

Health Consumers' Experiences of Long-COVID

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CONTENTS

IN BRIEF	4
METHODS	6
Design	6
Research Question	6
Recruitment	6
Data Collectoin	7
Data Analysis	7
Ethical Considerations	7
Limitations	8
FINDINGS	9
Themes	10
CONCLUSION	16
REFERENCES	17
ABOUT HEALTH CONSUMERS NSW	18
ABOUT NSW AGENCY FOR CLINICAL INNOVATION	18

IN BRIEF

- The Critical Intelligence Unit (CIU) partnered with Health Consumers NSW (HCNSW) to gather experiences from people with long-COVID, and to document their understanding of these experiences. The consultation was a quality assurance activity conducted for the primary purpose of informing the development of long-COVID care models for NSW Health.
- Consumer-led discussions occurred between 15 September 2022 and 20 September 2022 with 18 people from NSW who identified as having long-COVID.
- Six phases of reflexive thematic analysis identified four themes:
 - Debilitating and unexpected impacts of long-COVID across all aspects of life
 - No clear path for long-COVID diagnosis or treatment
 - A lack of awareness and knowledge about long-COVID within health services and the community
 - People taking action to 'get their life back'.
- Many people described being healthy, active, and high functioning before being infected with COVID-19. Comparatively, they now live with unexpected and debilitating symptoms post their COVID-19 infection, with physical, mental, cognitive, and financial impacts.
- People reported that they needed assistance with information and navigating the health system. The development of care navigators and peer-support opportunities were suggested as essential components of a model of care.

- The findings suggest there is no clear path for long-COVID diagnosis or treatment. People find it challenging to describe their symptoms to health professionals, and extensive diagnostic tests are often used to rule out other health conditions. Group members said that health professionals say, 'it must be long-COVID' when they have ruled out other health conditions and the diagnosis is ambiguous. Even after people receive a diagnosis of long-COVID, there is a sense of disappointment because of the limited treatment pathways and the realisation that their condition may be chronic, with available treatments being only symptom management and not curative.
- People indicated they were accessing services at different points in the health system. General Practitioners treated some people; others were treated at COVID clinics, while some sought alternative and complementary therapies. The group described a lack of awareness and knowledge about long-COVID from health services and the wider community. People felt especially stigmatised when treating clinicians expressed scepticism about their symptoms or the existence of long-COVID.
- Participants described how they searched for information about their symptoms and treatment options. The people interviewed were discerning in this search and looked for high-quality information from universities and academic journals. Many indicated they felt more knowledgeable about long-COVID than their general practitioner and other health professionals.

METHODS

Design

Qualitative, descriptive.

Research Question:

What are the experiences of people with long-COVID in NSW?

Recruitment:

The invitation to participate in the virtual discussions was disseminated via Health Consumers NSW networks, newsletters, alerts, and social media from 24 August 2022 to 9 September 2022. Prospective participants were required to opt-in by 9 September 2022 by completing the expression of interest (EOI) and participation was voluntary. The EOI included the following agreed definition of long-COVID from the World Health Organisation (WHO), and prospective participants were required to self-identify and opt in accordingly: long COVID is defined by the World Health Organisation as:

An illness that occurs in people who have a history of probable or confirmed SARS-CoV-2 (COVID-19) infection; usually within 3 months from the onset of COVID-19, with symptoms and effects that last for at least 2 months. [1]

Participants were also asked questions based on a function scale tool [2] as part of the EOI and this was used as a part of the sampling stratification process (see Table 2). Prospective participants received a participant information sheet and had an opportunity to ask questions as part of the consent process. Participants were required to provide written consent and consent was re-confirmed prior to the discussion. Participants could opt-out at any stage and withdraw their consent.

Data collection:

Qualitative 90-minute consumer-led discussions occurred between 15 September 2021 and 20 September 2022. The virtual discussions occurred using a video conferencing service (Teams). The sessions were recorded and then transcribed using Otter AI speech to text translation services. The discussions were conducted with an open framework to support and encourage focused yet conversational engagement. The questions were informed by previous studies on consumer experiences of long-COVID in community settings [3, 4] and these were reviewed by the Rehabilitation and Respiratory Network Managers at ACI.

Data analysis:

The qualitative analysis used Braun and Clarke's [5, 6] six phases of reflexive thematic analysis: data familiarisation; data coding (inductive with three coders); initial theme generation; theme development and review; theme refining, defining, and naming; and writing up. NVivo software and MURAL (a visual collaboration tool) were used to support data analysis. Reflective thematic analysis provided an inductively orientated experiential analysis and gave voice to those with long-COVID in NSW. Analytic insights, impressions and findings were sense-checked with the ACI Rehabilitation Network Manager.

