

Opinion: Why scrapping the term 'long COVID' would be harmful for people with the condition

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The assertion from Queensland's chief health officer [John Gerrard](#) that it's time to stop using the term "long COVID" has made waves in [Australian](#) and [international media](#) over recent days.

Gerrard's comments were related to [new research](#) from his team finding long-term symptoms of COVID are similar to the ongoing symptoms following other viral infections.

But there are limitations in this research, and problems with Gerrard's argument we should drop the term "long COVID." Here's why.

A bit about the research

The study involved texting a survey to 5,112 Queensland adults who had experienced respiratory symptoms and had sought a PCR test in 2022. Respondents were contacted 12 months after the PCR test. Some had tested positive to COVID, while others had tested positive to influenza or had not tested positive to either disease.

Survey respondents were asked if they had experienced ongoing symptoms or any functional impairment over the previous year.

The study found people with respiratory symptoms can suffer long-term symptoms and impairment, regardless of whether they had COVID, influenza or another respiratory disease. These symptoms are often referred to as "post-viral," as they linger after a viral infection.

Gerrard's research will be presented in April at the European Congress of Clinical Microbiology and Infectious Diseases. It hasn't been published in a peer-reviewed journal.

After the research was publicized last Friday, some experts highlighted flaws in the [study design](#). For example, [Steven Faux](#), a long COVID clinician interviewed on ABC's television news, said the study excluded people who were hospitalized with COVID (therefore leaving out people who had the most severe symptoms). He also noted differing levels of vaccination against COVID and influenza may have influenced the findings.

In addition, Faux pointed out the survey would have excluded many [older people](#) who may not use smartphones.

The authors of the research have acknowledged some of these and other limitations in their study.

Ditching the term 'long COVID'

Based on the research findings, [Gerrard said in a press release](#):

"We believe it is time to stop using terms like 'long COVID.' They wrongly imply there is something unique and exceptional about longer term symptoms associated with this virus. This terminology can cause unnecessary fear, and in some cases, hypervigilance to longer symptoms that can impede recovery."

But Gerrard and his team's findings cannot substantiate these assertions. Their survey only documented symptoms and impairment after respiratory infections. It didn't ask people how fearful they were, or whether a term such as long COVID made them especially vigilant, for example.

In discussing Gerrard's conclusions about the terminology, Faux noted that even if only 3% of people develop long COVID (the survey found 3% of people had functional limitations after a year), this would equate

to some 150,000 Queenslanders with the condition. He [said](#):

"To suggest that by not calling it long COVID you would be [...] somehow helping those people not to focus on their symptoms is a curious conclusion from that study."

Another clinician and researcher, Philip Britton, [criticized Gerrard's conclusion](#) about the language as "overstated and potentially unhelpful." He noted the term "long COVID" is recognized by the World Health Organization as a valid description of the condition.

A cruel irony

An [ever-growing body of research](#) continues to show how COVID can cause harm to the body across organ systems and cells.

We know from the experiences shared by people with long COVID that the condition can be highly disabling, preventing them from engaging in study [or paid work](#). It can also harm relationships with their friends, family members, and [even their partners](#).

Despite all this, people with long COVID have often felt gaslit and unheard. When seeking treatment from health-care professionals, many people with long COVID report they have been [dismissed](#) or turned away.

Last Friday—the day Gerrard's comments were made public—was actually [International Long COVID Awareness Day](#), organized by activists to draw attention to the condition.

The response from people with long COVID was immediate. They shared their anger [on social media](#) about Gerrard's comments, especially their timing, on a day designed to generate greater recognition for their

illness.

Since the start of the COVID pandemic, patient communities have [fought for recognition](#) of the long-term symptoms many people faced.

The term "long COVID" was in fact coined by people suffering persistent symptoms after a COVID infection, who were seeking words to describe what they were going through.

The role people with long COVID have played in defining their condition and bringing medical and [public attention](#) to it demonstrates [the possibilities of patient-led expertise](#). For decades, people with invisible or "silent" conditions such as ME/CFS (myalgic encephalomyelitis/[chronic fatigue syndrome](#)) have had to fight ignorance from health-care professionals and stigma from others in their lives. They have often been told their disabling symptoms are [psychosomatic](#).

Gerrard's comments, and the media's amplification of them, repudiates the term "long COVID" that community members have chosen to give their condition an identity and support each other. This is likely to cause distress and exacerbate feelings of abandonment.

Terminology matters

The words we use to describe illnesses and conditions are incredibly powerful. [Naming a new condition](#) is a step towards better recognition of people's suffering, and hopefully, better diagnosis, health care, treatment and acceptance by others.

The term "long COVID" provides an easily understandable label to convey patients' experiences to others. It is well known to the public. It has been routinely used in news media reporting and in many reputable [medical journal articles](#).

Most importantly, scrapping the label would further marginalize a large group of people with a chronic illness who have often been left to struggle behind closed doors.

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