Long COVID: Journeying together through the fog

Collaborating to support people with post-acute COVID-19 syndrome (PACS)

University of Otago
Te Whare Wānanga o Otāgo
New Zealand
Wellington

Victoria University of Wellington
Te Herenga Waka

AUT

Long COVID and Māori

#longcovid2022

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

65

Māori survey respondents

28

(43%)

Had symptoms for more than a month

21

(75%)

Had symptoms for 3+ months

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I did not feel understood (43%)

I did not know when it would end (61%)

My doctor thought I was still contagious, even months later (18%)

My doctor didn’t recommend or provide wrap around support (32%)

I was scared and unsure what to do next (52%)

I did not feel listened to (48%)

I didn’t know who to ask for help or support (52%)

My specialist referral was not accepted (13%)

My doctor didn’t know what to do next (32%)

I cannot get good information about vaccines for people with long COVID (50%)

My doctor did not refer me to a specialist (35%)

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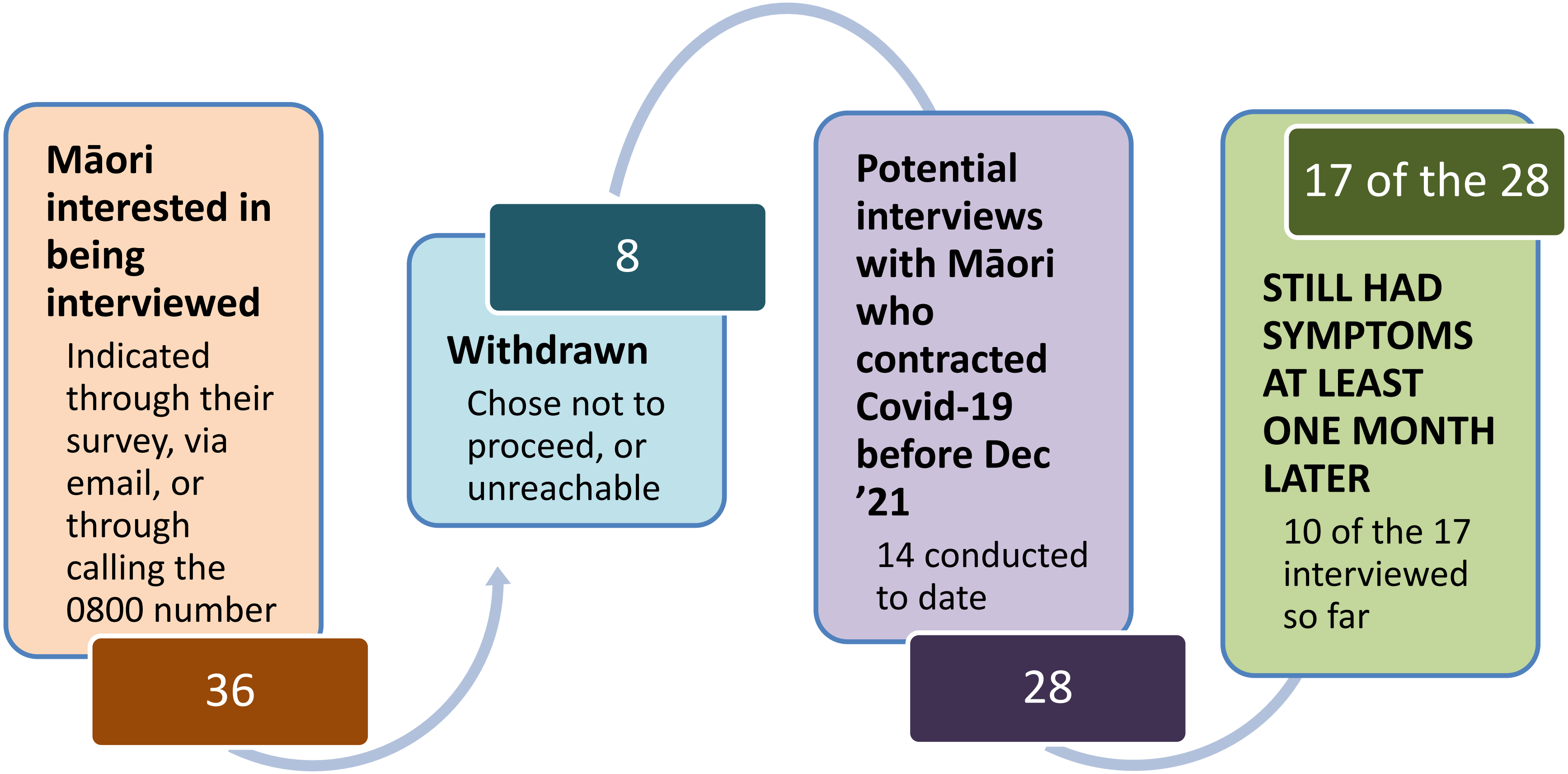