Ethical considerations

The consultation was a quality assurance activity conducted for the primary purpose of informing the development of a long-COVID care model for NSW Health. Partnering with consumers in governance, policy, and planning is recognised best practice, and this consultation aligned to the National Safety and Quality Health Services Standards in Australia. Participants voluntarily responded to the invitation to participate in the consumer-led discussions, received a Participant Information Sheet, and provided informed consent.

Limitations

The consultation occurred with 18 participants only. The groups represented people from metropolitan, regional, and rural NSW but were not representative in terms of gender and Aboriginality. Many participants were recruited via a long-COVID Facebook group. People with long-COVID who were not members of this Facebook group may have different experiences when it comes to connecting with peers and finding resources and support. The recruitment methods unwittingly biased the sample towards educated middle-class people and those with knowledge about long-COVID. Recruiting through electronic means (e-newsletters and social media posts) and facilitating the discussions virtually meant that people without access to digital communications were likely excluded from participating in the discussions.

This work documents people's experience and understandings of long-COVID. There may be clinical inaccuracies in how people describe these experiences, and the wording used reflects their own understanding of their experiences. Any discrepancies between the language people used and the clinical accuracy of the symptomology described should be seen as an additional finding of this work that reveal deficiencies in health services' communication around long-COVID.

The discussions also identified where people are sourcing information about long-COVID and the value they place on that information. However, it is beyond the scope of this consultation to evaluate the effectiveness or accuracy of that information.

FINDINGS

Consumer-led discussions occurred between 15 September 2022 and 20 September 2022 with 18 people from NSW who self-identified as having long-COVID. Two groups were formed based on the availability and preferences of participants: 4 people were in the first group and 14 people in the second group. In total, 15 participants were female, 2 were male and 1 identified as non-binary. Ages ranged from young adults (18 to 30 years) to older people (61+ years) as shown in Table 1. In total, 12 participants lived in metropolitan NSW and 6 in regional NSW. 3 participants identified as a person with disability and 7 were carers.

Table 1: Participant age ranges

Age range	Number of participants
18-30	2
31-45	4
46-60	9
61+	3

Participants described different levels of COVID-19 infection severity (e.g., mild, moderate, and severe); however, no one was hospitalised for COVID-19. Participants described debilitating symptoms from 3 – 24 months post their COVID-19 diagnosis. Responses to the EOI question 'How are your current symptoms impacting your daily life' are outlined in Table 2.

Table 2: How are your symptoms currently impacting your daily life?

Response	Number of participants
I am still able to perform my usual duties and activities	0
I occasionally need to avoid or reduce my usual duties or activities	3
I am not able to perform my usual duties or activities however I do not need assistance to take care of myself	10
I am not able to perform my usual duties or activities and I am dependent on others as I am unable to take care of myself due to my symptoms	5

Themes

The following four themes were identified using the six phases of reflexive thematic analysis:

1. debilitating and unexpected impacts across all aspects of life;
2. no clear path for long- COVID diagnosis or treatment;
3. a lack of awareness and knowledge about long-COVID within health services and the community;
4. people taking action to 'get their life back'.

Theme 1: Debilitating and unexpected impacts across all aspects of life

Participants described how their health was taken away instantly when infected with COVID-19 and how they are now living with debilitating symptoms consistent with the WHO definition of long-COVID. Many people described being healthy, active, and high functioning before being infected with COVID-19. Comparatively, they now live with unexpected and debilitating symptoms post their COVID-19 infection, which cause flow-on physical, mental, cognitive, and financial impacts.

People described a raft of symptoms that impacted their day-to-day life: fatigue, respiratory (e.g., breathlessness, chest pain and cough), gastrointestinal (e.g., inflamed liver and pancreas), musculoskeletal (e.g., pain and muscle aches and spasms), psychiatric (e.g., anxiety including panic attacks and depression), neurological (e.g., migraines, light sensitivity, tinnitus, brain fog, memory, and concentration difficulties), cardiac (e.g., tachycardia), viral infections (e.g., shingles), sweating, unexplained weight loss, and symptoms of Mast Cell Activation Syndrome.

Some participants described how they 'pushed on' despite having symptoms in the early stages post their COVID-19 infection to get their life back on track. One person said:

"The thing that first got me, I guess, was probably a couple of weeks after COVID. I started to feel a little bit better, and I thought it was the right time to get my life back on track. And I started going back to the gym and that sort of thing. And just going to a yoga class,

something as simple as that, I came home, and I would have to go to bed for about four or five hours because it just wiped me out. Like nothing has ever hit me like that before."

