

This review includes:

- COVID-19 illness severity and 2-year prevalence of symptoms.
- Experiences and care needs of children.
- Return to work experiences.
- Experiences of unmet support needs.
- The cost of primary care consultations associated with Long COVID.
- Glossary

Kia ora koutou katoa.

Welcome to the 'Long COVID Literature Review' by Te Hikuwai Rangahau Hauora | The Health Services Research Centre. We aim to bring you monthly summaries of interesting literature concerning Long COVID. We prioritise Aotearoa New Zealand and Indigenous research and publications determined to be high-quality, evidence-based research.

COVID-19 illness severity and 2-year prevalence of physical symptoms: An observational study in Iceland, Sweden, Norway and Denmark

(Shen et al., 2023)

[Find abstract here.](#)

SUMMARY:

This study assesses the prevalence of physical symptoms in relation to acute illness severity up to 2+ years after diagnosis of COVID-19 in four Nordic countries (Iceland, Sweden, Norway and Denmark). Of the 64,880 participants, 34.5% (22,382) were diagnosed with COVID-19. The prevalence of severe physical symptoms, measured by a score exceeding 15 on the 15-item Patient Health Questionnaire, ranged from 1.6% to 16% across the four cohorts with a pooled estimate of 1.37 (95%CI: 1.23 to 1.52), i.e., individuals with COVID-19 had a 37% higher prevalence of severe physical symptoms compared to those without COVID-19. Being bedridden during the acute illness was associated with a higher prevalence of severe symptoms up to two years later. There was a suggestion that persisting severe physical symptoms were more common in people who had been hospitalised compared to those who had not been.

COMMENT:

The study findings suggest an association between the severity of COVID-19 illness and the long-term risk of physical symptoms. This underscores the importance of ongoing monitoring of physical symptoms for individuals who suffered severe forms of COVID-19.



LONG COVID REVIEW

Experiences and care needs of children with Long COVID: A qualitative study

(Faux-Nightingale et al., 2023)

[Find abstract here.](#)

SUMMARY:

This study explores the lived experiences and care needs of children and young people with Long COVID. Drawing from the SPLaT-19 cohort in the United Kingdom, participants, including children and young people with Long COVID (symptoms persisting four weeks or longer), their parents and professionals associated with the care of children and families with Long COVID were involved in this study. Three main themes emerged: **(i) Living with Long COVID:** Participants reported various symptoms associated with Long COVID, notably fatigue and headaches. Long COVID affected children and young people's schooling, hobbies, and social life, leading to difficulties in making friends and a sense of identity loss. Lack of knowledge concerning Long COVID resulted in perceived judgement and stigma, prompting some to avoid discussing their experiences even with health professionals; **(ii) Uncertainty surrounding Long COVID:** Children and young people felt that their general practitioners had been unable to diagnose or provide solutions on how to improve symptoms. Professionals attributed this uncertainty, at least in part, to the presence of other factors that could be contributing to patient's symptoms, including the effects of the pandemic and associated lockdown restrictions. Parents did not fully accept these alternative explanations by health professionals. Parents also conveyed the emotional toll of Long COVID, expressing feelings of guilt due to uncertainty about how to help their child; **(iii) Seeking help for symptoms:** Participants reported difficulty accessing Long COVID services, primarily due to location and appointment availability. Health professionals noted additional challenges like funding and recruiting staff for Long COVID Clinics.

COMMENT:

Long COVID takes a toll on the lives of children and their families. Health professionals play a crucial role in listening to, supporting, and providing appropriate support, referrals and treatments for Long COVID patients. For this to happen effectively, governments must ensure funding for these services.

"It's a rollercoaster": The recovery and return to work experiences of workers with Long COVID

(Nielsen & Yarker, 2023)

[Find abstract here.](#)

SUMMARY:

This study explores the return-to-work experiences of twelve individuals from the United Kingdom who are managing Long COVID symptoms. This study uses the 'IGLOO Framework' that suggests that resources at five levels are needed to support workers with common mental disorders to return to and thrive at work: Individual, Group, Leader, Organisational and Overarching. At the **Individual level**, the severity and unpredictable nature of symptoms posed a significant challenge in sustained return to work. Participants grappled with confidence issues due to the fluctuating nature of their symptoms, feeling threatened about their future in the workplace. The conflict between tending to the care needs of Long COVID and being a 'good employee' triggered guilt and disrupted work performance. **Group level** support, notably from colleagues, emerged as a facilitator for recovery. However, a lack of understanding and interest in Long COVID fostered a toxic climate, hindering sustainable return to work. At the **Leader level**, leaders or managers were pivotal in making necessary work adjustments, such as manageable caseloads, part-time work, and working from home. Support from leaders validated worker returnees. **Organisational** support presented a mixed picture, with existing policies deemed inflexible. Participants felt that such policies overlooked the prolonged nature of Long COVID and solely focussed on physical recovery. Participants who joined Long COVID support groups within their workplaces felt these enabled a sense of belongingness and a sense of identity. At the **Overarching level**, returned workers felt that the lack of information about Long COVID resulted in a lack of knowledge in organisations about what can and needs to be done to support workers.