Māori interested in being interviewed

Indicated through their survey, via email, or through calling the 0800 number

36

8

Withdrawn

Chose not to proceed, or unreachable

Potential interviews with Māori who contracted Covid-19 before Dec ’21

14 conducted to date

28

17 of the 28

STILL HAD SYMPTOMS AT LEAST ONE MONTH LATER

10 of the 17 interviewed so far

Common themes emerging from interviews with Māori with Long COVID (preliminary)

- Surprisingly sicker than ever before
- Who am I now?
- How do I know if this is Long COVID or related to my other illnesses?
- Why won’t the doctor take me seriously?
- What can I actually do about this?

What Long COVID looks like

Ever since having it [Long COVID] my asthma has been worse, probably 10-fold. I would be on my puffer three times a day probably and I would never leave the house without it because it was that bad. It's under better control now but it's still not what it was pre-COVID … I'm still not well … I'm pretty sure it's affected my liver. I can't do alcohol, I can't exercise, I get migraines and headaches constantly. I battle fatigue, brain fog, like it's still all there … *(Wahine Māori)*

What I do know is that when I do get colds, and I've had a couple since I've had Covid, it lasts and lingers a lot longer than it would have before. So, I've had this cough and runny nose for more than a month now. It's annoying, but it's not life-threatening if that makes sense. *(Wahine Māori)*

We [wife and I] both got long-COVID, and still got some bad side effects from it, but she's probably the worse. She plays golf, and she used to walk eighteen holes. She can't do that anymore. We were staying in a hotel … and she carried a chair from room … around the corner into our room, and she was absolutely knackered by the time she got in there. I didn't realise how bad it was until I saw that. So, she's still suffering from major respiratory problems from it ... I have things like a cough, I sneeze a lot … Fuzzy brain, and remembering silly little things that you should be able to remember … if I try to remember a name or a place and I just can't get it … I just can't find the word for it … the biggest issue for me is smell and taste. After two years plus later, I still haven't got my smell and taste back properly … it's just annoying because food's part of life, and you just don't get that enjoyment out of it anymore ... I'm afraid the Māori really comes out in me when it comes to food. I enjoy my food, and it's part of your life.
(Kaumātua)

I work in rugby league … I was the person who cooked for the teams. I was the side-line medic for the two senior teams on Saturday. I go to training twice a week to check on injuries, strapping, and that sort of stuff; and, Saturday mornings I do all the strapping of the senior teams. So I was just full-on … About three weeks ago, our senior team had a trial game, and their physiotherapist was away down the line, and they rang me up, and they said to me, “Do you think you could come and give us a hand to do the boys tomorrow?” … on a six minute walk .. I stopped for or five times; I was absolutely knackered. When I got up there the girls met me, and they’re like, “Oh my God Mama … you look like you’ve blimmin’ just run a marathon.” … I was huffing and puffing, and wheezing and carrying on … I ended up with sleep apnoea as well … *(Wahine Māori)*

I was reduced to five hours a week … I couldn’t handle anything more than that. I struggled even with that and would pass out for the rest of the day after I’d worked my hours ... It was quite brain-drain stuff and it was really taxing on my head so I could concentrate for that really short period of time but I would be absolutely had it after that for the rest of the day. That reduced my income ... I’d love to extend my hours but currently I can’t handle it. I’ve got a bit of the ‘flu over the last week and because of Long COVID and because of the state of my health I can expect this for about three weeks or so. *(Wahine Māori)*

It's probably just me …

I wondered if it hit me harder because I had breast cancer and radiotherapy at the end of 2019 so I wondered whether the radiotherapy and stuff had left me a little bit immune compromised in a way ... I just wondered that and then after I had kind of recovered I had this ongoing cough, so I did go to the doctors because I wasn't sure if it was - because when you have radiotherapy on your chest they do say that it can sometimes affect your lungs, or whether it was like a Long Covid type scenario. *(Wahine Māori)*

