# Understanding the Impacts and Experiences of Long COVID and Invisible Illness on Australians

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#### Introduction

The aim of this MRFF-funded project is to inform a consumer-led model of care for people affected by post-acute sequelae of COVID-19 (PASC), or as it is more commonly known, Long COVID. Experiences of this condition align with other invisible illnesses, chronic health conditions that are not immediately visible to others but significantly affect a person's daily life. To better understand individual lived experiences, we interviewed 20 people with Long COVID, 10 with similar hidden illnesses and 10 carers. We sought to capture the impact of the condition(s) on their lives, understand individual health service needs, and the barriers they have faced accessing appropriate support.

### Background

10% of people who were infected with SARS-CoV-2 go on to develop Long COVID (a long-term illness that can follow COVID-19)<sup>(a)</sup>, with over 200 corresponding symptoms reported<sup>(b)</sup>. The needs of diverse Australian populations living with Long COVID are poorly understood by clinical and allied health providers, contributing to ongoing difficulties in developing and implementing integrated evidence-based models of best-practice care.<sup>(c)</sup>

#### Methods

We conducted 40 qualitative interviews comprising people with Long COVID (20), people with a similar invisible illness (10) and the carers of those with Long COVID (10). Participants were recruited from various sources, with in-person and online support groups contacted, as well as social media posts. A semi-structured interview guide was co-developed with lived experience advisors, and interviews were conducted online, addressing topics of condition impact and healthcare support.

## Analysis

Twenty-five female and fifteen male participants were interviewed from across the country (15 VIC, 9 NSW, 7 SA, 5 QLD, 2 TAS, 2 WA), with ages ranging from 24 to 82 years old. A reflexive thematic analysis of interview data is in progress. This poster reports on preliminary themes identified by our qualitative research team and lived-experience advisory network during the data immersion stage, centred on identity, environments, and technology supports.

# Long COVID

Smaller World: I may not be able to be doing the things I want to, expressing the way that I am through activity, being out and about and doing things, but okay, I can create that for myself in my own world...It does keep changing so you do have to keep moving with it. But I mean I suppose everyone does that in life too with big life changes, you know, divorces, moving house, work changes, kids. Everyone has that in their lives, this is probably just a different form of learning to adapt as life changes. In this instance your life shrinks, your world becomes a lot smaller. (Female, 47, 14 months)

Impact on Hobbies: One of the ways I managed the whole COVID shutdown experience was by doing whisky tastings. There's a whisky bar ...It's a nice community, I know the owners, I know the bartenders. But I (have) spent two and a half years not being able to smell anything or taste anything...Whisky is an olfactory experience, and nobody's going to whisky tastings to get drunk; they're going for the smells, the tasting notes and the conversation about the whiskies. I've largely stopped going because I can't, it's frustrating, it's like they all taste the same, they don't smell like anything, they just smell like alcohol, I'm not getting anything out of this... (Male, 57, 2.5yrs Long COVID)

Grief: It's a grief process. You grieve the life that you had before COVID, and I think it's coming to terms with the fact that I realise now that it's been... well, this is five years into it now, that this is something that I'm just going to have to deal with throughout my life. There is no cure until we get one. Look, it might change. Give me 10 years or something, and I might be talking in a very different way, and maybe some of those symptoms will dissipate, but the way I look at it is I've just got to learn to manage the symptoms and find joy in my life where I can. (Female, 38, 5yrs Long COVID)

Changes in Roles: As I said I'm not working, and so for me 54 year old male, primary provider of the household, been ingrained in me of sort of provide et cetera et cetera I made the call last August year I'm going to need to focus on my health and that means stop working. That means a reduction in income. But the alternative is where they say you've just got to give your body time to heal, time alone isn't working, and so for me life is very different now to what it was because I'm not working. (3yrs Long COVID)

