Core Outcome Measurement Set for Research and Clinical Practice in Post COVID-19 Condition (Long COVID) in Children and Young People

the PC-COS Children Study Group; Seylanova, Nina; Chernyavskaya, Anastasia; Degtyareva, Natalia; Mursalova, Aigun; Ajam, Ali; Xiao, Lin; Aktulaeva, Khazhar; Roshchin, Philipp; Bobkova, Polina; Aiyegbusi, Olalekan Lee; Anbu, Anbarasu Theodore; Apfelbacher, Christian; Asadi-Pooya, Ali Akbar; Ashkenazi-Hoffnung, Liat; Brackel, Caroline; Buonsenso, Danilo; De Groote, Wouter; Diaz, Janet V.; Dona, Daniele

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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'

Nina Seylanova MD*[1], Anastasia Chernyavskaya MD*[2,3], Natalia Degtyareva BSc[4], Aigun Mursalova MD[4], Ali Ajam BSc[4], Lin Xiao BSc[4], Khazhar Aktulaeva BSc[4], Philipp Roshchin BSc[4], Polina Bobkova MD[4], Olalekan Lee Aiyegbusi PhD[5], Anbarasu Theodore Anbu MD[6], Christian Apfelbacher PhD[7], Ali Akbar Asadi-Pooya MD[8,9], Liat Ashkenazi-Hoffnung MD[10], Caroline Brackel MD[11,12], Danilo Buonsenso MD, PhD[13,14], Wouter de Groote[15], Janet V. Diaz MD[15], Daniele Dona MD, PhD[16], Audrey Dunn Galvin PhD[17], Jon Genuneit[18], Helen Goss[19], Sarah E. Hughes PhD[20], Christina J Jones PhD[21], Krutika Kuppalli MD[15], Laura A. Malone MD, PhD[22,23], Sammie McFarland[19], Dale M. Needham, MD, PhD[24,25,26], Nikita Nekliudov MD, MSc[27], Timothy R Nicholson PhD[28], Carlos R. Oliveira MD, PhD[29,30,31], Nicoline Schiess[32], Terry Y Segal MD[33], Louise Sigfrid[34], Claire Thorne PhD[35], Susanne Vijverberg PhD[36], John O. Warner[37], Wilson Milton Were[15], Paula R. Williamson PhD[38], Daniel Munblit MD, PhD*[39,40,41], and the PC-COS Children Study Group**

1 Independent researcher, London, UK
2 Department of Paediatrics and Paediatric Rheumatology, Sechenov First Moscow State Medical University (Sechenov University), Moscow, Russia
3 National Medical Research Center for Children's Health, Moscow, Russia
4 Sechenov First Moscow State Medical University (Sechenov University), Moscow, Russia
5 University of Birmingham, Birmingham, UK
6 Alder Hey Children's NHS Foundation Trust, Liverpool, UK
7 University of Magdeburg, Magdeburg, Germany
8 Epilepsy Research Center, Shiraz University of Medical Sciences, Shiraz, Iran
9 Jefferson Comprehensive Epilepsy Center, Thomas Jefferson University, Philadelphia, USA
10 Schneider Children's Medical Center of Israel, Petah Tikva, Israel
11 Amsterdam University Medical Centers, Amsterdam, the Netherlands
12 Department of Pediatrics, Tergooi Hospital, Blaricum, the Netherlands
13 Università Cattolica del Sacro Cuore, Rome, Italy
14 Department of Woman and Child Health and Public Health, Fondazione Policlinico Universitario A. Gemelli IRCCS, Rome, Italy
15 World Health Organization, Switzerland
16 Department for Women's and Children's Health, University of Padua, Padua, Italy
17 University of Cork, Cork, Ireland
18 Pediatric Epidemiology, Department of Pediatrics, Medical Faculty, Leipzig University, Leipzig, Germany
19 Long Covid Kids Charity, UK
20 Institute of Applied Health Research, University of Birmingham, Birmingham, UK
21 University of Surrey, Guildford, UK
22 Kennedy Krieger Institute, Baltimore, USA
23 Johns Hopkins University, Baltimore, USA
24 Outcomes After Critical Illness and Surgery (OACIS) Research Group, Johns Hopkins University, Baltimore, USA
25 Pulmonary and Critical Care Medicine, Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, USA
26 Physical Medicine and Rehabilitation, Johns Hopkins University School of Medicine, Baltimore, USA
27 Institute for Health Metrics and Evaluation, University of Washington, Seattle, USA
28 King's College London, London, UK
29 Yale University School of Medicine, Department of Pediatrics, Section of Infectious Diseases, New Haven, USA

30 Yale University School of Public Health, Department of Biostatistics, Division of Health Informatics, New Haven, USA
31 Yale New Haven Children's Hospital, New Haven, USA
32 Brain Health Unit, Mental Health and Substance Use Department, World Health Organization, Switzerland
33 University College London Hospitals NHS Foundation Trust, London, UK
34 ISARIC Global Support Centre, Centre for Tropical Medicine and Global Health, University of Oxford, Oxford, UK
35 Population, Policy and Practice Research and Teaching Dept, University College London GOS Institute of Child Health, London, UK
36 Amsterdam University Medical Centers, Amsterdam, the Netherlands
37 Imperial College London, London, UK
38 Department of Health Data Science, University of Liverpool, Liverpool, UK
39 Division of Care in Long Term Conditions, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, UK
40 Department of Paediatrics and Paediatric Infectious Diseases, Institute of Child's Health, Sechenov First Moscow State Medical University (Sechenov University), Moscow, Russia
41 Research and Clinical Center for Neuropsychiatry, Moscow, Russia

*Authors contributed equally to the study: apart from the two joint first authors, who contributed equally, the primary study team members and the last author, authors are listed in alphabetical order.
** Listed at end of the manuscript

Corresponding author:
Daniel Munblit MD, PhD. Division of Care in Long Term Conditions, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United Kingdom
Email: daniel.munblit@kcl.ac.uk

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Contributions: DM conceived the idea for the study. DM led the methodological team and supervised the research team work throughout the project. DM, TN, PRW, DMN and NSe designed the study protocol. DM, TN, PRW, and DMN carried out the methodological discussions at the start of the project. DM, NSe and AC were responsible for the day-to-day running of the project. AM, ND, AA, LX, PB, PR, KA undertook the literature review, identified outcome measures and outcome measurement instruments and categorised them for inclusion in the online Delphi survey and expert Delphi survey. NSe and AC coordinated the data revision process. NSe and AC developed the online Delphi surveys and contributed to the day-to-day management of the project. NSe, AC, AM, ND were responsible for setting up the Delphi Manager. DM, NSe, AC, AM, ND were responsible for communication with stakeholders. NSe, AC, AM, ND prepared the instructions and materials for Delphi process participants. NSe, AM, ND were involved in the process of setting up and updating the website. DM, NSe, AC, AM, ND, AA, LX organised the 'What to measure' Consensus meeting. DM, NSe, AC, AM were responsible for instrument cards design and contents. DM, AC, NSe, AM, AA, LX organised the 'How to measure' Consensus meeting. DM, AC, NSe, DB, CB and SV participated in the project methodology discussions throughout the duration of the project. NN undertook the data analysis. NSe and AC organised the consensus meeting and consensus workshop. KK, NSc and JVD led the WHO administrative aspects of the study. SM provided and coordinated invaluable perspectives of people with lived experience throughout the study into its design and implementation. DM, NSe and AC drafted the manuscript; all authors reviewed and approved the final manuscript.

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Summary

The COVID-19 pandemic substantially impacted different age groups, with children and young people (CYP) not exempted. Many have experienced enduring health consequences. Presently, there is no consensus on the health outcomes to assess in CYP with post COVID-19 condition. Furthermore, it is unclear which measurement instruments are appropriate for use in research and clinical management of CYP 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 CYP. 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 'Neuro-cognitive' and 'EQ5D family' 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 CYP 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.

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Introduction

While the majority of people infected with SARS-CoV-2 recover quickly, a significant number experience ongoing or relapsing symptoms for a prolonged period of time. Most research on post COVID-19 condition has focused on adults, with a much smaller number of paediatric studies. The prevalence of signs/symptoms after COVID-19 in children and young people (CYP) remains largely unknown due to heterogeneous terminology across the studies, but a recent systematic review estimated prevalence of symptoms one month after infection to be up to 25% [1]. Estimation of post COVID-19 condition prevalence is somehow difficult due to heterogeneity in terminology used and methodology applied [2]. A large multinational study estimated that around three percent of individuals under 20 years old with symptomatic SARS-CoV-2 infections had persistent fatigue, cognitive, and respiratory symptom clusters upon recovery from the acute infection [3,4], while reassuring data from the recent UK Office for National Statistics suggests that the incidence of post COVID-19 condition is now less than one percent [5]. Some studies estimated cumulative incidence of persistent symptoms following SARS-CoV-2 infection between 24% and 58% of CYP [6].

A diversity of outcomes is being evaluated in research on post COVID-19 condition in CYP. This heterogeneity hinders the ability to compare findings and conduct meta-analyses to inform evidence-based decisions. There is also a risk that ongoing or future interventional trials will not address some critically important outcomes as some outcomes important in one group may not be important in another or vice versa. These issues highlight the need for core outcome set (COS) development, to ensure that important outcomes are not missed in research or clinical practice on post COVID-19 condition in CYP [7]. COS are useful in various medical fields and can improve data quality, harmonisation, and comparability between different studies and clinical practices [8,9]. A COS is a universally agreed-upon, harmonised set of outcomes that, at a minimum, should be measured and reported in every clinical trial within a specific medical area. These sets are also developed in other types of research and clinical practice. They represent a consensus on the most critical outcomes for people with lived experience, their families, researchers, health professionals and other key stakeholders. The "gold standard" approach to COS development has been outlined by the Core Outcome Measures in Effectiveness Trials (COMET) framework and consists of two steps: (a) "what to measure?", and (b) "how to measure?" Once the COS is developed, the most appropriate outcome measurement instruments for assessing the "core outcomes" should be defined to provide practical measurement instruments for researchers and practitioners [9].

In 2021, an international group of experts defined the COS domains recommended to be used in all future research and clinical care for adults with post COVID-19 condition [10] and the second phase of this project defined the Core Outcome Measurement Set (COMS) in 2022 [11]. However, adults and CYP have distinct physiological and developmental characteristics, which may result in different presentations and long-term implications of post COVID-19 condition. Hence, it is crucial to have a tailored COS and COMS specifically designed for CYP to accurately capture and address these nuances as COS/COMS potentially may be required for different groups of paediatric population. To this end, we conducted an international study to develop a COS and COMS for post COVID-19 condition in CYP for use in clinical research and practice.

Methods

First phase (COS development)

The development of the COS involved three stages: (1) reviewing the outcomes reported in studies on post COVID-19 condition in CYP to develop a list of outcomes for stakeholder consideration; (2) a two-round online modified Delphi consensus process to rate the importance of the outcomes for the COS; (3) an online interactive consensus meeting to review and agree upon the final COS. The study protocol was developed a priori, and the project was registered (https://www.comet-initiative.org/Studies/Details/1847). Ethical approval for the study was obtained from the Sechenov University Ethics Committee on 20.01.2022 (protocol number 01-22).

The intended COS was developed for CYP below 18 years old, to be applied to post COVID-19 condition in clinical research and practice settings. The terms post COVID-19 condition and Long COVID were used interchangeably throughout the process.

Study group and participants

An international and multidisciplinary group of experts, including CYP with post COVID-19 experience and their caregivers, conducted a project under the International Severe Acute Respiratory and Emerging Infection Consortium (ISARIC) umbrella. The Core Outcome Measures in Effectiveness Trials (COMET) Initiative and the World Health Organization (WHO) collaborated with this project.

Participants were categorised into three distinct stakeholder groups: (a) CYP with post COVID-19 condition and their carers; (b) health professionals working with CYP with post COVID-19 condition; and (c) researchers studying post COVID-19 condition in CYP. For health professionals and researchers, prerequisites for participation included experience in treating CYP with post COVID-19 condition and conducting research in CYP with post COVID-19 condition, respectively. More details can be found in the appendix 5, p 4.

Developing a list of outcomes

The COS consensus process was informed by a comprehensive search of Medline, Embase, and the WHO COVID-19 Research Database (from inception until December 29, 2021). An additional search was performed on June 1, 2023, prior to consensus meeting, to screen for more recent evidence. The search was limited to English-language publications and protocols. The detailed search strategy can be found in the appendix 1, pp 5-9.

Data from research protocols were extracted from two clinical trials registries, Clinical Trials.gov and the International Clinical Trials Registry Platform, and reviewed by the reviewers (NS, AC, AM, ND, AA, LX, PB, PR, KA), with two reviewers extracting the data from each record independently. We classified unique outcomes from the list into domains (appendix 1, pp 27-82) using an existing taxonomy by Dodd and colleagues [12].

Delphi process and definitions

We conducted a two-round online modified Delphi consensus process [9]. In the first round, survey participants anonymously rated each outcome using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) scale [13], which is a nine-point scale commonly divided into three categories for COS projects: not important (1-3), important but not critical (4-6), and critically important (7-9). Each outcome had an "unable to rate" option and an option to add text-based comments. More details can be found in the appendix 5, p 4.

In the second round of the Delphi process, participants were shown their original rating from the first round alongside overall ratings of each of the three stakeholder groups for each outcome. They were then asked to rate each outcome again using the same scale.

Consensus for inclusion of an outcome in the COS was defined a priori as 80% or more of participants in each stakeholder group rating the outcome as critically important . Consensus for exclusion of an outcome from the COS was defined as 50% or less of respondents in each stakeholder group rating the outcome as critically important . Outcomes that did not meet these criteria were discussed at the consensus meeting.

The Delphi materials and all participant information were available in English, Chinese, Russian, French, and Spanish. The Delphi survey was delivered using DelphiManager software (http://www.comet-

initiative.org/delphimanager). Further details of the Delphi consensus process are included in appendix 1, pp 80-106.

Consensus meeting

We conducted an interactive online consensus meeting via Zoom, extending invitations to individuals with firsthand experience and their caregivers. The consensus meeting was conducted in English under the guidance of an experienced independent facilitator. The meeting was organised around the results from the second round of the Delphi.

The agenda prioritised outcomes that met the inclusion consensus by at least one stakeholder group, despite not being agreed upon by all. Additionally, outcomes deemed 'critically important' by at least 50% (but not more than 80%) of the participants in each stakeholder group were also selected for discussion.

Each of three stakeholder groups assessed outcomes independently, utilising the aforementioned threshold for defining inclusion — i.e., an outcome rated as critically important by 80% or more participants in all stakeholder groups. For further details regarding the consensus meeting process, please refer to appendix 2.

Data analysis

Descriptive statistics were used to show the overall scores of each stakeholder group for the three GRADE categories for all outcomes considered at each stage, to determine whether they met the predefined criteria for inclusion or exclusion.

Similarly to the PC-COS adult project [10], we agreed a priori that only responses from Delphi participants who rated at least 50% of outcomes would be included in the analysis. Free-text comments were translated into English from the French, Russian, Spanish, and Chinese surveys and collated and reviewed by the core group. Bar plots displaying the distribution of ratings for each outcome, faceted by stakeholder group, were produced using R (version 4.2.1) and shown to participants in the second Delphi round.

Second phase (Outcome measurement instruments consensus)

Literature review of outcome measurement instruments

The core group reviewed all measurement instruments that emerged from our literature search. More details can be found in the appendix 5, p 4.
Given that the measurement properties of non-COVID specific instruments had not been assessed in a post COVID-19 population, assessment of the measurement properties of these instruments was not undertaken [11].
For all instruments, feasibility-related data (e.g. time, cost, language/translations) were considered by the experts and presented at consensus meeting to the participants. It was decided a priori that instruments requiring trained personnel, additional software, clinical facilities, or not pertaining to "core outcomes" would be excluded to ensure applicability of COMS across different settings. The instruments needed to be available for use even in “low resource areas” and not require in person assessment or medical equipment.

