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Core outcome measurement set for research and clinical practice in post-COVID-19 condition (long COVID) in children and young people: an international Delphi consensus study "PC-COS Children"

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Agreed measurement instruments should be considered in future work and insights from this study should guide policymakers in creating initiatives that address the effects of long COVID on children and young people in healthcare and research environments https://bit.ly/3NdHLFB

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Abstract

The coronavirus disease 2019 (COVID-19) pandemic substantially impacted different age groups, with children and young people not exempted. Many have experienced enduring health consequences. Presently, there is no consensus on the health outcomes to assess in children and young people with post-COVID-19 condition. Furthermore, it is unclear which measurement instruments are appropriate for use in research and clinical management of children and young people with post-COVID-19. To address these unmet needs, we conducted a consensus study, aiming to develop a core outcome set (COS) and an associated core outcome measurement set (COMS) for evaluating post-COVID-19 condition in children and young people. Our methodology comprised of two phases. In phase 1 (to create a COS), we performed an extensive literature review and categorisation of outcomes, and prioritised those outcomes in a two-round online modified Delphi process followed by a consensus meeting. In phase 2 (to create the COMS), we performed another modified Delphi consensus process to evaluate measurement instruments for previously defined core outcomes from phase 1, followed by an online consensus workshop to finalise recommendations regarding the most appropriate instruments for each core outcome. In phase 1, 214 participants from 37 countries participated, with 154 (72%) contributing to both Delphi rounds. The subsequent online consensus meeting resulted in a final COS which encompassed seven critical outcomes: fatigue; post-exertion symptoms; work/occupational and study changes; as well as functional changes, symptoms, and conditions relating to cardiovascular, neuro-cognitive, gastrointestinal and physical outcomes. In phase 2, 11 international experts were involved in a modified Delphi process, selecting measurement instruments for a subsequent online consensus workshop where 30 voting participants discussed and independently scored the selected instruments. As a result of this consensus process, four instruments met *a priori* consensus criteria for inclusion: PedsQL multidimensional fatigue scale for "fatigue"; PedsQL gastrointestinal symptom scales for "gastrointestinal"; PedsQL cognitive functioning scale for "neurocognitive" and EQ-5D for "physical functioning". Despite proposing outcome measurement instruments for the remaining three core outcomes ("cardiovascular", "post-exertional malaise", "work/occupational and study changes"), a consensus was not achieved. Our international, consensus-based initiative presents a robust framework for evaluating post-COVID-19 condition in children and young people in research and clinical practice *via* a rigorously defined COS and associated COMS. It will aid in the uniform measurement and reporting of relevant health outcomes worldwide.