Falling into Caring: It's tricky, and I'm not sure that I totally emotionally kind of processed it exactly...Do I think that this caring role is the natural role for me? Probably not. It's interesting because even though I keep an eye on him and I do check how he's doing, on the other hand, the disability is fairly invisible. I mean, it's not as though in any way – but also it's not as visible, bu it's also not curable. This is not a temporary role, and I mean, sometimes it's hard. (Female, 55, 2.5yrs Partner Carer)

Al Tools: These last few months, I found the game changer I found has been artificial intelligence as far as my day-to-day functioning goes. So it absolutely has become a game changer for me, and it's taken a lot of the lower-level cognitive activity that I was - what's for dinner, what do I cook, how do I cook it, even decisions like that, which took me away from being able to do higher-level cognitive work... But even too as far as information about my health and my energy and tracking my sleep and things like that and physical movement. (Female, 58, 3yrs Long COVID

Social Media: I joined that community and found out a lot, that's one of the best things that anyone with Long COVID in Australia can do, is join that community group on Facebook, because there's a lot of knowledge there and a lot of people who have suffered for a lot of years and they've tried all sorts of things and they're raising treatments they wouldn't have even heard of otherwise. So, then the challenge is just finding the right medical sort of help to help along the journey and be willing to prescribe you certain things... (Male, 52, 2.5yrs Long COVID)

Technologies

Wearables: The Garmin watches have a specific function called body battery, and you basically start the day at a score, which relates to how much good sleep and rest you get the night before, and your stress levels. Body battery, you treat it the same way, so if you've got a really good body battery in the morning, you go, oh yeah, I can do a few things. If it's really bad, then you go, oh no, today's a rest day, I've got to really take it easy...It's all subjective and all a bit of a rough guide, but if you use it as a rough guide, it sort of helps. I found that's something that's really helped me, and definitely tracking the heart rate as well, because I do still get heart rate spikes (Male, 52, 2.5yrs Long COVID)

Environments

Moving & Mobility: I think that's one of the biggest challenges for us, which is that this disease is so holistic. Yes, I use a wheelchair, but even with a wheelchair my brain doesn't work and I can't sustain anything... It's a real challenge with this disease, how to understand the limitations that it creates... I was fiercely independent until I got really sick, and then I was completely housebound apart from doctor's appointments, which my husband would take me to with a wheelchair, even before I got my own wheelchair, and so for two years, I wasn't able to leave the house. (Female, 54, 19yrs ME/CFS)

Identities

Tailored Spaces: I had enormous trouble finding accessible housing so right now my main sort of personal project is that I'm getting a tiny house built with materials that are actually like very low chemical, and that's been a bit of a trial-and-error process. But hopefully in the next two weeks we will have a tiny house, so that will be very exciting. (Female, 45, 20yrs ME/CFS)

Carer Language: Maybe a certain view of carers, I feel this will come to an end at some stage and since essentially carers are ones where it has been set in process it won't change. Maybe after three and a half years I should start to think of something different but I think if I use the word carer it would change the dynamic of how [Person with Long COVID] thinks about it... It's just the mental side of making sure she's healthy, mentally healthy, making sure that she sees a light at the end of the tunnel. That's why the word carer doesn't come into our vocabulary. (Male, 52, 3.5yrs Partner Carer)

Next Steps: Professional
Perspectives & Service Mapping

We are seeking participants to help us explore providers' approaches to, and experiences of, providing services to people with Long COVID. Please reach out to longcovid.project@rmit.edu.au

# Carer

#### References:

- a) Meeting the challenge of long COVID (2020). Nature Medicine 26;1803.
- b) Parums DV. (2024). Long COVID or Post-Acute Sequelae of SARS-CoV-2 Infection (PASC) and the Urgent Need to Identify Diagnostic Biomarkers and Risk Factors. Medical Science Monitoring 18;30
- c) Australian Institute of Health and Welfare (2022). Long COVID in Australia a review of the literature. Australian Government. ISBN: 9781922802491

Long COVID Assessment

Management Practice (LAMP)