Expert Delphi Consensus

The core group refined a comprehensive list of instruments derived from systematic literature and clinical trials review. Instruments requiring trained personnel, additional software, clinical facilities, or not pertaining to "core outcomes" were excluded.

A group of independent international experts, with extensive experience in post COVID-19 condition research and/or clinical practice, anonymously reviewed these instruments over two rounds. They provided feedback in excel spreadsheets on each instrument and suggested potential additions, which were assessed for feasibility and applicability by the core group. Approved new instruments were presented in the second round for further review. In the second round, each expert received a list of instruments accompanied by anonymised expert feedback from the first round. After reviewing the comments from the first round, they had the opportunity to modify their initial selection or retain it. Each expert indicated their preference for each instrument's inclusion in the consensus workshop.

Instruments that garnered "include" or "maybe" responses from more than 50% of the experts were forwarded to the online consensus meeting. We prepared "instrument cards", modified for the purposes of the project from the previous studies (https://www.improvelto.com/instruments/), for each outcome, collating a summary table of instruments selected for discussion. These were shared with the consensus workshop participants beforehand.

Consensus workshop

Upon obtaining expert review results, we convened at an online consensus workshop to discuss the shortlisted instruments. The consensus meeting was conducted in English and the study lead (DM) acted as a facilitator without voting rights.

Instruments selected as a result of 'expert review' as per criteria outlined above were discussed at the meeting. Consensus for an instrument to be included was defined as 70% or more participants from a total number of voting participants. If participants did not cast a vote on a given instrument, not less than 70% of voting participants were required to consider the vote valid.

Results

Literature review

We conducted a review of available studies and trial protocols on post COVID-19 condition in CYP. This review found 212 studies and protocols that met the inclusion criteria, as detailed in appendix 1, pp 10-27. These studies and protocols reported a total of 1097 outcomes, as detailed in appendix 1, pp 27-79.

The outcomes were classified and reviewed iteratively by the core group and project steering committee. After discussion, the steering committee approved 25 outcomes (appendix 1, pp 80-82) for consideration in the first round of the Delphi process. These 25 outcomes were categorised into four domains: survival (one outcome); physiological or clinical (17 outcomes); life impact (five outcomes); and resource use (two outcomes). Figure 1 summarises the steps taken in the development of the COS and COMS.

First phase (Core Outcome Set development)

Delphi process

The first round of the online Delphi process was conducted from November 23 to December 24, 2022. A total of 228 individuals registered to participate in the study, and 214 participants (94%) from 37 countries completed the first round, which required them to rate 50% or more of the 25 outcomes. Of these participants, 154 (72%) from 31 countries participated in the second round of the Delphi process and rated 50% or more of the outcomes in this subsequent round. Demographic characteristics of the participants for each Delphi round are presented in Table 1. Further details about the Delphi participants can be found in appendix 1 (pp. 83-90).

Upon completion of the first round of the Delphi process, the participant ratings indicated that the COS should include three of the 25 outcomes, while four outcomes should be excluded, and consensus criteria for 18 outcomes were not met. Table 2 and appendix 1, pp. 90-94 provide further details.

The core group reviewed 72 submitted free-text responses related to additional outcomes, with no new outcomes added in the second Delphi round. Four participants suggested adding “recurrent infections" as a new outcome. This suggestion was discussed within the core group with a decision made for not including it due to the lack of evidence for post-COVID immune deficiency in children, the complexity of the outcome, and the difficulty in differentiating it from infections stemming from other aetiologies. There was also overlap with some of the outcomes already present as a part of the Delphi process, and core group highlighted practical challenges in monitoring and documenting such infections.

The second Delphi round occurred from February 19 to March 31, 2023, during which 154 participants assessed the 25 outcomes. Subsequently, four outcomes met criteria for inclusion, with three in the physiological or clinical domain and one in the life impact domain. Eight outcomes were excluded. Thirteen other outcomes received mixed ratings across the stakeholder groups, which led to their discussion at a subsequent consensus meeting.

Consensus meeting

The consensus meeting was conducted online on April 28, 2023. For feasibility purposes voting participants were divided into two stakeholder groups: (a) CYP with post COVID-19 condition and their carers (n=11); (b) health professionals working with CYP with post COVID-19 condition and researchers studying post COVID-19 condition in CYP (n=12). Detailed descriptions of the participants who attended the consensus meeting can be found in appendix 2 (pp. 3-4).

Upon ratification of outcomes that were voted “in” and “out” upon the Delphi process the thirteen outcomes were discussed in the following order: survival; post-exertion symptoms; mental/psychological functioning, symptoms, and conditions; respiratory functioning, symptoms, and conditions; pain; sleep-related functioning, symptoms, and conditions; gastrointestinal functioning, symptoms, and conditions; muscle and joint symptoms and conditions; work/occupational and study changes; satisfaction with life or personal enjoyment; social role-functioning and relationships problems; healthcare resource utilisation; family/carer burden.

After discussions and subsequent voting, three additional outcomes met the predefined consensus definition for inclusion. These included “post-exertion symptoms” with 100% (11 out of 11) of the CYP with post COVID-19 condition and their carers and 84% (10 out of 12) of the health-care professionals and researchers rated it as critically important, based on the GRADE rating of 7–9; “gastrointestinal functioning; symptoms; and conditions” with 100% (11 out of 11) and 84% (10 out of 12) as well as “work/occupational and study changes” rate as critical by 100% (11 out of 11) and 91% (11 out of 12) participants respectively. Consequently, three outcomes were incorporated into the COS, joining the four previously agreed-upon outcomes. This brought the total number of outcomes in the COS to seven. The results derived from both the Delphi process and the consensus meeting can be accessed in appendix 1, pp. 90-106.A report of the consensus meeting is available in appendix 2.

Second phase (Core Outcome Measurement Set development)

Literature review of outcome measurement instruments

A comprehensive literature review found 1762 instruments used across post COVID-19 condition studies and trial protocols. Following removal of duplicates and mapping of identified instruments to the core outcomes, the number was reduced to 225. An independent assessment of these instruments by the core group, taking into account a priori defined criteria, further reduced the list to 30. In addition to these, the study group identified five relevant PROMIS instruments, bringing the total to 35 outcome measurement instruments. These instruments,

detailed in appendix 3, pp. 6-16, were mapped to seven "core outcomes" described above. The COS development steps are summarised in Figure 1.

Expert Delphi

A group of eleven international experts anonymously reviewed instruments provided by the study team over two Delphi rounds. Round 1 ran from June 8 to June 21, 2023, with all the experts completing this round. All the experts were invited to participate in round two. Round 2 ran from July 3 to July 13, 2023; with all the experts providing their feedback and scoring. Further details of experts involved in the Delphi process are detailed in appendix 3, pp. 16-17.

Of the instruments reviewed in round 1, 18 out of 35 instruments met pre-specified criteria for inclusion for discussion at consensus workshop. A single instrument (stomach reflux symptom by Visual Analog Score) was excluded by the core group due to the non-specific nature of this VAS. All other instruments from round 1 were taken forward to round 2. Additional potential instruments were assessed for feasibility and applicability by the core group. 15 approved new instruments were presented in the second round for further review, including one instrument that was specific to the post COVID-19 condition in adults which is currently in the process of validation for CYP. A total of 49 instruments were reviewed in round 2 and 20 of them met pre-specified criteria for inclusion for discussion at consensus workshop. The WHO Disability Assessment Schedule (WHODAS 2.0) Children and Youth 36-Item Version instrument was found upon the pre-meeting literature search update and included for discussion at the consensus workshop.

Consensus workshop

Ahead of the consensus workshop, materials were circulated to all individuals invited to the meeting. The online consensus workshop was held on July 31, 2023, with 46 individuals participating in this three and a half-hour session. This attendance included six study team members, nine observers, and 30 voting participants (eight carers of CYP with post COVID-19 condition; and 22 health professionals and researchers with expertise in post COVID-19 condition in CYP, mirroring the approach taken for the first phase of the project and previous process of COS development for the adult population [10,11]). Details of those who participated in the consensus workshop can be found in appendix 4, pp. 2-3.

At the start of the online workshop, participants were briefed about the process and a priori defined criteria for consensus. Participants were reminded that multiple instruments could be chosen or voted 'in' within a domain. Voting on each instrument was independent. The subsequent outcomes and measurement instruments discussed were: Cardiovascular functioning, symptoms, and conditions (PedsQL Cardiac Module; Symptom Burden Questionnaire for Long COVID (Circulation scale) and Malmo POTS score (MAPS)); Gastrointestinal functioning, symptoms, and conditions (PedsQL Gastrointestinal Symptoms Scales; Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS) and Symptom Burden Questionnaire for Long COVID (Stomach and Digestion Scale)); Neurocognitive functioning, symptoms, and conditions (PROMIS Pediatric Cognitive Function - Short Form 7a; PedsQL Cognitive Functioning Scale and Symptom Burden Questionnaire for Long COVID (Memory, Thinking & Communication scale, movement scale, muscles and joints, pain scales)); Fatigue (Chalder fatigue questionnaire; PROMIS Paediatric Fatigue; PedsQL Multidimensional Fatigue Scale and Symptom Burden Questionnaire for Long COVID (Fatigue scale)); Post-exertion symptoms (CDC symptom inventory for CFS; PEM items from DePaul Symptom Questionnaire and Symptom Burden Questionnaire for Long COVID (Fatigue scale)); and Physical functioning, symptoms, and conditions (EQ5DY instrument; PROMIS Physical Activity and Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)); Work occupational and study changes (Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale) and WHO DAS 2 Children and Youth 36-Item Version).

Following discussion and voting, 'PedsQL multidimensional Fatigue scale' instrument for 'fatigue' with 26/26 (100%) of consensus meeting participants voting 'Yes' for inclusion so it was added to the COMS; 'PedsQL Gastrointestinal symptom scales' for 'gastrointestinal' 23/26 (88%); 'PedsQL Cognitive Functioning Scale' for 'Neuro-cognitive' with 21/25 (84%) and 'EQ5D family' for physical functioning 24/25 (96%), respectively. Overall, four measurement instruments were selected for inclusion into COMS (see Table 3 and Figure 2).

Consensus was not achieved for recommending measurement instruments for the remaining three core outcomes. Table 3 indicates the voting results and reasons for exclusion for the instruments discussed at the meeting but not reaching consensus. Detailed consensus workshop report is available in the appendix 4.

Discussion

This manuscript presents the findings of a large, rigorous international consensus study aimed at developing a COS and a COMS for post COVID-19 condition that are intended for use in CYP in research and clinical practice settings. Seven outcomes achieved the predefined consensus definition for inclusion in the COS: 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. Agreement regarding the most appropriate instruments to be used was reached for four outcomes: these were the EQ5D family (for physical functioning) and the fatigue, gastrointestinal symptoms and cognitive functioning scales of the PedsQL. The consensus process reduced the number of potential instruments for measuring the seven core outcomes from over 200, despite no single measurement instrument reaching consensus for the remaining three outcomes.

Through our consensus process, we identified seven critical outcomes to be incorporated in both research and clinical practice, ensuring that the most salient aspects of the condition are consistently and effectively addressed. Five of the seven consensus-based outcomes in this COS are in the physiological or clinical outcomes domain and cover many of the frequently reported symptoms in CYP. While the WHO clinical case definition of post COVID-19 condition in CYP [14] offers a consistent clinical terminology, the COS delineates the essential outcomes that ought to be assessed in every study and clinical setting.

Across stakeholder groups, there was a broad consensus on the significance of most outcomes. Two outcomes, namely 'sleep-related functioning, symptoms, and conditions' and 'pain', narrowly missed the predefined threshold. A notable divergence in perspectives emerged regarding the 'family/carer burden' outcome. CYP with post COVID-19 condition and their carers deemed this outcome as critically important. In contrast, only 34% of health-care professionals and researchers viewed it with the same level of importance. Despite not meeting the criteria for inclusion in the COS, the significance of this outcome was recognised by both groups, with 100% of CYP and caregivers and 84% of health-care professionals and researchers rating it as either important or critically important (appendix 2). The emphasis placed on these outcomes suggests that they warrant consideration in research and clinical settings. It is important to note that COS is a necessary minimum that should always be measured but do not preclude from measuring other outcomes.

It is also worth noting that a small number of "CYP with Long COVID and their family and carers" acknowledged the critical importance of 'mental' outcome assessment, with concerns of stigmatisation being raised. Many parents shared their experience of being troubled and hesitant to discuss mental problems of their child with healthcare providers, as the symptoms in a child are often attributed to mental health challenges/issues. This is in contrast to the COS for post COVID-19 condition in adults, which includes this outcome [10]. All health professionals/researchers considered this outcome important with 7/12 (59%) feeling that it is critical. Mental health-related symptoms are common, and it is understandable to suffer effects on emotional wellbeing due to

having an illness such as post COVID-19 condition as it has a direct effect on an individual's life. Concerns of stigmatisation should not stand in the way of being able to assess the child or young person holistically and hence provide necessary support. Health professionals and researchers need to approach this delicate topic with care, while carers of CYP with post COVID-19 condition should not see attempt to assess mental health as lack of trust to their concerns about their child.

Overall, the paediatric COS seems to focus more on functional and symptomatic outcomes directly relevant to CYP's daily lives, such as school and physical activities, while the adult COS encompasses a broader range of health aspects, including respiratory, mental health and survival, which are important for all age groups, but more pertinent to the adult population. These differences underscore the unique health impacts and assessment needs of these two age groups in post-COVID-19 condition research.

The PedsQL and EQ5D families of instruments offer multiple age-specific versions [15,16]. These versions contain questions pertinent to a child's development, and they have been translated into various languages and are used across different medical disciplines.

Consensus regarding measurement instruments was not achieved for three outcomes. There were several potential reasons for this. Firstly, post COVID-19 condition is a recently discovered condition and the mechanistic understanding in CYP is still in its infancy. This heterogeneity can influence instrument preference, and the unique considerations of the paediatric population such as specific needs for different age groups or inability to appropriately articulate their complaints in younger children, introduce added complexity. Secondly, past experiences with various instruments may have introduced implicit bias, thereby influencing participant scoring. At least one of these measurement instruments can be potentially considered for each core outcome although they should be used with caution taking into account workshop participants feedback (appendix 4, pp. 4, 7, 10).