LONG COVID REVIEW

“It was almost like it’s set up for people to fail” A qualitative analysis of experiences and unmet supportive needs of people with Long COVID

(McNabb et al., 2023)

[Find abstract here.](#)

SUMMARY:

This study explores the support individuals with Long COVID require, both currently available and desired, to improve their symptoms and return to society and work. It is part of a bigger investigation, and participants were recruited through the Johns Hopkins University HOPE Registry. A total of 24 interviews were included in the final analysis. Three key areas of support were highlighted: **(i) Occupational and financial support:** Participants expressed mixed feelings about how their employers handled their symptoms. For example, short breaks did not allow for significant rest and recovery, few opportunities to sit at work, and a lack of privacy were some barriers to maintaining occupational roles. Working from home and flexible hours were critical to maintaining their employment and financial stability. Participants expressed their desire to stay in the workforce for financial reasons and their sense of identity but felt stressed about not meeting previous productivity levels. **(ii) Healthcare-related support:** Access to healthcare visits (both in-person and virtual), speciality care, and collecting medicines from the pharmacy for symptom management were influenced by various barriers. Some healthcare providers lacked knowledge about Long COVID, leading to delays in getting appropriate care and/or denying the existence of Long COVID, attributing symptoms instead to inadequate sleep, depression or other factors. Participants often had to advocate for themselves, which was stressful, exhausting and incredibly challenging. **(iii) Social and emotional support:** Delegation was necessary as family members supporting those with Long COVID had to take on extra responsibilities. Emotional support was crucial and often found through connection with others also experiencing Long COVID via social media and support groups. The study suggests a five-pronged policy approach to support those with Long COVID; these include (1) Increasing public awareness; (2) Improving clinical care quality and access; (3) Implementing school and workplace accommodations; (4) Strengthening socioeconomic benefits and social services; and (5) Developing Long COVID-related research.

COMMENT:

Those with Long COVID and their families experience significant financial hardship due to return-to-work barriers, inflexible working accommodations, and associated healthcare costs such as diagnostic challenges, and scarce speciality appointments. Improvement in occupational and healthcare areas may alleviate the strain that Long COVID places on family members in the social sphere. This article suggests five areas of action for supporting persons with Long COVID.

CONTINUED “It’s a rollercoaster”: The recovery and return to work experiences of workers with Long COVID

COMMENT:

Participants reported threats to their wellbeing, identity and their ability to manage symptoms in the workplace. Employers need guidance on implementing suitable adjustments and inclusive return-to-work policies. Employers must reassess flexible working policies, such as working from home, and engage in training on Long COVID symptoms and their impact on work. Addressing these aspects will provide a more compassionate and efficient work environment for those with Long COVID.



Long Covid Support
AOTEAROA

[Long COVID Support Aotearoa](#)



ME Support
Navigating ME/CFS and Long COVID

[ME Support](#)



[Complex Chronic Illness Support](#)

LONG COVID REVIEW

The cost of primary care consultations associated with Long COVID in non-hospitalised adults: A retrospective cohort study using UK primary care data

(Tufts et al., 2023)

[Find abstract here.](#)

SUMMARY:

This study estimates the primary care costs associated with consultations to support non-hospitalised people with Long COVID. It compares the frequency and costs of primary care consultations in the United Kingdom of those with confirmed SARS-CoV-2 infection at least 12 weeks post-infection ('Exposed') to a matched cohort of individuals without suspected or confirmed COVID-19 ('Unexposed'). The cost of consultations was calculated by dividing the hourly cost for each healthcare professional by 60 (representing 60 minutes per hour) and then multiplying the cost per minute by the average consultation duration. Cost estimates were based on data from the 2021 Unit Cost of Health and Social Care by the Personal Social Services Research Unit, reflecting the cost perspective of the UK National Health Service. The study included 472,173 patients in both cohorts, with 0.8% (3,871) of participants having a diagnosis of Long COVID and 6.4% (30,174) of participants having at least one symptom of Long COVID defined by the World Health Organisation in the exposed group. The number of primary care consultations was 209,620 (0.44 per patient) in the unexposed versus 245,177 (0.54 per patient) in the exposed, respectively. This indicates a 22.7% higher rate of consultations for patients in the exposed than those in the unexposed cohort. The incremental cost of primary care consultations for the exposed cohort compared to the unexposed ranged from £2.44 to £5.72 (\$5.00NZD to \$11.73 NZD) per patient per year. Consultation rates were three to six times higher for those with diagnosed and symptomatic Long COVID, with incremental costs of £30.52 (\$62.57NZD) and £57.56 (\$118.01NZD), respectively. Telephone consultations with general practitioners was the biggest contributor to total costs, especially for diagnosed and symptom Long COVID subgroups. National costs for primary care consultations supporting Long COVID individuals in the UK are approximately £23 million (\$47 million NZD), potentially rising to £60 million (\$123 million NZD). Specific population groups, such as those having a diagnosis or reporting symptoms of Long COVID, older age, females and obese individuals, were associated with having higher consultation costs.

COMMENT:

Translating these cost estimates to the context of Aotearoa New Zealand is not directly possible, but underlines the importance of significant investment in primary care services to effectively address the complex needs and ongoing symptoms of those living with Long COVID.

Glossary

95% Confidence Interval [95%CI]

The range of values we are certain the true value lies.

Prevalence

The total number of individuals in a population who have a disease or health condition at a point of time.

Mātauranga Raranga

Long COVID Registry
Aotearoa New Zealand

<https://www.lcregistry.auckland.ac.nz/>

If you or your family member has Long COVID and are interested in being involved in future Long COVID research, please contact us at:



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