I get fatigued but I'm getting older too. So I've got to sort of put it against that a little bit … and I still getting aching joints, and again, I'm probably getting old ... and sneezing which I do all the time, and we used to put that down as hay fever but it just keeps going on and on … It's a bit of a fine line trying to figure out which side of the fence you fall on. Is it age, or is Long COVID, or is it something else. I don't know. *(Kaumātua)*

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I was telling my old doctor that I'm just not well … I'm not back to where I was before I got sick. So I just kept on telling her, "I'm just not back to myself." I lost a lot of weight, like real lot of weight … It was only when I read all about that long COVID thing that was on the health board thing that I thought, my God, these are all the things that I've been having ... I felt like, oh my God there's a name to it. There's something to it, because I was sick, so sick … I've been in for a CAT scan, my bladder's been tested, my kidneys. I've just had so, so many tests.

Yeah but it's wicked. My memory, the fogginess. Jesus … I have panic attacks and all that now, like anxiety. And then if something happens around me, I can just feel my heart and then I've got to go and lie down, and it's like it's just popping out of my, you know just going flat tack … I never had those before … I didn't have all that before. I was fine.

… she [moko] was foggy and all that kind of stuff as well … they thought that she was naughty and lazy and everything else. She had the Long COVID.

I said to her, "I just really want to talk to you about some things because I feel like, I really feel that it makes sense that I must have got the COVID. I feel like I've got a lot of the symptoms. And then she said, "Look, we'll just have this test here and then we'll see where we go from there." And I'm thinking, "Oh no, you're flagging it eh? You're flagging it. You most probably think I must be a hypochondriac or something."

No-one's talked to me about the Long COVID … I'm the only one who has diagnosed myself and now I'm telling the respiratory lady that this is blah blah blah … I talked to my dietician about it, and she says, "Oh, that makes sense." So it makes sense to everybody but my doctor.

We sort of looked it up a little bit two or three months after we had COVID, because things still hadn’t come right. There were still things going on that we couldn’t figure out … and our doctors weren’t interested. They didn’t want to know about it, and basically think they’re still not interested, but it’s real, it happens ...

He’s a good enough doctor but the moment you start mentioning COVID, or especially Long COVID, he doesn’t want to know about it. Just doesn’t want to know about it. I haven’t been asked any additional questions in my doctors surgery, by anybody. “And so, what sort of things are you experiencing?” I expect that as a question, and I don’t get it, which tells me they’re not interested. *(Kaumātua)*

I ended up going in a couple of times because when you feel that crappy it's like surely you can offer me some kind of relief. I had every symptom under the sun, every symptom, and it went on for six weeks. And so I knew I needed something. I knew that I can't breathe properly. Give me a bloody inhaler. Give me something. Let me try something. And so I've always been pushy like that because actually I know that Māori in that medical system, it doesn't work for us, and so we need to push for what we need. And I have always known that. I've got a lot of whānau who are nurses, nurse practitioners, and so I've always known that if you wanna get something and you're not getting the service you need then you stand up for yourself. *(Wahine Māori)*

The times that I have gone to the GP or the only times where I've sought help it's been your stock-standard, "Well you just need to rest, take it easy, don't exercise too much." Everything I've done for my health there's been no investigation despite complaining about asthma, fatigue, headaches and migraines constantly. They've just only said, "Just rest." There's been no other investigation about what my chest looks like, of what damage has been done, understanding neurologically what's happened. There's been no investigation. I still don't know. It's all just me trying to test out my body, research into what would put me in the best position to battle fatigue. Spending shit-loads on vitamins and supplements to try and better my own health. It's all just been me. I think the last time I went was maybe the middle of last year and said, "Look is there anything you guys know now about Long COVID and how I can battle this," and it's "Just rest, listen to your body." *(Wahine Māori)*

I’ve been out dirt biking once and I’m scared … I bought a fitness watch to monitor my heart rate because I don’t know what is going on with me physically. I watch my heart rate when I’m riding and it goes up to 180 sustained for 40 minutes so I don’t know what that means … I think helping us to understand what is actually going on with our bodies [would help]. I know people are still trying to work that out but actually investigate it … we know now that it can affect your brain, your lungs, your heart … but I have no idea how to actually find out what’s going on so that I can try and better myself or work towards increasing cardio at a rate that’s safe for me. I have no idea what’s going on with it. *(Wahine Māori)*

I am starting to improve but it’s just having that diagnosis … I think it needs to be recognised that Long COVID is around, and don’t make it so hard to be diagnosed. *(Wahine Māori)*