Our study has some limitations. Firstly, while the Delphi consensus process for the COS incorporated individuals from diverse geographical locations, the majority were white, and were resident in the UK and the United States. The Delphi process also saw an underrepresentation of male participants, which is a common problem in survey/Delphi research, and particularly related to CYP, and has previously been acknowledged [18,19]. Both imbalances could potentially result in a lack of external validity or generalisability. Although the Delphi has been conducted in multiple languages some widely used languages (e.g. Hindi and Arabic) were missing. These demographic imbalances might challenge the external validity of our findings. Long COVID disproportionately impacts underprivileged groups, with potential rural vs. urban disparities in healthcare access and quality. This might influence the utilisation rating among family and carers, who form a significant portion of participants. Treatment for Long COVID can be costlier, hitting lower-income individuals and LMIC populations harder [20]. Secondly, a consensus meeting during the first phase of the project included only a limited subset of Delphi participants, whose perspectives might not encompass the full spectrum of views on the subject. However, this limitation is an inherent component in the Delphi methodology. It is also important to note that the meeting did not overturn the "in"/ "out" results from the Delphi, and it allowed discussion of those not reaching consensus previously. Thirdly, given the pressing public health implications of COS development, we expedited our study. Consequently, we did not gather data on chronicity, time since diagnosis, and participants' socioeconomic status. A similar approach was previously employed for the adult COS development. Yet, it is worth noting that comprehensive data collection on Delphi participants is not standard practice. In line with the WHO's definition, our study included individuals with both confirmed and probable SARS-CoV-2 infections. However, it is possible that some with a "probable" diagnosis might not have had the infection. Lastly, in the second phase of the project, aiming at outcome measurement instrument selection, the Delphi process has been conducted without involvement of CYP with post COVID-19 condition and their carers. Instead, an international panel of experts conducted a Delphi process. This approach aimed to expedite the consensus process and reduce the potential burden on participants, drawing insights from a similar process conducted for adults. This has been mitigated in

part by involvement of carers of CYP with post COVID-19 condition at the final consensus workshop. Another limitation is absence of COSMIN methodology for selecting instruments implementation in the COMS development, as measurement properties of non-COVID-19-specific instruments had not been assessed in a post-COVID-19 population.

While the incidence of new acute SARS-CoV-2 cases has seen a decline, it is imperative to address the lingering legacy of post COVID-19 condition, particularly due to its prolonged persistence. With the acute cases becoming less frequent, there is a potential risk of the broader community adopting an 'out of sight, out of mind' perspective. However, it is crucial to highlight the substantial absolute number of CYP globally who are grappling with Long COVID. The long-term implications of this condition on their growth, maturation, and overall development underscore the need to recognise post COVID-19 condition not merely as a transient concern but rather as a chronic health issue. This rigorous international consensus study has successfully delineated a COS and a COMS tailored for post COVID-19 condition in CYP. While the consensus provides clarity in a nascent and multifaceted field, it also underscores the need for continued exploration, especially for outcomes where consensus remains elusive. As we navigate the complexities of post COVID-19 conditions in CYP, this consensus serves as a guidance for both research endeavours and clinical practices towards a more unified and informed approach (Box 1). The outcomes of this study may also be useful not only within its immediate context but also as a model for future pandemic situations. We believe that the generalisable knowledge derived from this COMS exercise can significantly benefit the broader academic and medical communities in the future challenges.

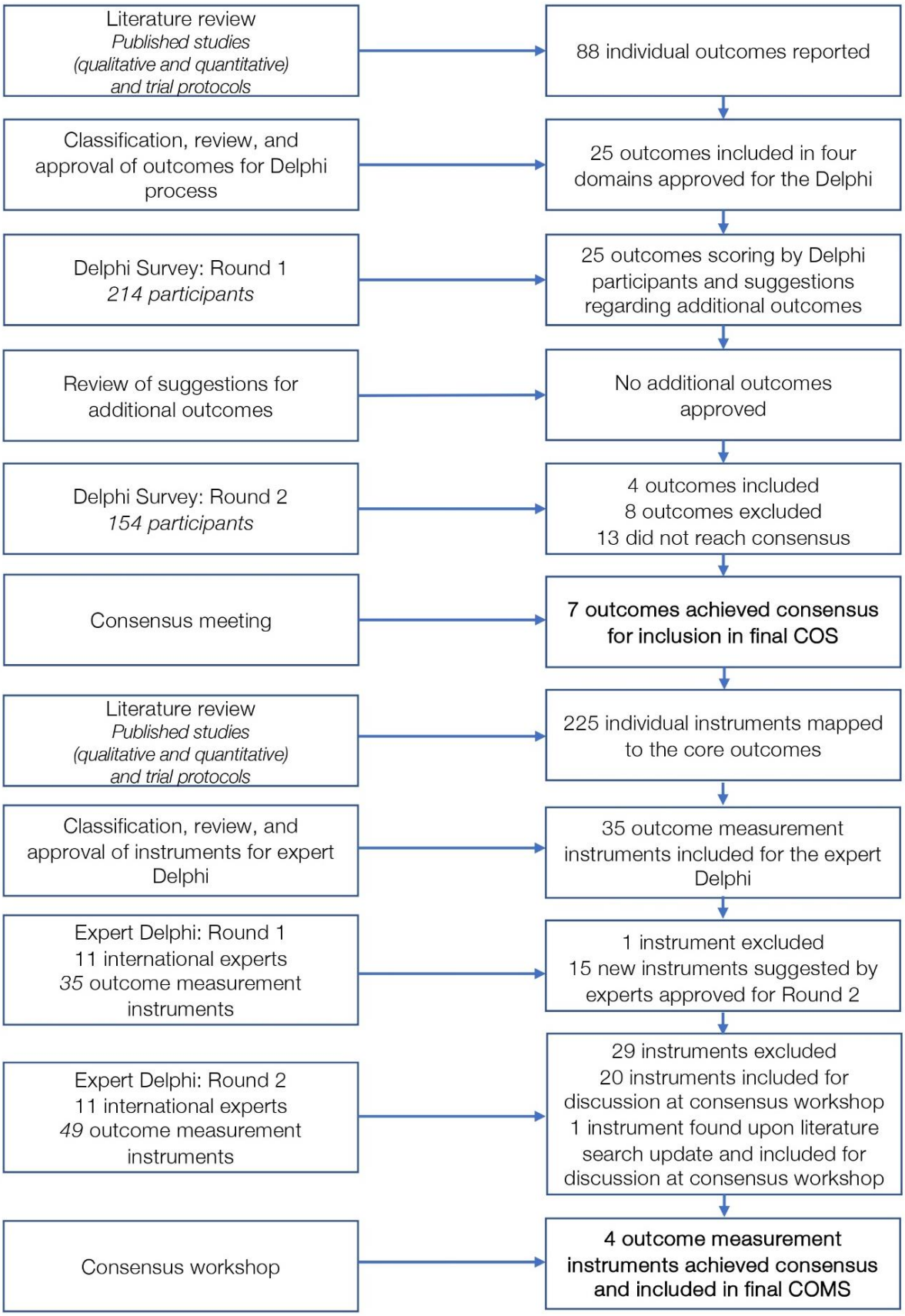

Figure 1. Overview of the COS and COMS development process.

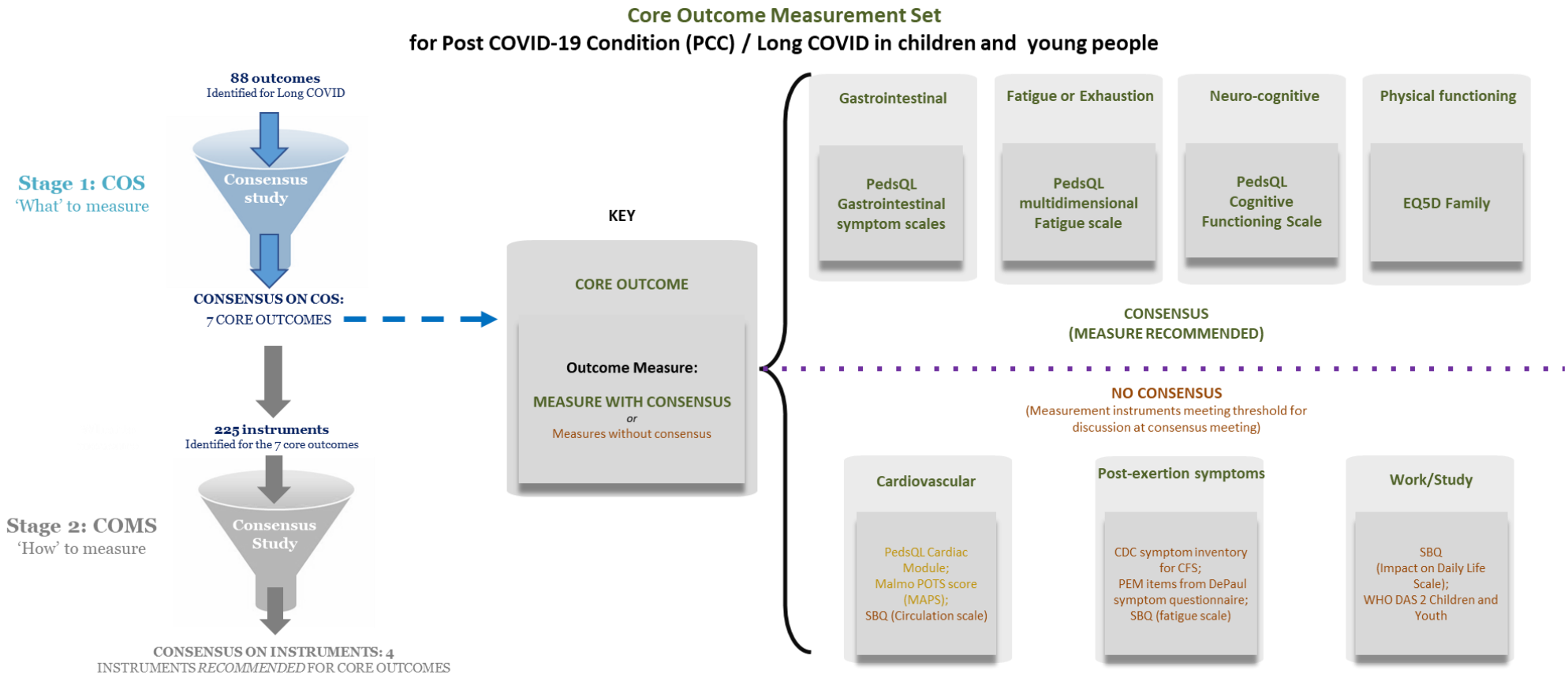

Figure 2. Core Outcome Measurement Set for post-COVID-19 condition in children and young people.

Green colour indicates core outcomes and instruments reaching consensus for use in relation to a particular outcome; Yellow colour indicates instruments not reaching consensus, with more than a half of consensus meeting participants voting for this instrument prioritisation; Red colour indicates instruments not reaching consensus, with less than a half of consensus meeting participants voting for this instrument prioritisation.

Table 1. Core Outcome Set (COS) Delphi participants demographics.

	Delphi Round 1 (*n* = 214)	Delphi Round 2 (*n* = 154)
Stakeholder group, *n (%)*		
Children and young people (≤18 years old) who have experience of living with post-COVID-19 condition (also known as Long COVID)	26 (12)	21 (14)
Family and carers of children and young people (≤18 years old) with Long COVID	115 (54)	76 (49)
Health professionals who have experience treating children and young people (≤18 years old) with Long COVID	37 (17)	32 (21)
Researchers studying Long COVID in children and young people (≤18 years old)	36 (17)	25 (16)
Other	*Participants reclassified after R1 review and analysed within appropriate groups*	
Gender, *n (%)*		
Male	47 (22)	34 (22)
Female	166 (78)	119 (77)
Non-binary	1 (<1)	1 (<1)
Other	0 (0)	0 (0)
Prefer not to answer	0 (0)	0 (0)
Age group, *n (%)*		
2-11	6 (3)	3 (2)
12-18	21 (10)	19 (12)
18-39	40 (19)	33 (21)
40-59	139 (65)	94 (61)
60-79	8 (4)	5 (3)
Geographical area, *n (%)*		
Asia	8 (4)	6 (4)
Africa	1 (<1)	1 (<1)
Australasia	11 (5)	8 (5)
Europe	163 (76)	120 (78)
North America	24 (11)	13 (8)
Central America	1 (<1)	0 (0)
South America	6 (3)	6 (4)
Ethnicity, *n (%)*		
White	180 (84)	130 (84)
South Asian	5 (2)	4 (3)
Hispanic/Latino/Spanish	8 (4)	6 (4)
East Asian/Pacific Islander	4 (2)	1 (<1)
Indigenous peoples	0 (0)	0 (0)
Black	1 (<1)	1 (<1)
Middle Eastern/North African	6 (3)	5 (3)
Other	10 (5)	7 (5)
Not all percentages add up to 100% owing to rounding		

Table 2. Summary of Delphi and consensus meeting voting on outcomes stratified by domains.

	Delphi Round 1	Delphi Round 2	Consensus meeting
Mortality/survival			
Survival	No consensus	No consensus: for discussion	Exclude
Physiological/clinical			
Cardiovascular functioning; symptoms; and conditions	No consensus	Include in the COS	N/A
Endocrine and metabolic functioning; symptoms; and conditions	No consensus	Exclude	N/A
Hearing-related functioning; symptoms; and conditions	Exclude	Exclude	N/A
Gastrointestinal functioning; symptoms; and conditions	No consensus	No consensus: for discussion	Include in the COS
Pain	No consensus	No consensus: for discussion	Exclude
Fatigue or Exhaustion	Include	Include in the COS	N/A
Sleep-related functioning; symptoms; and conditions	No consensus	No consensus: for discussion	Exclude
Muscle and joint symptoms and conditions	No consensus	No consensus: for discussion	Exclude
Taste- and/or smell-related functioning; symptoms; and conditions	Exclude	Exclude	N/A
Neuro-cognitive system functioning; symptoms; and conditions	Include	Include in the COS	N/A
Mental / Psychological functioning; symptoms; and conditions	No consensus	No consensus: for discussion	Exclude
Kidney and urinary-related functioning; symptoms; and conditions	No consensus	Exclude	N/A
Respiratory functioning; symptoms; and conditions	No consensus	No consensus: for discussion	Exclude
Skin; hair; dental and/or nail-related functioning; symptoms; and conditions	Exclude	Exclude	N/A
Post-exertion symptoms	No consensus	No consensus: for discussion	Include in the COS
Vision-related functioning; symptoms; and conditions	No consensus	Exclude	N/A
Fever/body temperature changes	No consensus	Exclude	N/A
Life impact			
Satisfaction with life; or personal enjoyment	No consensus	No consensus: for discussion	Exclude
Physical functioning; symptoms; and conditions	Include	Include in the COS	N/A

Social role-functioning and relationships problems	No consensus	No consensus: for discussion	Exclude
Work/occupational and study changes	No consensus	No consensus: for discussion	Include in the COS
Stigma	Exclude	Exclude	N/A
Resource use			
Healthcare resource utilisation	No consensus	No consensus: for discussion	Exclude
Family/carer burden	No consensus	No consensus: for discussion	Exclude

All outcomes from Delphi round 1 were included in round 2, regardless of ratings in round 1.
N/A = not applicable (outcomes were included in the COS after 2 rounds of Delphi).

Table 3. Consensus workshop voting results for outcome measurement instruments.

