Key outcomes of long COVID identified in international consensus study

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An international group of researchers and experts by experience have identified 12 core symptoms of Long COVID to be measured in research and clinical practice using a technique known as "Delphi

consensus."

The study, which was co-led by the Institute of Psychiatry, Psychology & Neuroscience (IoPPN) at King's College London, Imperial College London, Sechenov University Moscow, and the University of Liverpool, has described a set of core outcomes for Long COVID that are recommended for use in future research and clinical practice globally.

Published in *The Lancet Respiratory Medicine*, the study reports the findings of a large-scale international consensus study of 1535 participants from 71 countries. The 12 core outcomes of Long COVID to be measured in adults identified by the research include fatigue, pain, and experiencing symptoms following physical or mental exertion, as well as changes to the cardiovascular, respiratory and nervous systems.

According to the authors, defining these core outcomes will accelerate the development of evidence-based treatments for Long COVID by guiding the research community on collecting the most meaningful data, as a minimum, on whether a treatment works. This approach will ensure consistency of what is measured, enabling easier collation and comparison of results across clinical trials and other studies.

COVID-19 symptoms that persist for months after the initial infection are known as "Long COVID" or "post-COVID syndrome." Common symptoms include fatigue, shortness of breath, 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 therefore outcomes, challenging.

Dr. Tim Nicholson, the study's co-lead author and Clinical Senior Lecturer at King's IoPPN and Honorary consultant Neuropsychiatrist at South London and Maudsley NHS Foundation Trust says that "it is not feasible to measure all possible outcomes, so there needs to be a

prioritization of which are critical to measure, as a minimum, that is agreed by all relevant stakeholders, from expert researchers and clinicians to patients and caregivers."

The study team identified all commonly reported outcomes in previous research, then used a 'Delphi' technique to reach consensus amongst the stakeholders. This is a well-established approach in which participants are asked their opinions in a first round and then shown the views of others and given the chance to reflect on their own ratings.

12 outcomes are now recommended for use, as a minimum, in future clinical research studies and [clinical practice](link): 1. Survival; 2. Fatigue or exhaustion; 3. Pain; 4. Post-exertion symptoms; 5. Cardiovascular functioning; 6. Respiratory functioning; 7. Nervous system functioning; 8. Cognitive functioning; 9. Mental functioning; 10. overall physical functioning; 11. Work or occupational and study changes. 'Recovery' was included as an additional twelfth outcome to achieve consistency with a previously published core outcome set for acute COVID-19.

Dr. Daniel Munblit, Professor of Paediatrics from Sechenov University, co-lead and first author of the paper, said that authors "hope that the results of the project will help to improve the quality of the data collected worldwide and our understanding of Long COVID. This, in turn, will allow for the development of effective intervention strategies to help people suffering condition." He also highlighted that "there is a need in consensus on critical outcomes to be measured in children and young people with Long COVID and this work is already under way."

The next step in the research is to use a similar process to identify the best ways to measure these outcomes which will need to be feasible for use globally, including in low resource settings. This will be similarly done on an accelerated timescale to inform treatment trials, other studies, and clinical services to target this major new healthcare

challenge. As co-lead Professor Paula Williamson notes "It is equally important that we maximize participation in this stage of the work. Information can be found on the study website."

"The rapid development of this Core Outcome Set for Long COVID by the global research community in partnership with people with lived experience has set out a key milestone in the development of evidence-based treatments by allowing optimization, coordination and efficient collation of data in research and clinical services," says Dr. Nicholson.

More information: Daniel Munblit et al, A core outcome set for post-COVID-19 condition in adults for use in clinical practice and research: an international Delphi consensus study, *The Lancet Respiratory Medicine* (2022). DOI: 10.1016/S2213-2600(22)00169-2

Study website: www.pc-cos.org/

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