

Study: Most people with long COVID face stigma and discrimination

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Credit: Pixabay/CC0 Public Domain

The majority of people living with long COVID experience some form of stigma directly related to their condition, according to a new study published in the journal *PLOS ONE*.

An estimated 2.3 million people are living with long COVID in the UK according to the Office for National Statistics data, and numbers are not decreasing due to limited treatment options and continued high COVID infection rates. Testimonies illustrate profound stigmas experienced by

people living with long COVID, but until now there has been no quantitative assessment of the burden.

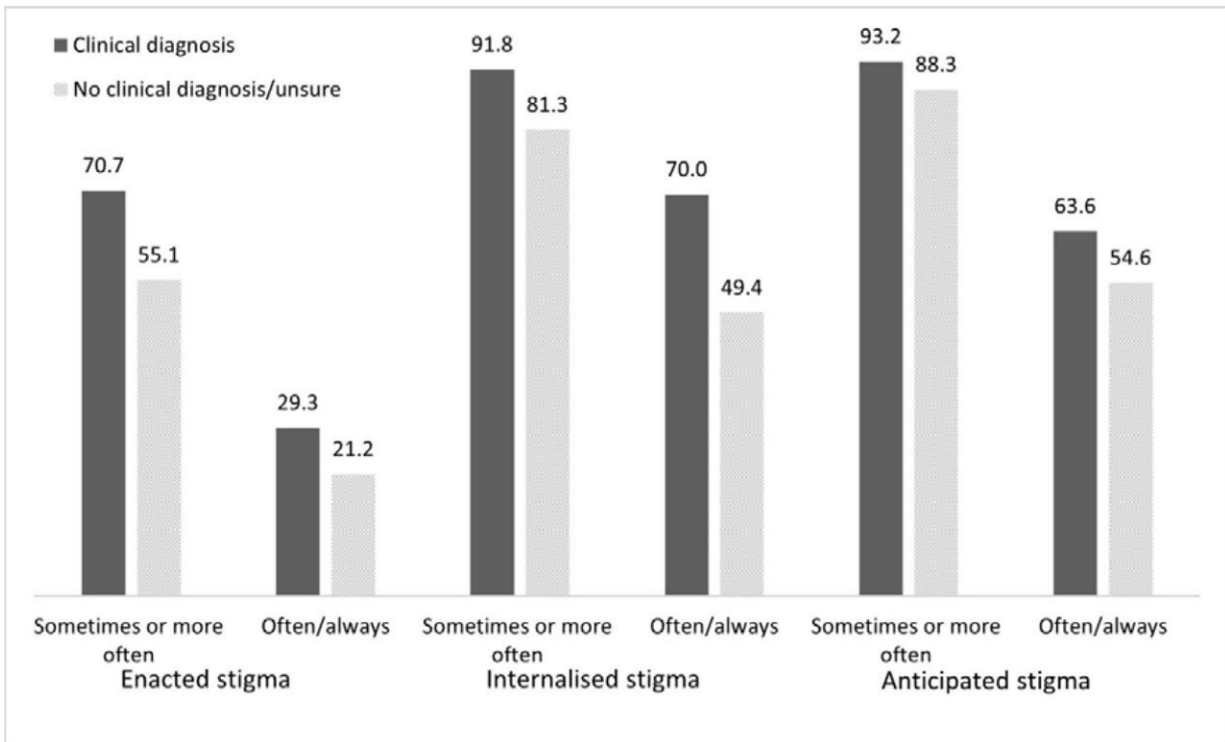
In the study, conducted by researchers at the University of Southampton and Brighton and Sussex Medical School and co-designed by people living with long COVID (from the charity Long COVID Support), people who took part in the 2020 long COVID [online survey](#) were invited to complete a follow up survey in November 2021.

More than 1100 people took part, including 966 people from the UK, and were asked about their experiences of [stigma](#) in three areas: Enacted stigma, where individuals were directly treated unfairly due to their health condition; internalized stigma, where people felt embarrassed or ashamed of their health condition, and anticipated stigma, which is the individual's expectation they will be treated poorly because of their condition.

Ninety-five percent of people experienced at least one type of stigma at least "sometimes," and 76% experiencing it "often" or "always," according to the results.

Dr. Marija Pantelic, lecturer in public health at Brighton and Sussex Medical School, who led the development of the stigma questions in the follow up survey, said, "There have been countless anecdotal reports of the stigma, dismissal and discrimination faced by people living with Long COVID. This study was the first to empirically measure this stigma and estimate prevalence. We were shocked to see just how prevalent it is, but the findings also empower us to do something about it."

"With the stigma questionnaire we developed, we can measure changes over time and the effectiveness of urgently needed anti-stigma interventions."



Prevalence estimates of stigma among people with diagnosed and undiagnosed Long COVID. Credit: *PLoS ONE* (2022). DOI: 10.1371/journal.pone.0277317

In the study, nearly two thirds (63%) of people reported experiences of stigma such as being treated with less respect or people they care about stopping contact with them due to their [health condition](#), while 91% expected to experience stigma and discrimination, for example they thought many people did not consider long COVID to be a real illness or they anticipated judgment.

Eighty-six percent of respondents felt a profound sense of shame related to having long COVID—they were embarrassed of their illness and felt 'very different' from people without long COVID.

In the study, 61% of people said they were very careful who they tell about their condition, and about one third (34%) of respondents regretted having told people about it. Overall, the prevalence of experiencing stigma was higher in those who reported having a clinical diagnosis of Long COVID compared to those without or who were unsure (83% v 69%).

Nisreen Alwan, professor of public health at the University of Southampton and co-lead author of the study, added, "We were surprised to find that people with a clinical diagnosis of long COVID were more likely to report stigma than people without a formal diagnosis."

"We are not sure why this is—perhaps because they are more likely to share their [health status](#) with others or perhaps because they have engaged more with [health services](#). More research is needed to unpack the potential mechanisms of how and where this stigma is manifested, and who is most likely to stigmatize and be stigmatized."

Claire Hastie from the charity Long COVID Support who also worked on the study, said, "Sadly we see the results of stigma all too often among members of our support group. In addition to the significant health burden of long COVID, the stigma and discrimination associated with the condition can lead to relationship breakdowns and problems at work. These cause immense additional distress, which itself can compromise healing. It is vital that people with the condition are believed and supported to help their chances of recovery."

"The stigma attached to long COVID is harming people living with Long COVID and is likely to leave a devastating mark on our society and health service provision," Dr. Pantelic added. "We know from decades of research with other long-term conditions such as asthma, depression, and HIV that stigma has dire consequences for [public health](#). Fear of

stigma is also likely to drive people away from health services and other support, which over time has detrimental consequences on people's physical and [mental health](#)."

More information: Marija Pantelic et al, Long COVID stigma: estimating burden and validating scale in a UK-based sample, *PLoS ONE* (2022). [DOI: 10.1371/journal.pone.0277317](https://doi.org/10.1371/journal.pone.0277317)

Provided by University of Southampton

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