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE in consensus meeting	Result
Cardiovascular functioning, symptoms and conditions	PedsQL Cardiac Module	16/28 (57)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Circulation scale)	7/27 (25)	Not included in the COMS
	Malmo POTS score (MAPS)	18/27 (64)	Not included in the COMS
Gastrointestinal functioning, symptoms, and conditions	PedsQL Gastrointestinal Symptoms Scales	23/26 (88)	Included in the COMS
	Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS)	2/26 (8)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Stomach and Digestion Scale)	6/26 (23)	Not included in the COMS
Fatigue or Exhaustion	Chalder fatigue questionnaire	3/26 (12)	Not included in the COMS
	PROMIS Paediatric Fatigue	3/26 (12)	Not included in the COMS
	PedsQL Multidimensional Fatigue Scale	26/26 (100)	Included in the COMS
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	3/26 (12)	Not included in the COMS
Post-exertion symptoms	CDC symptom inventory for CFS	5/26 (19)	Not included in the COMS
	PEM items from DePaul Symptom Questionnaire	10/26 (38)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	6/26 (23)	Not included in the COMS

Neuro-cognitive system functioning, symptoms, and conditions	PROMIS Pediatric Cognitive Function - Short Form 7a	9/24 (36)	Not included in the COMS
	PedsQL Cognitive Functioning Scale	21/25 (84)	Included in the COMS
	Symptom Burden Questionnaire for Long COVID (Memory, Thinking & Communication scale, movement scale, muscles and joints, pain scales)	4/24 (16)	Not included in the COMS
Physical functioning, symptoms, and conditions	EQ5DY instrument	24/25 (96)	Included in the COMS
	PROMIS Physical Activity	2/25 (8)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	3/25 (12)	Not included in the COMS
Work/occupational and study changes	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	5/22 (23)	Not included in the COMS
	WHO DAS 2 Children and Youth 36-Item Version	7/23 (30)	Not included in the COMS

Box 1: Key messages

Rationale and approach

- In children and young people, the post COVID-19 condition, also known as Long COVID is associated with a range of persistent symptoms following infection with SARS-CoV-2.
- Research on post COVID-19 condition varies in outcomes studied. A consensus on a minimum set of essential outcomes, referred to as Core Outcome Set (COS) is needed for better data comparison in children and young people.
- There is also an urgent need for decisions to be made on which measurement instruments are the most appropriate for assessing these core outcomes, in order to develop a Core Outcome Measurement Set (COMS), to optimise data comparability and synthesis.
- To develop the COS, we conducted a study that included a literature review, a two-round online Delphi process with over 214 participants from 37 countries, with over half of them being parents of children with post COVID-19 condition and children and young people, and an online consensus meeting. The Delphi process included rating 25 different outcomes.
- For the development of COMS, we then performed an expert online modified Delphi process and an online consensus workshop to discuss and then vote anonymously on measurement instruments.

Findings

- In the field of paediatric care, it is recommended that the following outcomes to be consistently measured in research and clinical practice when assessing post COVID-19 condition: fatigue; post-exertion symptoms; alterations in studies, work, or occupational activities; as well as functional changes, symptoms, and conditions relating to cardiovascular, neuro-cognitive, gastrointestinal, and physical health.
- Instruments for measurement of fatigue, gastrointestinal, neuro-cognitive outcomes and physical functioning were recommended for use in research and clinical practice for children and young people with post COVID-

19 condition. For the three other core outcomes, the most favoured measurement instruments identified from this consensus procedure have been documented, even though no individual measurement instrument met a priori criteria for consensus.

Future Directions and Implications

- To enhance our understanding of post COVID-19 condition in children, there is a need for further standardisation of clinical and research practices using the identified core outcomes and associated measurement instruments.

- Future research should focus on refining and validating the measurement instruments that were favoured but did not achieve consensus among participants.

- Incorporating the lived experiences and perspectives of children and young people affected by post COVID-19 condition as well as their carers is crucial for future research, including instrument development and improvements to patient care.

- Agreed measurement instruments should be considered in future work and insights from this research should guide policymakers in creating initiatives that address the effects of post-COVID-19 condition on children and young people in both healthcare and research environments.

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Appendix 1

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'

Nina Seylanova MD*[1], Anastasia Chernyavskaya MD*[2,3], Natalia Degtyareva BSc[4], Aigun Mursalova MD[4], Ali Ajam BSc[4], Lin Xiao BSc[4], Khazhar Aktulaeva BSc[4], Philipp Roshchin BSc[4], Polina Bobkova MD[4], Olalekan Lee Aiyegbusi PhD[5], Anbarasu Theodore Anbu MD[6], Christian Apfelbacher PhD[7], Ali Akbar Asadi-Pooya MD[8,9], Liat Ashkenazi-Hoffnung MD[10], Caroline Brackel MD[11,12], Danilo Buonsenso MD, PhD[13,14], Wouter de Groote[15], Janet V. Diaz MD[15], Daniele Dona MD, PhD[16], Audrey Dunn Galvin PhD[17], Jon Genuneit[18], Helen Goss[19], Sarah E. Hughes PhD[20], Christina J Jones PhD[21], Krutika Kuppalli MD[15], Laura A. Malone MD, PhD[22,23], Sammie McFarland[19], Dale M. Needham, MD, PhD[24,25,26], Nikita Nekliudov MD, MSc[27], Timothy R Nicholson PhD[28], Carlos R. Oliveira MD, PhD[29,30,31], Nicoline Schiess[32], Terry Y Segal MD[33], Louise Sigfrid[34], Claire Thorne PhD[35], Susanne Vijverberg PhD[36], John O. Warner[37], Wilson Milton Were[15], Paula R. Williamson PhD[38], Daniel Munblit MD, PhD*[39,40,41], and the PC-COS Children Study Group**

1 Independent researcher, London, UK

2 Department of Paediatrics and Paediatric Rheumatology, Sechenov First Moscow State Medical University (Sechenov University), Moscow, Russia

3 National Medical Research Center for Children's Health, Moscow, Russia

4 Sechenov First Moscow State Medical University (Sechenov University), Moscow, Russia

5 University of Birmingham, Birmingham, UK

6 Alder Hey Children's NHS Foundation Trust, Liverpool, UK

7 University of Magdeburg, Magdeburg, Germany

8 Epilepsy Research Center, Shiraz University of Medical Sciences, Shiraz, Iran

9 Jefferson Comprehensive Epilepsy Center, Thomas Jefferson University, Philadelphia, USA

10 Schneider Children's Medical Center of Israel, Petah Tikva, Israel

11 Amsterdam University Medical Centers, Amsterdam, the Netherlands

12 Department of Pediatrics, Tergooi Hospital, Blaricum, the Netherlands

13 Università Cattolica del Sacro Cuore, Rome, Italy

14 Department of Woman and Child Health and Public Health, Fondazione Policlinico Universitario A. Gemelli IRCCS, Rome, Italy

15 World Health Organization, Switzerland

16 Department for Women's and Children's Health, University of Padua, Padua, Italy

17 University of Cork, Cork, Ireland

18 Pediatric Epidemiology, Department of Pediatrics, Medical Faculty, Leipzig University, Leipzig, Germany

19 Long Covid Kids Charity, UK

20 Institute of Applied Health Research, University of Birmingham, Birmingham, UK

21 University of Surrey, Guildford, UK

22 Kennedy Krieger Institute, Baltimore, USA

23 Johns Hopkins University, Baltimore, USA

24 Outcomes After Critical Illness and Surgery (OACIS) Research Group, Johns Hopkins University, Baltimore, USA

25 Pulmonary and Critical Care Medicine, Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, USA

26 Physical Medicine and Rehabilitation, Johns Hopkins University School of Medicine, Baltimore, USA

27 Institute for Health Metrics and Evaluation, University of Washington, Seattle, USA

28 King's College London, London, UK

29 Yale University School of Medicine, Department of Pediatrics, Section of Infectious Diseases, New Haven, USA

30 Yale University School of Public Health, Department of Biostatistics, Division of Health Informatics, New Haven, USA

31 Yale New Haven Children's Hospital, New Haven, USA

32 Brain Health Unit, Mental Health and Substance Use Department, World Health Organization, Switzerland

33 University College London Hospitals NHS Foundation Trust, London, UK

34 ISARIC Global Support Centre, Centre for Tropical Medicine and Global Health, University of Oxford, Oxford, UK

35 Population, Policy and Practice Research and Teaching Dept, University College London GOS Institute of Child Health, London, UK

36 Amsterdam University Medical Centers, Amsterdam, the Netherlands

37 Imperial College London, London, UK

38 Department of Health Data Science, University of Liverpool, Liverpool, UK

39 Division of Care in Long Term Conditions, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, UK

40 Department of Paediatrics and Paediatric Infectious Diseases, Institute of Child's Health, Sechenov First Moscow State Medical University (Sechenov University), Moscow, Russia

41 Research and Clinical Center for Neuropsychiatry, Moscow, Russia

*Authors contributed equally to the study: apart from the two joint first authors, who contributed equally, the primary study team members and the last author, authors are listed in alphabetical order.

** Listed at end of the manuscript

Corresponding author:

Daniel Munblit MD, PhD. Division of Care in Long Term Conditions, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United Kingdom

Email: daniel.munblit@kcl.ac.uk

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1. Systematic review search strategy

The COS consensus process was informed by a comprehensive search of Medline, Embase, and the WHO COVID-19 Research Database. The search was limited to English-language publications and protocols. Data from research protocols were extracted from two clinical trials registries, Clinical Trials.gov and the International Clinical Trials Registry Platform.

1.1 Medline search strategy

Database: Ovid MEDLINE(R) ALL

Search Strategy:

1 exp child/

2 exp infant/

3 exp adolescent/

4 exp pediatrics/

5 "toddler*".ab,ti.

6 "paediatri*".ab,ti.

7 "pediatri*".ab,ti.

8 baby.ab,ti.

9 babies.ab,ti.

10 "neonat*".ab,ti.

11 "newborn*".ab,ti.

12 "new born*".ab,ti.

13 "girl*".ab,ti.

14 "boy*".ab,ti.

15 (kindergarten* or preschool* or school*).ab,ti.

16 "teen*".ab,ti.

17 "youth*".ab,ti.

18 "juvenile*".ab,ti.

19 (young adj (person or people)).ab,ti.

20 "minors*".ab,ti.

21 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20

22 (chronic adj3 (covid* or corona or coronavirus*)).ab,ti.

23 (persist* adj3 (covid* or corona or coronavirus*)).ab,ti.

24 (sustain* adj3 (covid* or corona or coronavirus*)).ab,ti.

25 (history adj3 (covid* or corona or coronavirus*)).ab,ti.

26 ((postcovid* or post covid* or postcoronavirus* or postcorona* virus* or post coronavirus* or post corona* virus* or postcoronovirus* or postcorono* virus* or post coronovirus* or post corono* virus* or postcoronavirinae* or postcorona* virinae* or post coronavirinae* or post corona* virinae* or postCov or post Cov or postsars* or post sars* or "post severe acute respiratory syndrome*" or postncov* or post ncov* or posthcov* or post hcov*) adj3 (syndrome* or disorder* or illness* or sickness* or disease* or condition* or symptom* or sign* or prognos* or followup* or "follow up*" or feature* or comorbid* or "co morbid*" or multimorbid* or "multi morbid*" or survivor* or survival* or risk* or care* or convalescen* or recuperat* or aftercare* or ambulatory* or outpatient* or "out patient*")).ab,ti.

27 ("long sars*" or "post acute COVID*" or "Covid* syndrome" or "post-acute sequelae SARS-CoV-2 infection").ab,ti.

28 ((longhaul* or long haul* or long-haul*) adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

29 ((long term or long-term or longterm) adj3 effect* adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

30 (sequela* adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

31 (persistent symptoms or persistant symptoms or persisting symptoms or longlasting symptoms or long lasting symptoms or long term symptoms or long-term symptoms or longterm symptoms).mp. and (Betacoronavirus* or Corona Virus* or Coronavirus* or Coronovirus* or CoV or CoV2 or COVID or COVID19 or COVID-19 or HCoV-19 or nCoV or SARS CoV 2 or SARS2 or SARSCoV or SARS-CoV or SARS-CoV-2 or 2019nCoV).ab,ti.

32 (long* adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

33 ((post acute or post-acute or postacute) adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

34 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33

35 21 and 34

1.2 Embase search strategy

Database: Embase Classic+Embase

Search Strategy:

1 exp child/

2 exp infant/

3 exp adolescent/

4 exp pediatrics/

5 "toddler*".ab,ti.

6 "paediatri*".ab,ti.

7 "pediatri*".ab,ti.

8 baby.ab,ti.

9 babies.ab,ti.

10 "neonat*".ab,ti.

11 "newborn*".ab,ti.

12 "new born*".ab,ti.

13 "girl*".ab,ti.

14 "boy*".ab,ti.

15 (kindergarten* or preschool* or school*).ab,ti.

16 "teen*".ab,ti.

17 "youth*".ab,ti.

18 "juvenile*".ab,ti.

19 (young adj (person or people)).ab,ti.

20 "minors*".ab,ti.

21 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20

22 (chronic adj3 (covid* or corona or coronavirus*)).ab,ti.

23 (persist* adj3 (covid* or corona or coronavirus*)).ab,ti.

24 (sustain* adj3 (covid* or corona or coronavirus*)).ab,ti.

25 (history adj3 (covid* or corona or coronavirus*)).ab,ti.

26 ((postcovid* or post covid* or postcoronavirus* or postcorona* virus* or post coronavirus* or post corona* virus* or postcoronovirus* or postcorono* virus* or post coronovirus* or post corono* virus* or postcoronavirinae* or postcorona* virinae* or post coronavirinae* or post corona* virinae* or postCov or post Cov or postsars* or post sars* or "post severe acute respiratory syndrome*" or postncov* or post ncov* or posthcov* or post hcov*) adj3 (syndrome* or disorder* or illness* or sickness* or disease* or condition* or symptom* or sign* or prognos* or followup* or "follow up*" or feature* or comorbid* or "co morbid*" or multimorbid* or "multi morbid*" or survivor* or survival* or risk* or care* or convalescen* or recuperat* or aftercare* or ambulatory* or outpatient* or "out patient*")).ab,ti.

27 ("long sars*" or "post acute COVID*" or "Covid* syndrome" or "post-acute sequelae SARS-CoV-2 infection").ab,ti.

28 ((longhaul* or long haul* or long-haul*) adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

29 ((long term or long-term or longterm) adj3 effect* adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

30 (sequela* adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

31 (persistent symptoms or persistant symptoms or persisting symptoms or longlasting symptoms or long lasting symptoms or long term symptoms or long-term symptoms or longterm symptoms).mp. and (Betacoronavirus* or Corona Virus* or Coronavirus* or Coronovirus* or CoV or CoV2 or COVID or COVID19 or COVID-19 or HCoV-19 or nCoV or SARS CoV 2 or SARS2 or SARSCoV or SARS-CoV or SARS-CoV-2 or 2019nCoV).ab,ti.

32 (long* adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

33 ((post acute or post-acute or postacute) adj3 (covid* or ncov* or novel coronavirus or novel betacoronavirus or sars-ncov-2 or sars-cov-2)).ab,ti.

