

# International study reaches consensus in how to measure improvement in long COVID

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Researchers have reached an agreement on how best to measure the severity and impact of long COVID by identifying a "Core Outcome Measure Set" (COMS).

The research, published in *The Lancet Respiratory Medicine*, is co-led by the Institute of Psychiatry, Psychology & Neuroscience (IoPPN) at King's College London and in collaboration with the World Health Organization (WHO).

COMS are designed to help researchers and clinicians measure symptoms and impacts of disorders such as long COVID in the same way, which optimizes how data can be compared and summarized. Researchers say this will accelerate the understanding of and the development of treatments for long COVID with major global impacts.

Symptoms that persist or develop after COVID-19 are known as long COVID, but are also described with other names such as post COVID-19 condition, post acute sequelae of COVID-19 (PASC) or post-COVID syndrome. Common symptoms include fatigue, shortness of breath, pain, exercise intolerance and cognitive dysfunction ("brain fog"), but patients can experience a wide range of other symptoms across all bodily systems, making identification of the key symptoms and how to measure them challenging.

The study involved identifying the ways in which long COVID and its symptoms and impacts have been measured to date, selecting the most popular ones that could be used in all settings and then summarizing and presenting these to a large international group of experts and patients in a series of surveys and then in a final consensus meeting to identify, where possible, agreement on what the best measurement instrument (or instruments) are.

The surveys used a "Delphi technique" to reach consensus among the stakeholders. This is a well-established approach in which participants are asked their opinions in a first round and then shown the results of others and given the chance to rethink their views, and this is repeated in subsequent rounds until consensus is achieved.

Dr. Tim Nicholson, a Reader in Neuropsychiatry and one of the study's co-leads from King's IoPPN said, "The development of this Core Outcome Measure Set for Long COVID by the global research community in partnership with patients with lived experience has set out a key plank in the development of evidence-based treatments for this new condition to allow the optimization, coordination and efficient collation of data in research and clinical services."

The research team had previously applied a similar methodology to achieve agreement on which aspects of long COVID—so-called "outcome domains"—should be in the minimum Core Outcome Set and therefore measured in all studies and clinical services. In total, 12 outcome domains were agreed on in a [research paper](#) published earlier this year.

Professor Nick Lemoine, Medical Director at the NIHR Clinical Research Network, said, "This ... research is taking us a step closer to having a clear and consistent way to measure the impact of long COVID—this is a vital tool to help speed up research to find the most effective treatments. Researchers and patients have worked closely together to agree on measures that encompass people's lived experience of long COVID."

Dr. Margaret O'Hara, from Long COVID Support, said, "People with long COVID, from Long COVID Support and other groups, have been involved in all stages of the design and implementation of this study. It is important to us because we need research to measure symptoms that are relevant, and to use measurement tools that can capture our actual experience. We also need researchers around the world to use the same instruments so that studies can be compared and we can rapidly build a body of evidence to assess if treatments work. The clock is ticking for people with long COVID; we urgently need treatments and we will only get them through research. This study will help to quicken the pace at

which evidence can be gathered."

The research was co-led by Professor Paula Williamson and Dr. Sarah Gorst at the University of Liverpool, Dr. Daniel Munblit, Reader in Pediatrics at Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King's College London and Sechenov University, Russia and Professor Dale Needham at Johns Hopkins University, U.S..

The researchers are now seeking to publicize these recommendations so that they are adopted by the scientific and clinical communities. Further work is also planned to update the COMS as new data on this new disorder emerges and how best to measure its improvement.

Professor Williamson said, "This research has significantly narrowed down the range of preferred outcome measurement instrument options for researchers and clinicians to consider."

Professor Needham added, "This project helps open the door to new research around measurement instruments for core outcomes that did not reach consensus."

Dr. Gorst remarked, "We are extremely grateful to 594 health professionals, researchers, people with lived experience and their family members who participated in this study."

Dr. Munblit concluded, "We sincerely hope that the outcomes of the project will be widely implemented worldwide, including low resource settings. It is important to note that we have also just completed a PC-COS Children project with results to be published soon, which defined a Core Outcome Measurement Set for long COVID for pediatric population so all age populations are covered now."

The project was in collaboration with the World Health Organization

(WHO), the Core Outcome Measures in Effectiveness Trials (COMET) Initiative, the International Severe Acute Respiratory and Emerging Infection Consortium (ISARIC)

**More information:** Sarah L Gorst et al, Core outcome measurement instruments for use in clinical and research settings for adults with post-COVID-19 condition: an international Delphi consensus study, *The Lancet Respiratory Medicine* (2023). DOI: 10.1016/S2213-2600(23)00370-3 , [doi.org/10.1016/S2213-2600\(23\)00370-3](https://doi.org/10.1016/S2213-2600(23)00370-3)

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