New tool to assess Long COVID symptoms

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A comprehensive tool that can assess the symptoms of Long COVID has been developed at the University of Birmingham for use in research and clinical care.

Developed with patients that have lived experience of Long COVID, the

tool can capture symptoms and their impact on [everyday life](link).

Currently more than 200 symptoms are associated with Long COVID which can affect people for months after the original coronavirus infection has gone. These can affect many organs in the body and include breathlessness, fatigue, or brain fog and are estimated to affect around 1.3 million people in the UK and more than 100 million people worldwide.

Healthcare providers and researchers need reliable ways of measuring these symptoms as they are experienced by patients to help them develop new treatments and provide the best possible care.

A team from the University of Birmingham's Center for Patient-Reported Outcomes Research designed the Symptom Burden Questionnaire for Long COVID to address this challenge. Patients can use it to report symptoms and the data can be used to help identify treatments, and test whether these are safe and effective. The approach is published today (27 April 2022) in the *BMJ*.

"People living with Long COVID say they experience a huge range of symptoms but getting these recognized by healthcare practitioners and [policy-makers](link) has been a struggle," said senior author, Dr. Sarah Hughes. "We designed and tested this tool with our patient partners to ensure it is as comprehensive as possible, while also not being burdensome for patients to complete."

Public partner Karen Matthews from LongCOVID SOS noted "I participated in a study quite early on in my condition and the questionnaire used didn't capture the breadth of what I was feeling. Being able to shape something that could record that experience more effectively is worthwhile and I hope it gives researchers and people like me taking part in future studies some valuable evidence."

The resulting questionnaire measures different symptoms of Long COVID and the impact of these symptoms on daily life. It was developed with extensive patient input following regulatory guidance, meaning its scores may be used to support regulatory decisions around the approval of new therapies for Long COVID and by policymakers.

The study was carried out in partnership with patient data technology specialist, Aparito Ltd, and funded by the National Institute for Health Research and UK Research and Innovation. The team plans to carry out more development and testing to explore how the tool can be used in routine clinical practice, including translating it for use in other countries and minority ethnic communities.

More information: Development and validation of the Symptom Burden Questionnaire for Long COVID: a Rasch analysis., *BMJ* (2022).

Further details regarding the measure and access for use can be found at www.birmingham.ac.uk/sbq

Provided by University of Birmingham