34 exp long COVID/

35 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34

36 21 and 35

1.3 The WHO COVID-19 Research Database search strategy

(tw:("long covid"~3 OR "long-covid" OR "long covid" OR "post-covid"~3 OR "post covid" OR "post-covid" OR "long term" OR "post acute" OR "post-acute" OR "chronic covid"~3 OR "post discharge" OR postdischarge* OR "post-discharge" OR "after hospital" OR "persistent symptom" OR "persistent symptoms" OR "after hospitalisation" OR "after hospitalization" OR "after sars" OR "after covid" OR "long haul" OR "persistant effects" OR "persistent effects" OR "prolonged symptoms" OR "prolonged symptom")) AND (tw:(mh:("Child" OR "Maternal-Child Health Centers" OR "Child Nutrition Sciences" OR "Child Health Services" OR "Child Nutritional Physiological Phenomena" OR "Child Nutrition Disorders" OR "Child Mortality" OR "Child Welfare" OR "Child Care" OR "Child Reactive Disorders" OR "Child Guidance" OR "Child Reactive Disorders" OR "Child Behavior Disorders" OR "Child, Orphaned" OR "Child, Institutionalized" OR "Child, Hospitalized" OR "Child Development" OR "Child Behavior" OR "Developmental Disabilities" OR "Mental Disorders Diagnosed in Childhood" OR "Disabled Children" OR "Pediatric Nursing"OR "Pediatric Nursing" OR "Pediatric Assistants" OR "Hospitals, Pediatric" OR "Intensive Care Units, Pediatric" OR "Pediatrics" OR "Pediatricians") OR child OR children OR newborn* OR childhood OR baby OR babies OR toddler OR toddlers OR infants OR infant OR infantile OR "young patient" OR "young patients" OR "young people" OR "paediatricians" OR "Pediatrician" OR "paediatrician" OR "Pediatrics" OR "paediatrics" OR Pediatric OR paediatric))

2. References used for the development of the long list of outcomes.

	1. References from initial systematic review	
	1a. Original studies	
	Document type	**Study title**
1	Preprint	Dumont R, Nehme M, Lorthe E, et al. Persistent symptoms among children and adolescents with and without anti-SARS-CoV-2 antibodies: a population-based serological study in Geneva, Switzerland. medRxiv. Published online January 1, 2021:2021.12.23.21268298. doi:10.1101/2021.12.23.21268298
2	Preprint	Miller F, Nguyen V, Navaratnam AMD, et al. Prevalence of persistent symptoms in children during the COVID-19 pandemic: evidence from a household cohort study in England and Wales. medRxiv. Published online January 1, 2021:2021.05.28.21257602. doi:10.1101/2021.05.28.21257602
3	Preprint	Roessler M, Tesch F, Batram M, et al. Post COVID-19 in children, adolescents, and adults: results of a matched cohort study including more than 150,000 individuals with COVID-19. medRxiv. Published online January 1, 2021:2021.10.21.21265133. doi:10.1101/2021.10.21.21265133
4	Preprint	Knoke L, Schlegtendal A, Maier C, Eitner L, Lücke T, Brinkmann F. More complaints than findings - Long-term pulmonary function in children and adolescents after COVID-19. medRxiv. Published online January 1, 2021:2021.06.22.21259273. doi:10.1101/2021.06.22.21259273
5	Preprint	Sante G Di, Buonsenso D, Rose C De, et al. Immune profile of children with post-acute sequelae of SARS-CoV-2 infection (Long Covid). medRxiv. Published online 2021. doi: 10.1101/2021.05.07.21256539
6	Preprint	Larsen VB, Størdal K, Telle K, Methi F, Magnusson K. A comparison of health care use after severe COVID-19, respiratory syncytial virus, and influenza in children. medRxiv. Published online January 1, 2021:2021.11.22.21266522. doi:10.1101/2021.11.22.21266522
7	Preprint	Heiss R, Wagner A, Tan L, et al. Persisting pulmonary dysfunction in pediatric post-acute Covid-19. medRxiv. Published online January 1, 2022:2022.02.21.22270909. doi:10.1101/2022.02.21.22270909
8	Article	Asadi-Pooya AA, Nemati H, Shahisavandi M, et al. Long COVID in children and adolescents [published correction

		appears in World J Pediatr. 2022 Jul 3;:]. World J Pediatr. 2021;17(5):495-499. doi:10.1007/s12519-021-00457-6
9	Article	Zavala M, Ireland G, Amin-Chowdhury Z, Ramsay ME, Ladhani SN. Acute and Persistent Symptoms in Children With Polymerase Chain Reaction (PCR)-Confirmed Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) Infection Compared With Test-Negative Children in England: Active, Prospective, National Surveillance. Clin Infect Dis. 2022;75(1):e191-e200. doi:10.1093/cid/ciab991
10	Article	Ashkenazi-Hoffnung L, Shmueli E, Ehrlich S, et al. Long COVID in Children: Observations From a Designated Pediatric Clinic. Pediatr Infect Dis J. 2021;40(12):e509-e511. doi:10.1097/INF.0000000000003285
11	Article	María Bergia, Elena Sanchez-Marcos, Blanca Gonzalez-Haba et al. Study of Prevalence and Characteristics of Long Covid in Spanish Children, 14 December 2021, PREPRINT (Version 1) available at Research Square [https://doi.org/10.21203/rs.3.rs-1068678/v1]
12	Article	Cara J Bossley, Ema Kavaliunaite, Katharine Harman et al. Post-Acute COVID-19 Outcomes In Children Requiring Hospitalisation, 12 November 2021, PREPRINT (Version 1) available at Research Square [https://doi.org/10.21203/rs.3.rs-1001103/v1]
13	Article	Brackel CLH, Lap CR, Buddingh EP, et al. Pediatric long-COVID: An overlooked phenomenon?. Pediatr Pulmonol. 2021;56(8):2495-2502. doi:10.1002/ppul.25521
14	Article	Buonsenso D, Munblit D, De Rose C, et al. Preliminary evidence on long COVID in children. Acta Paediatr. 2021;110(7):2208-2211. doi:10.1111/apa.15870
15	Article	Roge I, Smane L, Kivite-Urtane A, et al. Comparison of Persistent Symptoms After COVID-19 and Other Non-SARS-CoV-2 Infections in Children. Front Pediatr. 2021;9:752385. Published 2021 Oct 29. doi:10.3389/fped.2021.752385
16	Article	Radtke T, Ulyte A, Puhan MA, Kriemler S. Long-term Symptoms After SARS-CoV-2 Infection in Children and Adolescents [published online ahead of print, 2021 Jul 15]. JAMA. 2021;326(9):869-871. doi:10.1001/jama.2021.11880
17	Article	Osmanov IM, Spiridonova E, Bobkova P, et al. Risk factors for post-COVID-19 condition in previously hospitalised children using the ISARIC Global follow-up protocol: a prospective cohort study. Eur Respir J. 2022;59(2):2101341. Published 2022 Feb 3. doi:10.1183/13993003.01341-2021
18	Article	Molteni E, Sudre CH, Canas LS, et al. Illness duration and symptom profile in symptomatic UK school-aged children tested for SARS-CoV-2 [published correction appears in Lancet Child Adolesc Health. 2021 Aug 31;:]. Lancet Child Adolesc Health. 2021;5(10):708-718. doi:10.1016/S2352-4642(21)00198-X

19	Article	Erol N, Alpinar A, Erol C, Sari E, Alkan K. Intriguing new faces of Covid-19: persisting clinical symptoms and cardiac effects in children. Cardiol Young. 2022;32(7):1085-1091. doi:10.1017/S1047951121003693
20	Article	Fink TT, Marques HHS, Gualano B, et al. Persistent symptoms and decreased health-related quality of life after symptomatic pediatric COVID-19: A prospective study in a Latin American tertiary hospital [published correction appears in Clinics (Sao Paulo). 2022 Mar 3;77:100024]. *Clinics (Sao Paulo)*. 2021;76:e3511. Published 2021 Nov 26. doi:10.6061/clinics/2021/e3511
21	Article	Lars Christian Lund, Jesper Hallas, Henrik Nielsen et al. Post-acute effects of SARS-CoV-2 infection in individuals not requiring hospital admission: a Danish population-based cohort study. Lancet Infect Dis 2021; 21: 1373–82. Published Online May 10, 2021. doi: 10.1016/S1473-3099(21)00211-5
22	Article	Leftin Dobkin SC, Collaco JM, McGrath-Morrow SA. Protracted respiratory findings in children post-SARS-CoV-2 infection. Pediatr Pulmonol. 2021;56(12):3682-3687. doi:10.1002/ppul.25671
23	Article	Guemes-Villahoz N, Burgos-Blasco B, Perez-Garcia P, et al. Retinal and peripapillary vessel density increase in recovered COVID-19 children by optical coherence tomography angiography. J AAPOS. 2021;25(6):325.e1-325.e6. doi:10.1016/j.jaapos.2021.06.004
24	Article	Clavenna A, Francesco CD, Maio LD, et al. Risk of Sequelae of COVID-19 in Children Cared for by Primary Care Pediatricians. Indian Pediatr. 2022;59(1):87-88. doi:10.1007/s13312-022-2427-3
25	Article	Matteudi T, Luciani L, Fabre A, et al. Clinical characteristics of paediatric COVID-19 patients followed for up to 13 months. Acta Paediatr. 2021;110(12):3331-3333. doi:10.1111/apa.16071
26	Article	Say D, Crawford N, McNab S, Wurzel D, Steer A, Tosif S. Post-acute COVID-19 outcomes in children with mild and asymptomatic disease. Lancet Child Adolesc Health. 2021;5(6):e22-e23. doi:10.1016/S2352-4642(21)00124-3
27	Article	Smane L, Stars I, Pucuka Z, Roge I, Pavare J. Persistent clinical features in paediatric patients after SARS-CoV-2 virological recovery: a retrospective population-based cohort study from a single centre in Latvia. BMJ Paediatr Open. 2020;4(1):e000905. Published 2020 Dec 29. doi:10.1136/bmjpo-2020-000905
28	Article	Zhang J, Xu J, Zhou S, et al. The characteristics of 527 discharged COVID-19 patients undergoing long-term follow-up in China. Int J Infect Dis. 2021;104:685-692. doi:10.1016/j.ijid.2021.01.064
29	Article	Petersen MS, Kristiansen MF, Hanusson KD, et al. Long COVID in the Faroe Islands: A Longitudinal Study Among Nonhospitalized Patients. Clin Infect Dis. 2021;73(11):e4058-e4063. doi:10.1093/cid/ciaa1792
30	Article	Borch L, Holm M, Knudsen M, Ellermann-Eriksen S, Hagstroem S. Long COVID symptoms and duration in SARS-CoV-2 positive children - a nationwide cohort study. Eur J Pediatr. 2022;181(4):1597-1607. doi:10.1007/s00431-021-

		04345-z
31	Article	Stephenson T, Pinto Pereira SM, Shafran R, et al. Physical and mental health 3 months after SARS-CoV-2 infection (long COVID) among adolescents in England (CLoCk): a national matched cohort study. Lancet Child Adolesc Health. 2022;6(4):230-239. doi:10.1016/S2352-4642(22)00022-0
32	Article	Karolina Dolezalova, Jana Tukova, Petr Pohunek. Respiratory Consequences of Pediatric Post-COVID Syndrome: Case Series. Authorea. October 28, 2021. DOI: 10.22541/au.163544403.31818690/v1
33	Article	Sterky E, Olsson-Åkefeldt S, Hertting O, et al. Persistent symptoms in Swedish children after hospitalisation due to COVID-19. Acta Paediatr. 2021;110(9):2578-2580. doi:10.1111/apa.15999
34	Article	Smane L, Roge I, Pucuka Z, Pavare J. Clinical features of pediatric post-acute COVID-19: a descriptive retrospective follow-up study. Ital J Pediatr. 2021;47(1):177. Published 2021 Aug 26. doi:10.1186/s13052-021-01127-z
35	Article	Khodeir MM, Shabana HA, Rasheed Z, et al. COVID-19: Post-recovery long-term symptoms among patients in Saudi Arabia. PLoS One. 2021;16(12):e0260259. Published 2021 Dec 8. doi:10.1371/journal.pone.0260259
36	Article	Denina M, Pruccoli G, Scolfaro C, et al. Sequelae of COVID-19 in Hospitalized Children: A 4-Months Follow-Up. Pediatr Infect Dis J. 2020;39(12):e458-e459. doi:10.1097/INF.0000000000002937
37	Article	Chapagain RH, Adhikari S, Pokharel S, Shrestha SM, Bichha RP. Presenting Clinico-laboratory Characteristics, Hospital Course and Outcomes of Admitted Children with COVID19 in a Tertiary Pediatric Hospital of Nepal. J Nepal Health Res Counc. 2021;19(2):349-354. Published 2021 Sep 6. doi:10.33314/jnhrc.v19i2.3569
38	Article	Smith MP. Estimating total morbidity burden of COVID-19: relative importance of death and disability. J Clin Epidemiol. 2022;142:54-59. doi:10.1016/j.jclinepi.2021.10.018
39	Article	Parisi GF, Diaferio L, Brindisi G, et al. Cross-Sectional Survey on Long Term Sequelae of Pediatric COVID-19 among Italian Pediatricians. Children (Basel). 2021;8(9):769. Published 2021 Aug 31. doi:10.3390/children8090769
40	Article	Hernandez-Romieu AC, Carton TW, Saydah S, et al. Prevalence of Select New Symptoms and Conditions Among Persons Aged Younger Than 20 Years and 20 Years or Older at 31 to 150 Days After Testing Positive or Negative for SARS-CoV-2. JAMA Netw Open. 2022;5(2):e2147053. Published 2022 Feb 1. doi:10.1001/jamanetworkopen.2021.47053
	1b. Clinical trials protocols	

	Trial ID	Study title
1	ChiCTR2000038134	Half-year follow-up of novel coronavirus pneumonia (COVID-19) rehabilitated patients in Chongqing Municipality
2	ChiCTR2000033980	A follow-up study of novel coronavirus pneumonia (COVID-19) patients in Wanzhou District, Chongqing
3	ChiCTR2100043802	Follow up study on health status of rehabilitation patients with novel coronavirus pneumonia (COVID-19)
4	CTRI/2020/11/029026	Assessment of long term respiratory sequelae in children who had infection with COVID 19 virus.
5	CTRI/2021/01/030235	Lung Function Indices Measured by Forced Oscillation Test in Post Covid patients: An Observational Study.
6	ISRCTN34804192	Study of children and young people who may be experiencing long COVID
7	NCT05172011	Understanding the Long-term Impact of COVID on Children and Families
8	CTRI/2020/07/026821	Study of dermatological changes post COVID-19 illness within 3 months of recovery.
9	NCT04479293	Post COVID-19 Functional Status in Egypt
10	NCT04799444	LATE-COVID/LATE-COVID-Kids - Observational Study in Children and Adults (LATE-COVID)
11	ACTRN12620000527965	Neonatal CoVID-19 Study to evaluate the population health impacts of COVID-19 in mothers and their newborn infants cared for in tertiary and non-tertiary hospitals in Australia.
12	NL8926	Clinical features of COVID-19 in Pediatric Patients, long term effects
13	ChiCTR2000032895	Epidemiological, clinical and prognosticated features of novel coronavirus pneumonia (COVID-19) in Zhuhai
14	ChiCTR2000030849	Investigation on psychological status of novel coronavirus pneumonia (COVID-19) rehabilitation patients in Zhengzhou City and research on coping strategies
15	CTRI/2020/06/025588	Clinical profile and outcomes of patients with Corona virus disease 19 (COVID – 19) admitted to a tertiary care hospital in Mumbai.
16	DRKS00024835	"LONG-COVID-19" also in pediatric patients. A pilot study asking if a comprehensive aftercare is necessary for children and young adults after a SARS-CoV-2 infection
17	NCT04741412	Pediatric SARS-CoV-2 Infections: Course of COVID-19, Immune Responses, Complications and Long-term

		Consequences (PEDCOVID-19)
18	NCT05097677	Follow-up of Covid-19 Long Term Sequelae
19	NCT04335773	COVID-19 in Hospitalised Norwegian Children - Risk Factors, Outcomes and Immunology
20	NCT04588363	COVID-19: Pediatric Research Immune Network on SARS-CoV-2 and MIS-C (PRISM)
21	ChiCTR2100048440	Study on the correlation between multi-omics parameters and clinical features, severity and prognosis of COVID-19 patients
22	ChiCTR2000038943	Outcomes of and Prognosis Factors for COVID-19 Patients: an Observational Study
23	CTRI/2020/05/025221	Create registry of Childhood Cancer patients in India with COVID 19 to provide guidelines for prevention and treatment
24	CTRI/2020/11/029058	Cross sectional study to assess the impact of COVID 19 infection on pulmonary function tests in children
25	NCT04270383	Clinical Characteristics and Long-term Prognosis of 2019-nCoV Infection in Children
26	NCT04342702	A Study on the Prospective Cohort Library of COVID-19 in Southeran
27	NCT04359914	Neurocognitive Impairment in Patients With COVID-19 (NCoV)
28	NCT04379089	Neurologic Manifestations of COVID 19 in Children
29	NCT04388436	Post Covid-19 Cardiopulmonary and Immunological Changes (covid-19)
30	NCT04448145	Determinants of SARS-COV2 (COVID-19) Persistence After Convalescence (C-PIC)
31	NCT04448717	COVID-19: Longitudinal Study of Seroprevalence of SARS-CoV-2 Antibodies and Development of Immunity in School Children (CiaoCorona)
32	NCT04449978	TARGet Kids! COVID-19 Study of Children and Families
33	NCT04632719	The MentalPlus® for Assessment and Rehabilitation of Cognitive Function After Remission of the Symptoms of COVID-19 (MP-COVID)
34	NCT04659486	Adolescents With COVID-19/MIS-C at HCFMUSP