Most of the group said it was hard to ignore the physical impacts of long-COVID when their bodies would not let them do things that they were previously able to do. Cognitive impacts included memory and concentration difficulties and several people described experiencing "brain fog" where it was difficult to gather their thoughts and words to communicate effectively.

"That headache kind of disappeared that around the six-week mark and became the brain fog"

The mental health impacts were also significant; people described helplessness and worry for their future. These feelings were exacerbated when health professionals were dismissive about their experiences or did not validate their symptoms.

"It's just something that happened to me suddenly, without any warning, and ... I still struggle with that a lot mentally, and I think anyone would because it is just a sort of huge loss of function and ability. And I am only 23. So, it feels like my life is over before it begins. Like it is just horrible"

Financial impacts were caused by an inability to work and generate an income because of the severity of their symptoms. Some people had to reduce the number of hours they could work, while others had to cease work completely. People with more physically demanding jobs reported that there were less strategies they could use to reduce work and maintain employment. The cost of seeing health professionals, including General Practitioners and specialists, and the associated diagnostic tests and treatment (both medically prescribed and alternative therapies) also created a financial burden. Having long-COVID was described as a financial sinkhole. One person said:

"The naturopath kind of places seem to be a little bit more attuned to what might help. I've spent thousands of dollars on supplements. It's disgraceful. I'm really, like I'm embarrassed by how much money I've actually spent on trying to get better because it's just like ripping up cash. So, I've got a vitamin box that's like a box full. Trying this, that, and the other"

Overall, the impacts affected their ability to function and live their life in the same way. There were also flow-on effects at work and in their relationships with friends and family.

"And then in terms of work, I can't [work] because I'm tired all the time, I'm not performing like I used too, and I am much less productive. Luckily, my company has been very, very accommodating and understanding, and they allowed me to work from home, which really allows me to conserve energy. So, I'm grateful for that. I know that if I didn't work with such an understanding company, or if I had a physical job, or if I had to go into the office, I would be looking at part-time or resigning from my job. So, I, this is not something that has a small impact on your life, this is not something that you can just push to the back of your mind and get on with your day".

Parents reported the negative impact of long-COVID on their families. Some people were visibly upset when talking about the impact on their children and their inability to continue parenting in the way they had pre-COVID:

"I'm a mother of two boys. I feel so guilty. I can't give them what I need to give them and I just hope it doesn't affect them and my relationship with them".

Theme 2: No clear path for long-COVID diagnosis or treatment

Findings suggested there was no clear path for long-COVID diagnosis or treatment. Participants perceived that health professionals were often out of their depth and needed to be more knowledgeable about long-COVID. Most of the group struggled to find a health professional with knowledge about long-COVID. Many reported that health professionals had a narrow and misconceived view of who was able to get long COVID, making diagnosis and any referrals difficult.

"While my GP listens and seems to believe my symptoms, he doesn't know what to do about them. He's basically said he's done what he can, but can't really help me further with it."

People also found it challenging to describe their symptoms to health professionals, and extensive diagnostic tests were often used to rule out other health conditions. Most people in the group suggested that health professionals say, 'it must be long-COVID' when they have ruled out other health conditions and that the diagnosis is ambiguous. Even after people received a diagnosis of long-COVID, there was a sense of disappointment because of the realisation that this was, potentially, a chronic condition with limited treatment pathways. People spoke of their frustration in discovering that the only treatment available was not curative but just symptom management. People were also concerned that health professionals were responding to long-COVID-19 in silos and not taking a holistic approach to diagnose and provide treatment.

"It isn't a holistic approach, and the doctors work in silos. This causes stress, wasted time, financial strain, and diagnostic confusion".

In some cases, the General Practitioner asked the participant if they wanted a long-COVID diagnosis to open referral pathways. One participant said:

"She actually asked me. She said, 'Would you like me to put the label of long COVID on?' And I said, 'yes' because I hoped that would mean, I would be able to access some additional help. And by doing that, she was then able to refer me to a long COVID clinic. So, it was sort of a discussion between us, but it was the GP who brought it up. And I already had my suspicions because of how long it was going on, and the sort of symptoms that I had, as well".

Several people in the group had accessed care through a long-COVID clinic. They described relief when referred to the clinic but were disappointed when it did not meet their expectations. Further screening and testing were used at the clinics to rule out other conditions, and people were disappointed when they were offered symptom management, rather than a cure or resolution of their symptoms altogether.

