

The impact and implications of long-COVID

A Health Issues Centre survey report on the direct and consequential impacts of long-COVID.



Health Issues Centre
Consumer voices for better healthcare

Introduction

International research has suggested that [10-30% of people infected with COVID-19](#) will go on to develop long-COVID which is defined by a broad spectrum of symptoms commonly effecting respiratory, olfactory, cognitive, joint and muscular function.

HIC conducted a prevalence and impact survey of consumers who identified as suffering from long-COVID.

The research sought to better understand which symptoms occur most commonly, their direct impact on health and wellbeing and to assess indirect impacts that might be consequently experienced. The survey also sought feedback on the most pressing needs of people suffering long-COVID.

Findings

Respondents reported a broad range of physiological symptoms including fatigue/ loss of energy, respiratory difficulties, pain, cognitive impairment and loss of appetite, mobility and sensory acuity. They also reported consequential impacts including financial stress and an inability to perform routine domestic tasks or paid work.

53%

Reported consequential impacts on their mental health particularly relating to anxiety and depression.

When asked how COVID had affected them respondents said:

“Severe body fatigue and tired, especially mental fatigue (e.g. I can’t read more than a couple pages of a book or drive much more than 20 mins without a headache/getting much more tired), headaches, brain fog, declining mental health.”

“Short of breath (and pre covid I went to the gym two to three times a week) Dulled sense of smell and taste (it hasn't fully come back) and I feel sad about it. It doesn't entice me to eat food. It's re-triggered Asthma and that's something I haven't needed medical management for in nearly 10 years.”

“I don't have enough sick leave and had to take unpaid leave. Financially it's very stressful as I'm not sure when I'll be able to return to work.”

An analysis of impact responses shows that consequential impact was as significant as direct impact.

IMPACT REPORTED	DIRECT/CONSEQUENT IMPACT	PROPORTION OF ALL RESPONDENTS
Mental Health	Consequent	53%
Fatigue	Direct	47%
Inability to work	Consequent	43%
Lack of energy	Direct	35%
Personal relationship stress	Consequent	20%
Difficulty performing domestic chores	Consequent	20%
Pain	Direct	18%
Respiratory issues	Direct	18%
Cognitive issues (inc "brain fog")	Direct	15%
Loss appetite/smell/taste	Direct	10%
Mobility	Direct	8%

Support needs

When asked what kind of assistance they would like respondents most commonly cited mental health support, assistance with domestic duties, access to long-COVID experienced GPs, rehab support, peer support and financial assistance.

Most respondents complained that there was little or no information available for them to access on long-COVID, particularly on treatment pathways or prognosis.

50%

Indicated that they would be interested in participating in an on-line support group.

When asked how COVID had affected them respondents said:

"cleaning help, medical support and help around the house, someone to help me build up my exercise. I used to love to walk and now i cannot go more then a couple

"Long Covid clinics/online resources where multi-disciplinary drs share information, between themselves, & interstate & o/s clinics. To be listened to."

"I need people around me to believe me. The biggest issue has been convincing work colleagues and friends I am suffering because of my Covid infection."

"There also is a desperate need for home support for those with young families who are too unwell to care for children/take to school/cook etc. Many are struggling with lack of support in this area."

Conclusions

The evidence suggests that consumers with long-COVID commonly suffer multiple physiological symptoms and that these can be debilitating. The impacts of physical symptoms are exacerbated by consequential impacts on daily life including deteriorating mental health, withdrawal from workforce participation, inability to undertake domestic duties, financial duress and strained social relationships.

A significant proportion of those suffering long-COVID are seeking support that includes counselling, assistance with domestic duties, integrated rehabilitation services and financial relief.

50% of respondents indicated they would welcome the opportunity to compare lived experience and receive emotional support as well as qualified advice from within an on-line peer support group. A peer support community organisation would not only provide emotional support for its members and curate authoritative clinical information but would also act as an information exchange for consumers looking for practical solutions to the consequential impacts of long-COVID.

It would also create a communications channel to the long-COVID community for service providers and researchers investigating yet to emerge long-term consequences of long-COVID such as potential neurological impact.

It is not possible to conclude from the modest survey sample size ($n = 100$) what proportion of people with long-COVID will suffer significant adverse impacts, however even a small proportion of a very large cohort will put additional stress on already strained clinical and social support resources.

As responsibility for COVID treatment increasingly shifts from the acute to primary sector, the increased demands on GP clinics may further exacerbate already limited access to clinical support.

The potential demand for rehabilitation services cannot be extrapolated from this study snapshot but it may be that there will be a need for rehabilitation clinics providing a broader set of integrated services than currently offered by respiratory clinics.

It should also be noted that if impacts such as inability to perform everyday work and domestic activities are indicative of the experiences of the larger cohort of people with long COVID, this has significant implications for workforce participation rates, unemployment support benefits, carer support and disability support services.

More extensive research is urgently required to determine the extent of future needs and to factor these into service demand planning for the coming years.

Methodology

A short survey was constructed and promoted directly to consumers through social media advertising and through referral by condition specific support groups through their data bases. Due to constrained resources and time-frame, the survey was capped at 100 respondents.

Participants were asked to list their symptoms, describe the impact of those symptoms and to reflect on whether they were able to access and utilise the information and support services they considered necessary to assist their recovery.

The limited data collected provides a snapshot rather than robust quantitative analysis, however it gives a sense of the breadth and consistency of the physiological symptoms of long-COVID, the experience of living with long-COVID and its clinical and sociological impact.