35	NCT04686734	Long-term Effects of COVID-19 in Adolescents (LoTECA)
36	NCT04786353	Long COVID Kids DK - Investigating Long-term Covid-19
37	NCT04830852	Pediatric COVID Outcomes Study (PECOS)
38	NCT05059080	A Six-Month Follow-Up Study of Participants With Coronavirus Disease 2019 (COVID-19) Previously Enrolled in a RO7496998 (AT-527) Study (MEADOWSPRING)
39	NCT05074953	Post-COVID-19 Monitoring in Routine Health Insurance Data (POINTED)
40	NCT04346212	Oropharyngeal Dysphagia in Patients With COVID-19
41	NCT04410107	Lung Function, Exercise Capacity and Health-Related Quality of Life After Severe COVID-19
42	NCT04457505	One Year Follow-ups of Patients Admitted to Spanish Intensive Care Units Due to COVID-19
43	NCT04523051	Rehabilitation After Admission in Intensive Care Unit for COVID-19 (RECOVER)
44	NCT04702945	Canadian COVID-19 Emergency Department Registry (CCEDRRN)
45	NCT04724850	Evolution of Coronavirus Disease 2019 (COVID-19) Patients in Extremadura (COVIXTREM)
46	NCT04764773	Persistence of Symptoms After Improvement of Acute COVID-19 (COVID-19)
47	NCT04846010	Recovering Damaged Cells for Sequelae Caused by COVID-19, SARS-CoV-2 (sequelae)
48	NCT04900961	CISCO-21 Prevent and Treat Long COVID-19. (CISCO-21)
49	NCT05004246	Longitudinal Changes in Characteristics of COVID-19 Survivors and Their Long-term Follow-up Study
50	NCT05130736	Rehabilitation Robot in Patients With Post-Coronavirus Disease (COVID-19) Fatigue Syndrome

1c. Additional

	Document type	**Title**
1	Case report form (CRF)	ISARIC COVID-19 & other acute respiratory infections Initial Follow Up Survey for children and young people (less than 18 years of age) v.1.3 (18 October 2021)

	2. References from additional systematic review	
	2a. Original studies	
	Document type	**Study title**
1	Preprint	Britton, P. N., Burrell, R., Chapman, E., Boyle, J., Alexander, S., Belessis, Y., Dalby-Payne, J., Knight, K., Lau, C., McMullan, B., Milne, B., Paull, M., Nguyen, J., Selvadurai, H., Dale, R., & Baillie, A. (2023). Post COVID-19 conditions in Children and Adolescents at 3 months following a Delta outbreak in Australia: a cohort study. MedRxiv, 2023.03.14.23287239.doi.org/10.1101/2023.03.14.23287239
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96	Article	Lorman V, Rao S, Jhaveri R, et al. Understanding pediatric long COVID using a tree-based scan statistic approach: an EHR-based cohort study from the RECOVER Program. JAMIA Open. 2023;6(1):ooad016. Published 2023 Mar 14. doi:10.1093/jamiaopen/ooad016
97	Article	Sabatino J, Di Chiara C, Di Candia A, et al. Mid- and Long-Term Atrio-Ventricular Functional Changes in Children after Recovery from COVID-19. J Clin Med. 2022;12(1):186. Published 2022 Dec 26. doi:10.3390/jcm12010186
98	Article	Buonsenso D, Martino L, Morello R, De Rose C, Valentini P. Chronic Olfactory Dysfunction in Children with Long COVID: A Retrospective Study. Children (Basel). 2022;9(8):1251. Published 2022 Aug 19. doi:10.3390/children9081251
99	Article	Erol N, Alpinar A, Erol C, Sari E, Alkan K. Intriguing new faces of Covid-19: persisting clinical symptoms and cardiac effects in children. Cardiol Young. 2022;32(7):1085-1091. doi:10.1017/S1047951121003693

2b. Clinical trials protocols

	Trial ID	**Study title**
1	NCT05722717	Genetic Risk Factors for Multi-system Inflammatory Syndrome in Children and Pediatric Post COVID Condition (GRIP)
2	NCT05793723	Long-term Respiratory Complications in Infants With Perinatal COVID-19
3	NCT05638724	Munich Long COVID Registry Study for Children, Adolescents and Adults (MLC-R)
4	NCT05633472	The Roles of Vitamin D and Microbiome in Children With Post-acute COVID-19 Syndromes (PACS) and Long COVID
5	NCT05817006	Research of the Long-COVID-19 Syndrome in the Children
6	NCT05216549	Water and Land-based Exercise for Children With Post COVID-19 Condition
7	NCT05745974	Post COVID-19 Complications in Children
8	NCT05729217	Long COVID Symptoms in SARS-CoV-2-positive Children in China
9	NCT05799508	Consequences of COVID-19 Infection for Child Health and Wellbeing: Protocol for a Prospective, Observational, Longitudinal Study in Children

10	NCT05582512	Clinical Characteristics and Long Term Impact on Pediatric COVID-19 in Taiwan
11	NCT05747534	AT1001 for the Treatment of Long COVID
12	NCT05705154	Connecting Breath and Mind for CYP With Long COVID
13	NCT05566392	Longterm Influence of Pediatric Long COVID Syndrome
14	NCT05445531	Low-field Magnetic Resonance Imaging in Pediatric Post Covid-19
15	DRKS00029354	"coverCHILD Telemonitoring"
16	DRKS00028742	Post COVID Kids Bavaria (PoCO) study on long-term effects of coronavirus infections in children and adolescents in Bavaria: detection and early treatment of sequelae
17	CTRI/2022/07/043846	A study to understand the changes in lung after corona virus infection in children undergoing heart surgery, using ultrasound examination.
18	DRKS00028523	Long COVID in Children
19	ISRCTN99910769	The impact of COVID-19 infection in newborns or in pregnancy on children's development at 18-24 months
20	DRKS00028963	Telemedicine-assisted rehabilitation after Covid-19 in children
21	TCTR20220510005	The study to follow-up and provide holistic healthcare in children and adolescents (aged 6 months-18 years) following the COVID-19 infection
22	DRKS00028539	Determination of aerosol particle number and aerosol particle size distribution in exhaled air of healthy children as well as children with respiratory tract infections, especially also children with and after SARS-CoV2 infection/Covid-19.
	Total number of references - 212	

3. THE LONG LIST OF OUTCOMES USED IN POST-COVID-19 CONDITION STUDIES.

OUTCOME DOMAIN (PER COMET TAXONOMY*)	OUTCOME	N = 1097
1. MORTALITY/SURVIVAL	DEAD AFTER DISCHARGE	
1. MORTALITY/SURVIVAL	MORBIDITY	

1. Mortality/survival	Mortality	3
2. Blood and lymphatic system outcomes	Abnormal lab result (D-dimer)	
2. Blood and lymphatic system outcomes	Coagulation Abnormality	
2. Blood and lymphatic system outcomes	Coagulopathy after COVID-19	
2. Blood and lymphatic system outcomes	COVID-19-associated thrombosis	
2. Blood and lymphatic system outcomes	Disseminated intravascular coagulation	
2. Blood and lymphatic system outcomes	Enlarged lymph nodes	
2. Blood and lymphatic system outcomes	Blood markers correlation with FOT indices	
2. Blood and lymphatic system outcomes	Hemoglobin	
2. Blood and lymphatic system outcomes	Increased/Decreased/Normal result	
2. Blood and lymphatic system outcomes	Laboratory assessment	
2. Blood and lymphatic system outcomes	Laboratory changes	
2. Blood and lymphatic system outcomes	Leucocytes <4 × 109/L	
2. Blood and lymphatic system outcomes	Leukocytes	
2. Blood and lymphatic system outcomes	Low neutrophils	

2. Blood and lymphatic system outcomes	Lymphadenopathy	
2. Blood and lymphatic system outcomes	Lymphocytes <1·2 × 109/L	
2. Blood and lymphatic system outcomes	Negative D-dimers	
2. Blood and lymphatic system outcomes	PBMC	
2. Blood and lymphatic system outcomes	Swollen lymph glands	
2. Blood and lymphatic system outcomes	Thrombocytes	20
3. Cardiac outcomes	Abnormal findings	
3. Cardiac outcomes	Blood pressure	
3. Cardiac outcomes	Cardiac function	
3. Cardiac outcomes	Cardiac function and ejection fraction changes	
3. Cardiac outcomes	Cardiac palpitations	
3. Cardiac outcomes	Cardial abnormalities	
3. Cardiac outcomes	Cardiovascular complications	
3. Cardiac outcomes	Cardiovascular symptoms	
3. Cardiac outcomes	Cardiovascular system	
3. Cardiac outcomes	Carditis due to viruses	
3. Cardiac outcomes	Coronary Artery Abnormalities	
3. Cardiac outcomes	Damage to the heart	
3. Cardiac outcomes	Difference in relative wall thickness	
3. Cardiac outcomes	Difference in tricuspid annular plane systolic excursion values	
3. Cardiac outcomes	Elevated pulse	
3. Cardiac outcomes	Heart failure	

3. Cardiac outcomes	Heart murmurs	
3. Cardiac outcomes	Heart pounding or racing	
3. Cardiac outcomes	Heart rate abnormality	
3. Cardiac outcomes	Heart rhythm disturbances	
3. Cardiac outcomes	Highest heart rate	
3. Cardiac outcomes	Hypotension	
3. Cardiac outcomes	Intervals	
3. Cardiac outcomes	Left ventricular posterior wall diameter	
3. Cardiac outcomes	Lowest heart rate	
3. Cardiac outcomes	Maximal pulse was lower than the age-specific mean	
3. Cardiac outcomes	Mild lateral wall thickening	
3. Cardiac outcomes	Myocardial infarction	
3. Cardiac outcomes	Myocarditis	
3. Cardiac outcomes	Myocarditis after COVID-19	
3. Cardiac outcomes	Normal left ventricular ejection fraction and the absence of pulmonary hypertension	
3. Cardiac outcomes	Orthostatic intolerance	
3. Cardiac outcomes	Other cardiac arrhythmias	
3. Cardiac outcomes	Pains in heart or chest	
3. Cardiac outcomes	Palpitation	
3. Cardiac outcomes	Palpitation±chest pain	
3. Cardiac outcomes	Palpitations	
3. Cardiac outcomes	Palpitations (heart racing)	
3. Cardiac outcomes	Palpitations / tachycardia	
3. Cardiac outcomes	Pericarditis	
3. Cardiac outcomes	Pulmonary Hypertension	
3. Cardiac outcomes	Rhythms	

3. Cardiac outcomes	Right ventricular systolic function (in patients w/biventricular physiology)	
3. Cardiac outcomes	Severe post-COVID-19 complications	
3. Cardiac outcomes	Significant tachycardia for age	
3. Cardiac outcomes	Tachycardia	
3. Cardiac outcomes	Tachycardia/Palpitation	
3. Cardiac outcomes	Transiently elevated troponin levels	
3. Cardiac outcomes	Tricuspid regurgitation severity	
3. Cardiac outcomes	Type(s) and number of pulmonary hypertension targeted therapies	
3. Cardiac outcomes	Variations in heart rate	
3. Cardiac outcomes	Variations in heart rate (tachycardia or bradycardia)	
3. Cardiac outcomes	Velocity	
3. Cardiac outcomes	Voltages	54
4. Congenital, familial and genetic outcomes	Genetic predisposition	
4. Congenital, familial and genetic outcomes	Genetic predisposition in children to COVID-19 late complications	
4. Congenital, familial and genetic outcomes	Human and viral genetic markers	3
5. Endocrine outcomes	Type 1 Diabetes after COVID-19	
5. Endocrine outcomes	Type 2 Diabetes after COVID-19	
5. Endocrine outcomes	Type 2 diabetes	3
6. Ear and labyrinth outcomes	Change in hearing/ringing in ears	
6. Ear and labyrinth outcomes	Ear fullness	
6. Ear and labyrinth outcomes	Ear pain	
6. Ear and labyrinth outcomes	Ear pain (otalgia)	
6. Ear and labyrinth outcomes	Ear symptoms	

6. Ear and labyrinth outcomes	Earache or ringing in ears	
6. Ear and labyrinth outcomes	Hearing deficit	
6. Ear and labyrinth outcomes	Hearing loss/tinnitus	
6. Ear and labyrinth outcomes	Hearing problems	
6. Ear and labyrinth outcomes	Loss of hear	
6. Ear and labyrinth outcomes	Ringing in ears (tinnitus)	
6. Ear and labyrinth outcomes	Tinnitus	
6. Ear and labyrinth outcomes	Vertigo	
6. Ear and labyrinth outcomes	Vertigo/World Spinning	14
7. Eye outcomes	Avoiding bright light (photophobia)	
7. Eye outcomes	Bilateral conjunctivitis	
7. Eye outcomes	Bilateral conjunctivitis (If yes, purulent/non-purulent)	
7. Eye outcomes	Blurred vision	
7. Eye outcomes	Changes in vision	
7. Eye outcomes	Conjunctivitis	
7. Eye outcomes	Dry eyes	
7. Eye outcomes	Eye pain	
7. Eye outcomes	Eye soreness	
7. Eye outcomes	Eye-soreness/discomfort (light sensitivity/excessive tears/pink/red eye)	
7. Eye outcomes	Flashes of light (photopsia)	
7. Eye outcomes	Foveal avascular zone: Area	
7. Eye outcomes	Foveal avascular zone: Circularity	
7. Eye outcomes	Foveal avascular zone: Perimeter	
7. Eye outcomes	High flux index	
7. Eye outcomes	Increase in macular perfusion density	
7. Eye outcomes	Increase in retinal vessel density	

7. Eye outcomes	Inferior flux index	
7. Eye outcomes	Inferior peripapillary perfusion density	
7. Eye outcomes	Macular perfusion density: Central	
7. Eye outcomes	Macular perfusion density: Inner ring	
7. Eye outcomes	Macular perfusion density: Outer ring	
7. Eye outcomes	Nasal flux index	
7. Eye outcomes	Nasal peripapillary perfusion density	
7. Eye outcomes	Ocular findings	
7. Eye outcomes	Photophobia	
7. Eye outcomes	Problems seeing/ blurred vision	
7. Eye outcomes	Problems seeing/blurred vision	
7. Eye outcomes	Red eye syndrome	
7. Eye outcomes	Superior flux index	
7. Eye outcomes	Superior peripapillary perfusion density	
7. Eye outcomes	Temporal peripapillary perfusion density	
7. Eye outcomes	Unusual eye-soreness	
7. Eye outcomes	Vessel density: Central	
7. Eye outcomes	Vessel density: Full area	
7. Eye outcomes	Vessel density: Inner ring	
7. Eye outcomes	Vessel density: Outer ring	
7. Eye outcomes	Visual acuity/hearing problems	
7. Eye outcomes	Visual blurring	
7. Eye outcomes	Visual deficit	
7. Eye outcomes	Visual disturbances	41
8. Gastrointestinal outcomes	Abdominal discomfort	
8. Gastrointestinal outcomes	Abdominal pain	

