

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)^(a), with over 200 corresponding symptoms reported^(b). 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.^(c)

Methods

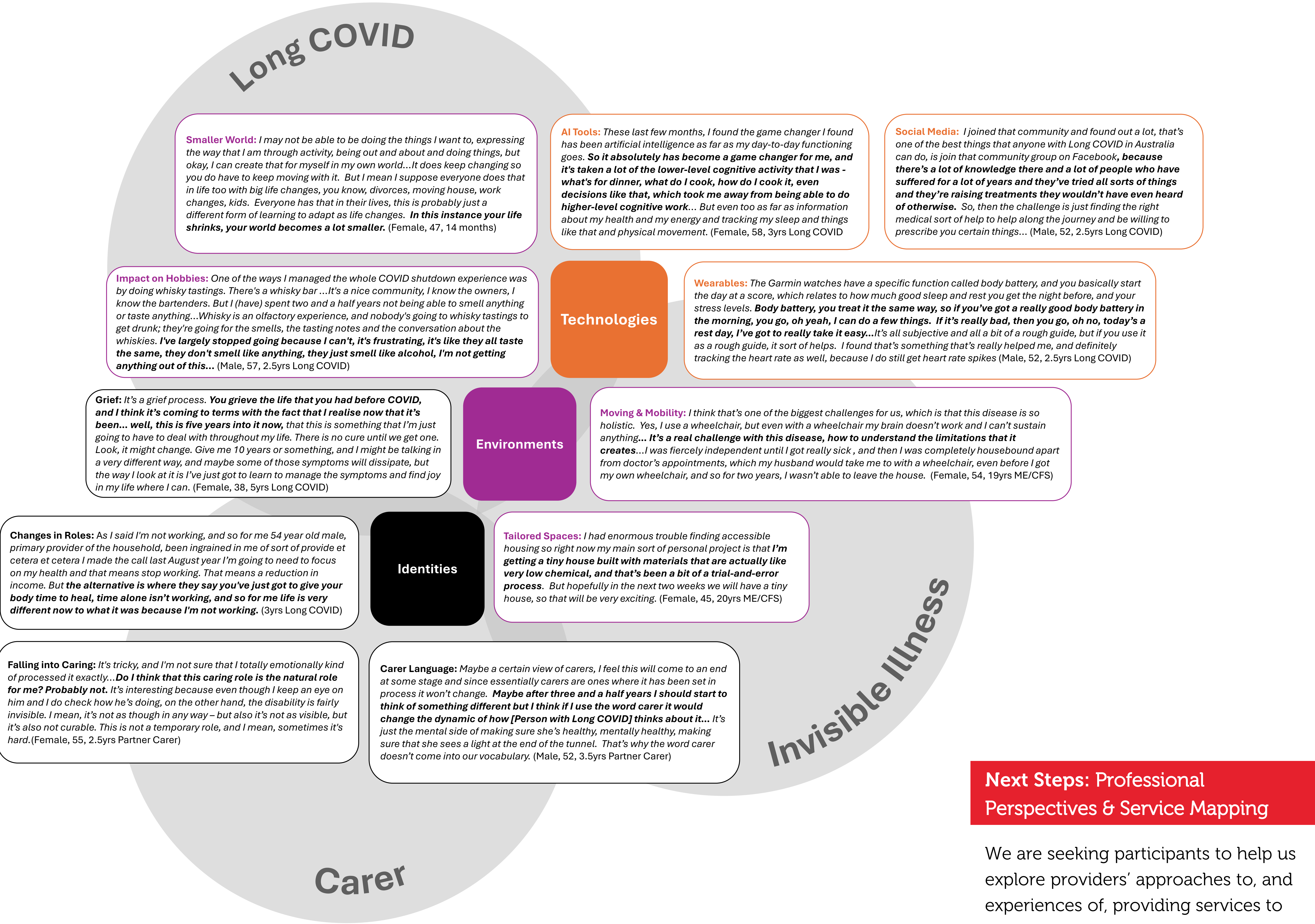
We conducted 40 qualitative interviews comprising people with Long COVID (20), people with a similar invisible illness (10) and the carers of those with Long COVID (10). Participants were recruited from various sources, with in-person and online support groups contacted, as well as social media posts. 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.

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)