One suggestion from the group was to give people access to a central connection point to help navigate and coordinate access to appropriate medical and social services. One person said:

"a model of care with a "case manager" would be helpful - similar to disability care models - so that the patient isn't solely responsible for coordinating their medical care".

Theme 3: A lack of awareness and knowledge about long COVID within health services and the community

People indicated they were accessing a range of health and community services. They described an overall lack of awareness and knowledge about long-COVID by health professionals and the broader community. People indicated it was challenging to have long-COVID acknowledged by health professionals and how their family and friends were unaware of the condition until they shared their experiences and diagnosis.

The group reported frustrations at the stark contrast in messaging around long-COVID compared to the government messaging around the COVID-19 vaccines. Several people described how health professionals and even their own family and friends did not believe their symptoms, which had flow-on adverse impacts on their mental health. They indicated that stigma had been perpetuated through the silence and scepticism around long-COVID, and public health messaging was needed to inform the public about what it is and who is at risk.

"GPs need training in recognising and responding to long COVID, there is too much gaslighting from doctors that long COVID is just psychosomatic."

Theme 4: Taking action to 'get their life back'

Searching for information and joining online groups were ways that people could take some control of their situation and take action to get their life back. These activities gave people a degree of autonomy while navigating circumstances that left them frustrated and disheartened.

Participants described how they actively searched for information about their symptoms and treatment options. Some participants reported they were discerning in this search and

looked for high-quality information from universities and academic journals. For example, most people had researched long-COVID and referred to international studies and peer-reviewed literature. Many indicated they felt more knowledgeable than their General Practitioner and other health professionals.

Finding this information was empowering; participants described how they shared new knowledge and treatment options with their General Practitioners. However, what some people found left them more concerned, especially when they identified treatments offered internationally were not available in Australia.

"I follow quite a few professors and doctors around the world who are entering into discussions about long COVID and a couple of Australian medical professionals as well.

And a lot of the information that has been peer reviewed ... [from] overseas is frightening. We're being neglected."

People also spoke positively about connecting with a local online community developed on Facebook for people with long-COVID in Australia.

"We're getting info from NICE¹, research networks on Twitter, Podcasts, FaceBook support groups"

If it wasn't for the Australian Long Covid Community Facebook group, I don't know where I'd be. most of my support, understanding and ideas to research myself comes from there.

Participants described how they valued connecting with others who had similar experiences, sharing, and receiving information about long-COVID, and their symptoms and diagnosis of long-COVID were accepted and validated. This experience was in sharp contrast to most people's reported experiences with health professionals. There were some concerns, however, that the online group was not something that could be sustained long-term and that it had a "shelf life".

The Facebook group helped me from day to day, but you

¹ National Institute for Health and Care Excellence – a UK based website that provides guidance and advice on health issues www.nice.org.uk

got to move away from it because otherwise, you get too involved. But when you're feeling down, you can vent on this thing and no one's gonna shoot you down. So, I have found this support group very beneficial."

The internet was a valuable tool for people to improve their health literacy around long-COVID and make meaningful connections with peers. People reported that, despite these health-sustaining results, health professionals could be sceptical and dismissive of these self-directed activities. While some people received useful information from General Practitioners and specialists, many took action and proactively found resources and connections on their own. People saw these resources and connections as helping them 'get their life back'.

CONCLUSION

Many participants found their interactions with the healthcare system to receive support for long-COVID frustrating and convoluted. It often took a long time to receive a diagnosis, and health professionals seemed unsure or hesitant when making this diagnosis. People did not receive information from health professionals that met their needs about the condition and treatments, and they proactively sought information and support from peers and online.

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About Health Consumers NSW

Health Consumers NSW is a membership-based, independent, not-for-profit organisation that promotes and practises consumer engagement in the NSW health sector. We create meaningful partnerships between consumers, the health sector and policymakers. Our mission: Consumers shaping health in NSW. We promote the best quality, appropriate health outcomes for consumers of healthcare services. We believe that all perspectives are important and necessary to create better health outcomes for people. Consumer engagement leads to better health outcomes, more efficient and effective services, consumer-centred care and happier patients and staff. We work to ensure that health consumers are involved in the design and delivery of healthcare in NSW.

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About the Agency for Clinical Innovation

The ACI brings clinicians, consumers and system leaders together to design and implement innovations in health care. The ACI supports innovations that are person-centred, clinically led, evidence-based and value-driven.

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