8. Gastrointestinal outcomes	Abdominal pain/stomach ache *(mild and tolerable-moderate-severe and incapacitating)*	
8. Gastrointestinal outcomes	Bloating	
8. Gastrointestinal outcomes	Bowel incontinence	
8. Gastrointestinal outcomes	Change in bowel habits	
8. Gastrointestinal outcomes	Colitis/diarrhoea	
8. Gastrointestinal outcomes	Constipation	
8. Gastrointestinal outcomes	Diarrhea	
8. Gastrointestinal outcomes	Diarrhoea/Vomiting	
8. Gastrointestinal outcomes	Dysphagia	
8. Gastrointestinal outcomes	Feces	
8. Gastrointestinal outcomes	Feeling nauseous	
8. Gastrointestinal outcomes	Flatulence	
8. Gastrointestinal outcomes	Gastrointestinal disorders	
8. Gastrointestinal outcomes	Gastrointestinal symptoms	
8. Gastrointestinal outcomes	Heartburn	
8. Gastrointestinal outcomes	Intussusception	
8. Gastrointestinal outcomes	Jaundice	
8. Gastrointestinal outcomes	Loose stool	
8. Gastrointestinal outcomes	Nausea	
8. Gastrointestinal outcomes	Nausea or upset stomach	
8. Gastrointestinal outcomes	Pain abdomen	
8. Gastrointestinal outcomes	Patterns of intestinal microbiome	
8. Gastrointestinal outcomes	Skipping meals	
8. Gastrointestinal outcomes	Stomach ache	
8. Gastrointestinal outcomes	Stomach pain	
8. Gastrointestinal outcomes	Stomach pains/cramps	

8. Gastrointestinal outcomes	Stomach/ abdominal pain	
8. Gastrointestinal outcomes	Stomach/abdominal pain	
8. Gastrointestinal outcomes	Stomachache	
8. Gastrointestinal outcomes	Tenderness in abdomen	
8. Gastrointestinal outcomes	Tummy ache	
8. Gastrointestinal outcomes	Unusual abdominal pain	
8. Gastrointestinal outcomes	Vomiting	
8. Gastrointestinal outcomes	Vomiting and abdominal pain	
8. Gastrointestinal outcomes	Vomiting/nausea	
8. Gastrointestinal outcomes	Vomits	38
9. General outcomes	Abnormal body movements	
9. General outcomes	Abnormal findings	
9. General outcomes	Acute pain	
9. General outcomes	Additional biomarker analysis	
9. General outcomes	Any chronic medical illness/problem after COVID-19	
9. General outcomes	Assessment of rehabilitation	
9. General outcomes	Asthenia	
9. General outcomes	Body aches	
9. General outcomes	Body pain	
9. General outcomes	Cause of recent fever (Covid-19, Other respiratory infection (cough/cold/sore throat), TB, Stomach infection (diarrhea/vomiting), Urinary infection, Other, Unknown, Prefer not to say)	
9. General outcomes	Change in smell	
9. General outcomes	Change in taste	
9. General outcomes	Chest and backache	
9. General outcomes	Chest tightness	
9. General outcomes	Child Symptoms	

9. General outcomes	Chills	
9. General outcomes	Chills or shivers (feel too cold)	
9. General outcomes	Chronic fatigue	
9. General outcomes	Chronic fatigue syndrome	
9. General outcomes	Chronic fatigue syndrome-type symptoms	
9. General outcomes	Clinical outcome	
9. General outcomes	Complete remission	
9. General outcomes	Connectedness	
9. General outcomes	Covid-19 associated secondary diseases predictors	
9. General outcomes	Damage to other vital systems which caused death	
9. General outcomes	Daytime sleepiness	
9. General outcomes	Decreased appetite	
9. General outcomes	Demographics	
9. General outcomes	Diagnoses	
9. General outcomes	Difficulty falling asleep	
9. General outcomes	Difficulty sleeping	
9. General outcomes	Difficulty swallowing	
9. General outcomes	Disability-adjusted life years (DALY) lost per COVID-19 case	
9. General outcomes	Distance walked in meters and % predicted	
9. General outcomes	Dry mouth	
9. General outcomes	Easy fatigability	
9. General outcomes	Excess sweating	
9. General outcomes	Excessive fatigue	
9. General outcomes	Excessive night sweat	
9. General outcomes	Excessive sleepiness	
9. General outcomes	Exhaustion	

9. General outcomes	Factors related to the severity	
9. General outcomes	Fatigue	
9. General outcomes	Fatigue after COVID-19 (less/the same/more)	
9. General outcomes	Fatigue related disorders	
9. General outcomes	Fatigue/Low energy	
9. General outcomes	Fatigue/tiredness	
9. General outcomes	Feel sleepy or drowsy	
9. General outcomes	Feel weak	
9. General outcomes	Feeling relaxed	
9. General outcomes	Fever	
9. General outcomes	Fever (within the last 7 d, 1-2 wks, >2-4 wks, >1-2 mo, >2-3 mo, >3-6 mo since discharge)	
9. General outcomes	Fever >38.5°C	
9. General outcomes	General symptoms	
9. General outcomes	Head circumference	
9. General outcomes	Health	
9. General outcomes	Hot or cold spells	
9. General outcomes	Hypersomnia	
9. General outcomes	Hypothermia	
9. General outcomes	Illness resolution	
9. General outcomes	Imaging finding	
9. General outcomes	Increased daytime fatigue	
9. General outcomes	Increased fatigue	
9. General outcomes	Increased need for sleep	
9. General outcomes	Increased sleep need	
9. General outcomes	Insomnia	
9. General outcomes	Insomnia (hard to fall asleep, hard to stay asleep)	

9. General outcomes	Lab results out of the normal ranges	
9. General outcomes	Laboratory parameters	
9. General outcomes	Lack of a good night's sleep	
9. General outcomes	Lack of energy	
9. General outcomes	Length	
9. General outcomes	Length of COVID-19 sequelae	
9. General outcomes	Long COVID symptoms	
9. General outcomes	Long COVID symptoms	
9. General outcomes	Long term outcome (prevalence and risk factors of long-lasting complication)	
9. General outcomes	Long-term consequences of a COVID19 disease (Long-COVID)	
9. General outcomes	Long-term outcomes of COVID-19 in patients diagnosed with COVID-19	
9. General outcomes	A lump in your throat	
9. General outcomes	Malaise	
9. General outcomes	Malaise/fatigue/exhaustion	
9. General outcomes	Medical sequelae	
9. General outcomes	Metallic taste	
9. General outcomes	MIS	
9. General outcomes	Multiple organ failure	
9. General outcomes	Need of hospital admission	
9. General outcomes	Need to rest more	
9. General outcomes	Newly diagnosed diseases	
9. General outcomes	Night sweating	
9. General outcomes	Nonspecific pain	
9. General outcomes	Not elsewhere classified	
9. General outcomes	Oedema	
9. General outcomes	Organ damage	

9. General outcomes	Organ function	
9. General outcomes	Organ function damage	
9. General outcomes	Organic secondary outcomes	
9. General outcomes	Other condition after COVID-19	
9. General outcomes	Other important symptoms	
9. General outcomes	Other New Symptoms	
9. General outcomes	Other symptoms	
9. General outcomes	Other symptoms (if yes, duration)	
9. General outcomes	Other symptoms or complain	
9. General outcomes	Pain	
9. General outcomes	Pain, not elsewhere classified	
9. General outcomes	Persistent fatique	
9. General outcomes	Poor sleep quality	
9. General outcomes	Population based data on spectrum and recovery from COVID-19 symptoms	
9. General outcomes	Post-COVID	
9. General outcomes	Postviral fatigue	
9. General outcomes	Predictors of recovery	
9. General outcomes	Primary symptoms	
9. General outcomes	Problem in second month	
9. General outcomes	Problem in third month	
9. General outcomes	Problem within 1 month	
9. General outcomes	Problems swallowing or chewing	
9. General outcomes	Problems with handwriting	
9. General outcomes	Radiological assessment	
9. General outcomes	Radiological parameters	
9. General outcomes	Recovery	

9. General outcomes	Recurrent pain in the body	
9. General outcomes	Restless sleep with interruptions	
9. General outcomes	Risk factors for medical sequelae	
9. General outcomes	Risk of late complications	
9. General outcomes	Severity of symproms	
9. General outcomes	Shock	
9. General outcomes	Shock / Toxic shock syndrome after COVID-19	
9. General outcomes	Sleep difficulty	
9. General outcomes	Sleep difficulty (mild and tolerable-moderate-sever and incapacitating)	
9. General outcomes	Sleep disorders	
9. General outcomes	Sleep disturbance	
9. General outcomes	Sleep Disturbance and quality	
9. General outcomes	Sleep disturbances	
9. General outcomes	Sleep that is restless or disturbed	
9. General outcomes	Sleeping	
9. General outcomes	Sleeping disorders	
9. General outcomes	Some/lots of pain/discomfort	
9. General outcomes	Somnolence	
9. General outcomes	Speech difficulty	
9. General outcomes	Splenomegaly	
9. General outcomes	Symptoms during and after Covid-19 infection	
9. General outcomes	Temperature	
9. General outcomes	The risk of late complications	
9. General outcomes	Tiredness	
9. General outcomes	Tiredness	
9. General outcomes	Tiredness after sleep	

9. General outcomes	Total Difficulties	
9. General outcomes	Voice changes	
9. General outcomes	Wake up at night	
9. General outcomes	Wake up tired	
9. General outcomes	Weakness	150
10. Hepatobiliary outcomes	Ascites	
10. Hepatobiliary outcomes	Hepatomegaly	
10. Hepatobiliary outcomes	Hepatomegaly and splenomegaly	
10. Hepatobiliary outcomes	Liver function abnormality	
10. Hepatobiliary outcomes	Liver/Metabolic function	5
11. Immune system outcomes	Antibody determinations	
11. Immune system outcomes	CD4+ and CD8+ T cell levels in central memory	
11. Immune system outcomes	CD4+ and CD8+ T cell levels in effector memory	
11. Immune system outcomes	Copies of SARS-CoV-2	
11. Immune system outcomes	Duration of fever	
11. Immune system outcomes	Elevated levels of IL6 and IL1B in serum	
11. Immune system outcomes	FOT indices correlation	
11. Immune system outcomes	Habit to evaluate the antibody	
11. Immune system outcomes	Hemophagocytosis syndrome	
11. Immune system outcomes	High level of IgM	
11. Immune system outcomes	High levels of IgD-CD27+ memory	
11. Immune system outcomes	High levels of plasmablasts	
11. Immune system outcomes	IgA, IgG, IgM, RBD, S1, S2, N-protein	
11. Immune system outcomes	IgG	
11. Immune system outcomes	IgM	
11. Immune system outcomes	IGM and IGG level and if there is immunological changes	

11. Immune system outcomes	Immune system	
11. Immune system outcomes	Immunological markers	
11. Immune system outcomes	Immunological panel	
11. Immune system outcomes	Kawasaki disease after COVID-19	
11. Immune system outcomes	Kawasakis disease	
11. Immune system outcomes	Levels of antibodies	
11. Immune system outcomes	Low grade fever	
11. Immune system outcomes	Low-grade fever	
11. Immune system outcomes	Lower level of IgM+ CD27-CD38dim B-cell subsets	
11. Immune system outcomes	Lower level of naïve and unswitched IgM+ IgD+ B-cell subsets (cf. to healed children)	
11. Immune system outcomes	MIS-C after COVID-19	
11. Immune system outcomes	Multisystem inflammatory syndrome in children (MIS-C)	
11. Immune system outcomes	Neutralizing antibody	
11. Immune system outcomes	Neutralizing antibody of SARS-CoV-2	
11. Immune system outcomes	Non-neutralizing antibodies	
11. Immune system outcomes	Nucleocapsid antibody	
11. Immune system outcomes	Occasional fever	
11. Immune system outcomes	Persistent fever	
11. Immune system outcomes	PIMS	
11. Immune system outcomes	Probable sepsis	
11. Immune system outcomes	Prolonged fever	
11. Immune system outcomes	Prolonged low-grade fever	
11. Immune system outcomes	Recurrent febrile episodes	
11. Immune system outcomes	SARS-CoV-2 antibodies	
11. Immune system outcomes	SARS-CoV-2-specific CD4 + and CD8 + T cells	
11. Immune system outcomes	SARS-CoV-2-specific IgG positivity	

11. Immune system outcomes	Seropositive patients	
11. Immune system outcomes	Spike protein antibody	
11. Immune system outcomes	Switched IgM IgD-B cells	
11. Immune system outcomes	Virus antibody	
11. Immune system outcomes	Virus specific neutralizing antibodies	
11. Immune system outcomes	Virus-neutralizing antibodies	48
12. Infection and infestation outcomes	Change in Child SARS-CoV-2 Vaccination Status	
12. Infection and infestation outcomes	Culture positive sepsis	
12. Infection and infestation outcomes	Duration of antibiotics	
12. Infection and infestation outcomes	Incidence and prevalence of reinfection	
12. Infection and infestation outcomes	No redetectable positive	
12. Infection and infestation outcomes	Positive/Negative	
12. Infection and infestation outcomes	Re-detectable positive (RP)	
12. Infection and infestation outcomes	Reinfection	
12. Infection and infestation outcomes	Reinfections	
12. Infection and infestation outcomes	RNA levels of ACE2, TMPRSS2 in organs	
12. Infection and infestation outcomes	Specific T cell response to SARS-CoV-2	11
13. Injury and poisoning outcomes	Bruises	

13. Injury and poisoning outcomes	Burn	2
14. Metabolism and nutrition outcomes	Anorexia	
14. Metabolism and nutrition outcomes	Anorexia (Loss of appetite)	
14. Metabolism and nutrition outcomes	Body weight changes	
14. Metabolism and nutrition outcomes	Cachexia	
14. Metabolism and nutrition outcomes	Eating changes after COVID-19 (less/the same/more)	
14. Metabolism and nutrition outcomes	Lack of appetite	
14. Metabolism and nutrition outcomes	Loss of appetite	
14. Metabolism and nutrition outcomes	Loss of appetite (No eating or off their food)	
14. Metabolism and nutrition outcomes	Meals skip	
14. Metabolism and nutrition outcomes	Not feeding well	
14. Metabolism and nutrition outcomes	Overeating	
14. Metabolism and nutrition outcomes	Poor appetite	
14. Metabolism and nutrition outcomes	Poor feeding/lethargy	
14. Metabolism and nutrition outcomes	Weight	

14. Metabolism and nutrition outcomes	Weight after Covid-19	
14. Metabolism and nutrition outcomes	Weight after Covid-19 illness	
14. Metabolism and nutrition outcomes	Weight before Covid-19	
14. Metabolism and nutrition outcomes	Weight before Covid-19 illness	
14. Metabolism and nutrition outcomes	Weight before/after	
14. Metabolism and nutrition outcomes	Weight gain/loss	
14. Metabolism and nutrition outcomes	Weight gain/loss, eating disorders	
14. Metabolism and nutrition outcomes	Weight loss	
14. Metabolism and nutrition outcomes	Weight loss of >5% of body weight	23
15. Musculoskeletal and connective tissue outcomes	Arthralgia	
15. Musculoskeletal and connective tissue outcomes	Arthritides	
15. Musculoskeletal and connective tissue outcomes	Back pain	
15. Musculoskeletal and connective tissue outcomes	Elbow pain	
15. Musculoskeletal and connective tissue outcomes	Joint pain	
15. Musculoskeletal and connective tissue outcomes	Joint pain or swelling	

