collects socio-demographic information including age, area of residence, etc.

HRQoL is collected using the EQ-5D-5L, with recall for pre-COVID HRQoL and today with long COVID symptoms. Participants can also complete monthly EQ-5D-5L follow-up surveys.

The registry is underpinned by a Tiriti o Waitangi Framework which seeks to avoid deficit framing. Separate analyses of tangata whenua (Māori) and tāngata tiriti (non-Māori) explore the demographic decomposition of the registry by deprivation quintiles and then EQ-5D-5L values and profiles in the top and bottom quintiles.

Analyses explore the difference in EQ-5D-5L over time and any mediators of this relationship.

#### Results

The registry remains open to enrolment; these results are based on a data extract on the 31<sup>st</sup> March 2024 – 8 months after the opening of the registry. The sample size is N=1,348, 8.5% Māori; 91.5% non-Māori. The demographics of the sample are presented in Table 1. 73% | 75% of Māori | non-Māori participants are female, and the average age is 45 | 49 years old. Vaccination rates are high due to vaccine mandates.

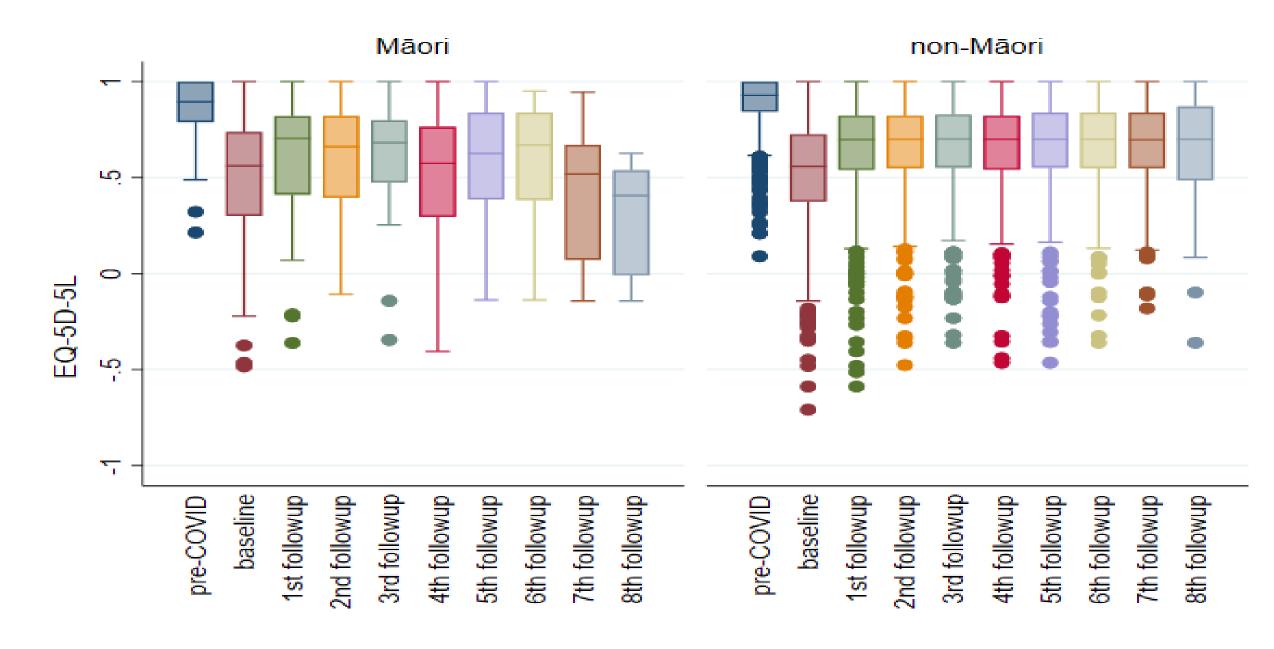
Pre-COVID EQ-5D-5L had a mean value of 0.856 | 0.887 for Māori | non-Māori; at enrolment with long COVID symptoms the mean value was 0.488 | 0.529. The difference in EQ-5D-5L is statistically significant across those two time points. Analysis of the monthly follow-up data shows the disutility associated with long COVID symptoms persists (see Figure 2).

Table 1: Demographics of the sample

	Māori (%)	non-Māori (%)		Māori (%)	non-Māori (%)
Sex			Highest educational attainment		
Female	75.2	73.5	No schooling/Primary school	‡	0.6
Male	24.8	23.3	High school/secondary	23.1	12.0
Non-binary / third gender	‡	2.7	Post-school education	24.1	19.5
Age (mean)	45.69	48.80	Bachelor's degree	34.3	31.1
			Bachelor Honours degree	9.3	13.8
Current household income			Master's degree	9.3	15.6
\$0 - \$30,000	15.3	12.7	Doctoral degree	‡	5.9
\$30,001 - \$50,000	16.7	7.8	Food antical Markery		
\$50,001 - \$100,000	25.0	29.0	Essential Worker	07.0	00.0
> \$100,000	43.1	39.5	Yes	37.9	32.0
IMD Quintile			of which healthcare worker	36.4	40.0
1 - least deprived	15.2	23.8	Num. vaccinations (mean)	3.26	3.44
2	25.0	23.7	Num. of COVID infections (mean)	1.69	1.46
3	15.2	21.2	Number of comorbidities (mean)	3.02	2.64
4	19.6	19.7	Number of comorbidities (mean)	3.02	2.64
5 - most deprived	25.0	11.6	‡ Cells with fewer than 6 people have been suppressed, with rounding to support secondary suppression.		

Pre-COVID EQ-5D-5L and time in study are used to calculate potential QALYs in the absence of long COVID. The AUC method is employed to estimate the QALYs of experiencing long COVID. QALYs lost due to long COVID range from 0.721 to -0.097 | 0.705 to -0.143, mean QALYs lost is 0.142 | 0.133 for Māori | non-Māori.

Figure 2: Box plot of EQ-5D-5L over time



### Discussion

This study shows that the impact of long COVID symptoms on HRQoL is similar to that of individuals with MS and cancer. Further research is warranted to understand the determinants of this burden and whether time or treatment mediates the impact. Additional analysis is planned once more data are available from six-monthly follow-up. Further research has explored the impact of deprivation on HRQoL, see poster HPR3.

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