Long COVID Conference: Communiqué

Victoria's scientific conference on long COVID, held in Melbourne on 1 September 2023, announced the release of key findings from the Victorian Long COVID Health Survey. It also showcased:

- **Leading researchers, clinicians and policymakers presenting on the latest evidence on long COVID and its care.**
- **People with lived and living experience of long COVID sharing their stories about its impact on their lives.**

A broad cross-section of other Victorian and interstate experts in long COVID research, clinical fields, policy and lived experience enriched the conversation through their participation.

We would like to thank those living with long COVID who contributed their experiences and stories at the conference, through the posters and via survey responses, and acknowledge you choosing to use your limited energy to advocate for others.

25 presenters

195 attendees
86 in-person/109 online

Sessions covered:

Victorian Long COVID Health Survey results

The biology of long COVID

Long COVID models of care

Health, economic and system impacts of long COVID

What were the main findings shared?

Living with long COVID

- Long COVID affects multiple body systems and presents as a diverse range of symptoms. Feeling tired/fatigued, 'brain fog', rapid heartbeat and breathlessness are the most common symptoms reported in the Victorian Long COVID Health Survey and the literature. Other evidence shows long COVID can affect speech and language skills.
- 14.2 per cent of COVID positive respondents to the Victorian Long COVID Health Survey were classified as having long COVID at the time of the survey. Around 1 in 5 respondents with long COVID may be experiencing more severe impacts on their physical and mental health and quality of life, following their acute COVID infection.
- While there is no single test for long COVID, and a definitive diagnosis relies on the exclusion of other conditions, a person's COVID-19 infection date provides a starting point to understanding the development of this chronic and complex condition.
- Conference presenters with lived and living experience of long COVID described how it impacts every aspect of life; physical and mental wellbeing, access to services and supports, lifestyle and engagement with community, financial and business decisions, ability to exercise and move around, and to work or study.
- Some presenters experienced the additional pain and frustration of not having their symptoms taken seriously and shared that navigating the healthcare system to get the care they need can be a huge challenge with considerable out-of-pocket costs.
- Presenters described how long COVID forces them to make hard decisions about activities most people take for granted, such as choosing between medication or food, how they interact with others in their local community, downsizing their home to maintain it, or opting for early retirement.
- The most common group affected by long COVID were people aged 40–59 years, and whilst many people recover over the first 6–12 months, there is a significant proportion who have to endure a much longer-term impact on their health, function and any pre-existing health conditions.

Long COVID care

- Survey data showed that 3 in 4 people who sought care for persistent COVID-19 symptoms saw a General Practitioner (GP) or family doctor.
- Clinicians and researchers described various models of multidisciplinary care to address the unique combination of symptoms experienced by people living with long COVID, usually based in primary care and with strong allied health support. The multidisciplinary care for long COVID discussed included cognitive training, respiratory rehabilitation, support to re-engage with activities of daily living, psychological counselling, and patient education.
- Presenters found these evidence-based interventions in primary care settings can improve quality of life, facilitate recovery, promote better equity of care and the overall wellbeing of people experiencing long COVID.
- Presenters from both GP- and hospital-based multidisciplinary long COVID care teams identified that most of their patients improved over time and were able to be discharged back to their community/local GP.
- Multidisciplinary, team-based care approaches were also discussed as being a supportive base for clinicians who care for the complex needs of people with long COVID. A multidisciplinary team approach offers opportunities to share ideas and draw on collegiate support when providing healthcare for long COVID, a condition that clinicians are still learning about and presents as a condition with no 'easy fix'. It was observed that our health system does not always enable these approaches.
- More support is needed for GPs and allied health in the primary care sector; with more research required to provide evidence on effective management strategies and to understand the optimal balance of interventions across disciplines.
- An up to date, trusted source of evidence on best care for long COVID, that is centrally coordinated and maintained, is also needed. Further, discussions noted there may be value in a centrally coordinated and widely available source of advice for people experiencing long COVID.

Advancing research on the biology of long COVID

- Research on the mechanisms of infection and pathology of COVID-19 is shining a light on how the virus causes long COVID and may contribute to a broader understanding of post-viral syndromes and other conditions such as Chronic Fatigue Syndrome (CFS)/ Myalgic Encephalomyelitis (ME).
- Presenters spoke of markers of immune dysfunction that persist for up to 2 years after a COVID-19 infection, especially in those with long COVID symptoms. Other research shows viral particles can persist in the lung, brain, and gut long after acute COVID-19.
- The number of blood and tissue samples available with consent for long COVID research is greater than researchers have previously been able to access for research on other viruses. This will allow for research to be stratified by different symptoms, biomarkers, and other criteria without losing statistical power.

Impact on the health system

- Preventing long COVID by avoiding acute COVID–19 infection can reduce system impacts. The risk of long COVID can also be reduced through improvements in indoor air quality, uptake of vaccination boosters and prescription of antiviral medications for high-risk groups.
- Without robust surveillance data, it is hard to know the true scale of the economic impact of long COVID in Australia, but there is emerging evidence of an increase in long-term sickness and disability.
- Preliminary analyses from different studies using Victorian linked administrative data showed:
  - few people received sub-acute rehabilitation (including allied health care) after hospitalisation for COVID-19
  - hospitalisation costs for these patients were also significantly higher than a comparison group of patients with viral pneumonia
  - people recovering from COVID-19 use a range of healthcare services significantly more often in the 3-6 months following their infection than the general population.

- Opportunities for further investigation include:
  - the influence of demographic factors such as location, age, and cultural and linguistic diversity on costs, service use, equity of access and patient outcomes
  - the effect of early intervention via proactive rehabilitation (including allied health) on patient outcomes and the costs of managing long COVID.
- Long COVID has system-wide impacts with broader implications for all parts of the healthcare system and Australian economy. A value-based approach to designing services that prioritises the outcomes that matter to patients provides the best opportunities to address these challenges.

Stories from people with lived and living experience of long COVID and survey data show that the Victorian experience of long COVID is consistent with what is being reported nationally and globally.

The presentations from researchers, clinicians and policymakers demonstrate that Victoria is making a significant contribution to long COVID research and developing the best models of care in Australia.

Researchers are invited to partner with VAHI/Department of Health to access Victorian data and enhance the long COVID evidence base

Researchers with ethics approval can apply to use the Victorian Long COVID Health Survey to generate further insights. Contact vahi@vahi.vic.gov.au for further information on how to access this data. Note that:

- 77 per cent of respondents consented for their survey data to be linked to hospital data and other administrative data sets
- 67 per cent of respondents consented to be followed up to participate in further research.

In addition, applications through Australian Government's Medical Research Future Fund's (MRFF) $50 million 2023 Post-Acute Sequelae of COVID-19 Grant Opportunity opened on 6 September 2023.

To receive this document in another format email the Victorian Agency for Health Information <vahi@vahi.vic.gov.au>

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LONG COVID CONFERENCE
IMPACTS, EVIDENCE AND BETTER CARE