15. Musculoskeletal and connective tissue outcomes	Joint pains	
15. Musculoskeletal and connective tissue outcomes	Knee pain	
15. Musculoskeletal and connective tissue outcomes	Less strength in muscles	
15. Musculoskeletal and connective tissue outcomes	Limb pain	
15. Musculoskeletal and connective tissue outcomes	Muscle aches	
15. Musculoskeletal and connective tissue outcomes	Muscle and Joint pain	
15. Musculoskeletal and connective tissue outcomes	Muscle pain	
15. Musculoskeletal and connective tissue outcomes	Muscle spasms	
15. Musculoskeletal and connective tissue outcomes	Muscle strength of lower (iliopsoas (hip flexion) left and right limbs	
15. Musculoskeletal and connective tissue outcomes	Muscle strength of quadriceps (knee extension) left and right limbs	
15. Musculoskeletal and connective tissue outcomes	Muscle strength of the upper (biceps (elbow flexion) left and right limbs	
15. Musculoskeletal and connective tissue outcomes	Muscle strength of tibialis anterior (ankle dorsiflexion) left and right limbs	
15. Musculoskeletal and connective tissue outcomes	Muscle strength of triceps (elbow extension) left and right limbs	
15. Musculoskeletal and connective tissue outcomes	Muscle weaknes	
15. Musculoskeletal and connective tissue outcomes	Muscle weakness	

15. Musculoskeletal and connective tissue outcomes	Muscle weakness	
15. Musculoskeletal and connective tissue outcomes	Myalgia	
15. Musculoskeletal and connective tissue outcomes	Myalgias	
15. Musculoskeletal and connective tissue outcomes	Neck/shoulder pain	
15. Musculoskeletal and connective tissue outcomes	Pains in lower back	
15. Musculoskeletal and connective tissue outcomes	Persistent muscle pain	
15. Musculoskeletal and connective tissue outcomes	Soreness of your muscles	
15. Musculoskeletal and connective tissue outcomes	Stiffness	
15. Musculoskeletal and connective tissue outcomes	Strong muscle pains	
15. Musculoskeletal and connective tissue outcomes	Unusually strong muscle pains	31
16. Outcomes relating to neoplasms: benign, malignant and unspecified (including cysts and polyps)		
17. Nervous system outcomes	Ageusia	
17. Nervous system outcomes	Anosmia	
17. Nervous system outcomes	Anosmia-ageusia or parosmia/euosmia	
17. Nervous system outcomes	Anosmia/ageusia	
17. Nervous system outcomes	Autonomic dysfunction	
17. Nervous system outcomes	Balance problems	

17. Nervous system outcomes	Cerebral haemorrhage	
17. Nervous system outcomes	Changed state of consciousness	
17. Nervous system outcomes	Changed taste	
17. Nervous system outcomes	Chronic Headache	
17. Nervous system outcomes	Collapse	
17. Nervous system outcomes	Coma	
17. Nervous system outcomes	Confusion	
17. Nervous system outcomes	Confusion/brain fog/trouble focusing attention	
17. Nervous system outcomes	Confusion/disorientation/drowsiness	
17. Nervous system outcomes	Constantly fidgeting or squirming (I am constantly fidgeting....)	
17. Nervous system outcomes	Coordination issues	
17. Nervous system outcomes	Decreased sense of smell	
17. Nervous system outcomes	Decreased Sense of Smell/Taste	
17. Nervous system outcomes	Decreased sense of taste	
17. Nervous system outcomes	Developmental delay	
17. Nervous system outcomes	Developmental regression	
17. Nervous system outcomes	Difficulty swallowing	
17. Nervous system outcomes	Disturbed smell	
17. Nervous system outcomes	Disturbed taste	
17. Nervous system outcomes	Dizziness	
17. Nervous system outcomes	Dizziness ± syncope	
17. Nervous system outcomes	Dizziness/ light headedness	
17. Nervous system outcomes	Drowsiness	
17. Nervous system outcomes	Duchenne muscular dystrophy	
17. Nervous system outcomes	Dysgeusia	
17. Nervous system outcomes	Dysgeusia/anosmia	

17. Nervous system outcomes	Dyslexia	
17. Nervous system outcomes	Encephalitis	
17. Nervous system outcomes	Facial nerve paralysis	
17. Nervous system outcomes	Facial pain/pressure	
17. Nervous system outcomes	Fainting/ blackouts	
17. Nervous system outcomes	Faintness	
17. Nervous system outcomes	Faintness or dizziness	
17. Nervous system outcomes	Feeling off-balance or unsteady	
17. Nervous system outcomes	Feeling tense or keyed up	
17. Nervous system outcomes	Feeling weak in parts of your body	
17. Nervous system outcomes	Growth and neurodevelopment	
17. Nervous system outcomes	Guillian-Barré syndrome	
17. Nervous system outcomes	Headache, dizziness	
17. Nervous system outcomes	Headaches	
17. Nervous system outcomes	Heavy feelings in your arms or legs	
17. Nervous system outcomes	Impaired balance	
17. Nervous system outcomes	Increased nightmares or sleepwalking	
17. Nervous system outcomes	Ischaemic stroke or TIA	
17. Nervous system outcomes	Loss of balance	
17. Nervous system outcomes	Loss of smell	
17. Nervous system outcomes	Loss of smell/taste	
17. Nervous system outcomes	Loss of taste	
17. Nervous system outcomes	Loss of taste and/or smell	
17. Nervous system outcomes	Meningismus	
17. Nervous system outcomes	Meningitis	
17. Nervous system outcomes	Motor problems	

17. Nervous system outcomes	Neurodevelopmental outcome	
17. Nervous system outcomes	Neurologic sequelae	
17. Nervous system outcomes	Neurological abnormalities	
17. Nervous system outcomes	Neurological manifestation of Post-COVID	
17. Nervous system outcomes	Neuropathies	
17. Nervous system outcomes	Normosmia	
17. Nervous system outcomes	Numbness or tingling in parts of your body	
17. Nervous system outcomes	Often complains of headaches... (I get a lot of headaches...)	
17. Nervous system outcomes	Olfaction recovery	
17. Nervous system outcomes	Other coordination disorders/ataxia	
17. Nervous system outcomes	Paraesthesia and anesthesia	
17. Nervous system outcomes	Paresis	
17. Nervous system outcomes	Paresthesia	
17. Nervous system outcomes	Paresthesia of skin	
17. Nervous system outcomes	Pathological reflexes	
17. Nervous system outcomes	Pins and needles	
17. Nervous system outcomes	Problems with balance	
17. Nervous system outcomes	Reduced smell	
17. Nervous system outcomes	Reduced taste	
17. Nervous system outcomes	Seizure	
17. Nervous system outcomes	Seizures	
17. Nervous system outcomes	Seizures/fits	
17. Nervous system outcomes	Sensation and perception	
17. Nervous system outcomes	sensation and perception disorder	
17. Nervous system outcomes	Sensory disturbances	
17. Nervous system outcomes	Severe recurrent headaches	

17. Nervous system outcomes	Shaking	
17. Nervous system outcomes	Slips of the tongue when speaking	
17. Nervous system outcomes	Slurred speech	
17. Nervous system outcomes	Sopor	
17. Nervous system outcomes	Sopor/coma	
17. Nervous system outcomes	Stroke	
17. Nervous system outcomes	Syncope	
17. Nervous system outcomes	Tetany	
17. Nervous system outcomes	Tic exacerbation	
17. Nervous system outcomes	Tingling	
17. Nervous system outcomes	Tingling feeling/ 'pins and needles'	
17. Nervous system outcomes	Tingling/numbness in arms/legs	
17. Nervous system outcomes	Trembling	
17. Nervous system outcomes	Tremor	
17. Nervous system outcomes	Tremor/shakiness	
17. Nervous system outcomes	Tremulousness	
17. Nervous system outcomes	Trouble falling asleep	
17. Nervous system outcomes	Twitching of fingers/toes	
17. Nervous system outcomes	Vertigo	103
18. Pregnancy, puerperium and perinatal outcomes		
19. Renal and urinary outcomes	Acute kidney injury	
19. Renal and urinary outcomes	Anuria	
19. Renal and urinary outcomes	Anuria/oliguria	
19. Renal and urinary outcomes	Dysuria	
19. Renal and urinary outcomes	Kidney failure	
19. Renal and urinary outcomes	Kidney function	

19. Renal and urinary outcomes	Kidney problems after COVID-19	
19. Renal and urinary outcomes	Kidney/metabolic function	
19. Renal and urinary outcomes	Microhaematuria	
19. Renal and urinary outcomes	Oliguria	
19. Renal and urinary outcomes	Other symptoms of the urinary system	
19. Renal and urinary outcomes	Polyuria	
19. Renal and urinary outcomes	Problems with urination	
19. Renal and urinary outcomes	Renal failure	
19. Renal and urinary outcomes	Urethral discharge	
19. Renal and urinary outcomes	Urinary incontinence	
19. Renal and urinary outcomes	Urinary retention	
19. Renal and urinary outcomes	Urination problems	
19. Renal and urinary outcomes	Urine	19
20. Reproductive system and breast outcomes	Change in menstruation	
20. Reproductive system and breast outcomes	Changes in menstruation	
20. Reproductive system and breast outcomes	Dysmenorrhea	
20. Reproductive system and breast outcomes	Menstrual disturbances	
20. Reproductive system and breast outcomes	Pathological findings from male genital tract	5
21. Psychiatric outcomes	Ability to make up own mind about things	
21. Psychiatric outcomes	Adaptive behavior score	
21. Psychiatric outcomes	Adjustment disorder	
21. Psychiatric outcomes	Anxiety	
21. Psychiatric outcomes	Anxiety disorder	

21. Psychiatric outcomes	Anxiety or depression	
21. Psychiatric outcomes	Anxiety/depression	
21. Psychiatric outcomes	Apathy, sad feeling	
21. Psychiatric outcomes	Awakening in the early morning	
21. Psychiatric outcomes	Behavioral symptoms	
21. Psychiatric outcomes	Behaviour	
21. Psychiatric outcomes	Blaming yourself for things	
21. Psychiatric outcomes	Concentration impairment	
21. Psychiatric outcomes	Constantly crying	
21. Psychiatric outcomes	Crying easily	
21. Psychiatric outcomes	Dealing with problems well	
21. Psychiatric outcomes	Depressed mood	
21. Psychiatric outcomes	Depression	
21. Psychiatric outcomes	Depressive symptoms	
21. Psychiatric outcomes	Difficulty making decisions	
21. Psychiatric outcomes	Easily distracted, concentration wanders (I am easily distracted)	
21. Psychiatric outcomes	Embarrassed	
21. Psychiatric outcomes	Emotional and behavioral disorder	
21. Psychiatric outcomes	Emotional and mental health	
21. Psychiatric outcomes	Emotionality	
21. Psychiatric outcomes	Emotions	
21. Psychiatric outcomes	Euphoria	
21. Psychiatric outcomes	Excessive crying	
21. Psychiatric outcomes	Feeling afraid in open spaces or on the streets	
21. Psychiatric outcomes	Feeling afraid to go out of your house alone	
21. Psychiatric outcomes	Feeling afraid to travel on buses, subways, trains	

21. PSYCHIATRIC OUTCOMES	FEELING AFRAID YOU WILL FAINT IN PUBLIC	
21. PSYCHIATRIC OUTCOMES	FEELING BLOCKED IN GETTING THINGS DONE	
21. PSYCHIATRIC OUTCOMES	FEELING BLUE	
21. PSYCHIATRIC OUTCOMES	FEELING CRITICAL OF OTHERS	
21. PSYCHIATRIC OUTCOMES	FEELING EASILY ANNOYED OR IRRITATED	
21. PSYCHIATRIC OUTCOMES	FEELING EVERYTHING IS AN EFFORT	
21. PSYCHIATRIC OUTCOMES	FEELING FEARFUL	
21. PSYCHIATRIC OUTCOMES	FEELING HOPELESS ABOUT THE FUTURE	
21. PSYCHIATRIC OUTCOMES	FEELING INFERIOR TO OTHERS	
21. PSYCHIATRIC OUTCOMES	FEELING LONELY	
21. PSYCHIATRIC OUTCOMES	FEELING LONELY EVEN WHEN YOU ARE WITH PEOPLE	
21. PSYCHIATRIC OUTCOMES	FEELING LOW IN ENERGY OR SLOWED DOWN	
21. PSYCHIATRIC OUTCOMES	FEELING NERVOUS WHEN YOU ARE LEFT ALONE	
21. PSYCHIATRIC OUTCOMES	FEELING NO INTEREST IN THINGS	
21. PSYCHIATRIC OUTCOMES	FEELING OF BEING TRAPPED OR CAUGHT	
21. PSYCHIATRIC OUTCOMES	FEELING OTHERS ARE TO BLAME FOR MOST OF YOUR TROUBLES	
21. PSYCHIATRIC OUTCOMES	FEELING OTHERS DO NOT UNDERSTAND YOU OR ARE UNSYMPATHETIC	
21. PSYCHIATRIC OUTCOMES	FEELING PUSHED TO GET THINGS DONE	
21. PSYCHIATRIC OUTCOMES	FEELING SHY OR UNEASY WITH THE OPPOSITE SEX	
21. PSYCHIATRIC OUTCOMES	FEELING SO RESTLESS YOU COULDN'T SIT STILL	
21. PSYCHIATRIC OUTCOMES	FEELING THAT FAMILIAR THINGS ARE STRANGE OR UNREAL	
21. PSYCHIATRIC OUTCOMES	FEELING THAT MOST PEOPLE CANNOT BE TRUSTED	
21. PSYCHIATRIC OUTCOMES	FEELING THAT PEOPLE ARE UNFRIENDLY OR DISLIKE YOU	
21. PSYCHIATRIC OUTCOMES	FEELING THAT PEOPLE WILL TAKE ADVANTAGE OF YOU IF YOU LET THEM	
21. PSYCHIATRIC OUTCOMES	FEELING THAT YOU ARE WATCHED OR TALKED ABOUT BY OTHERS	
21. PSYCHIATRIC OUTCOMES	FEELING UNCOMFORTABLE ABOUT EATING OR DRINKING IN PUBLIC	

21. Psychiatric outcomes	Feeling uneasy in crowds, such as shopping or at a movie	
21. Psychiatric outcomes	Feeling uneasy when people are watching or talking about you	
21. Psychiatric outcomes	Feeling useful	
21. Psychiatric outcomes	Feeling very self-conscious with others	
21. Psychiatric outcomes	Feelings of guilt	
21. Psychiatric outcomes	Feelings of worthlessness	
21. Psychiatric outcomes	Floppy or difficulty rousing	
21. Psychiatric outcomes	Frustrated/restless/irritable	
21. Psychiatric outcomes	Getting into frequent arguments	
21. Psychiatric outcomes	Hallucinations	
21. Psychiatric outcomes	Having difficulty sleeping at night/getting to sleep	
21. Psychiatric outcomes	Having ideas or beliefs that others do not share	
21. Psychiatric outcomes	Having thoughts about sex that bother you a lot	
21. Psychiatric outcomes	Having thoughts that are not your own	
21. Psychiatric outcomes	Having to avoid certain things, places, or activities because they frighten you	
21. Psychiatric outcomes	Having to check and double-check what you do	
21. Psychiatric outcomes	Having to do things very slowly to insure correctness	
21. Psychiatric outcomes	Having to repeat the same actions such as touching, counting, washing	
21. Psychiatric outcomes	Having to sleep upright	
21. Psychiatric outcomes	Having urges to beat, injure, or harm someone	
21. Psychiatric outcomes	Having urges to break or smash things	
21. Psychiatric outcomes	Hearing voices that other people do not hear	
21. Psychiatric outcomes	Ideas of persecution	
21. Psychiatric outcomes	Increased aggressiveness	
21. Psychiatric outcomes	Increased anxiety	
21. Psychiatric outcomes	Increased mood swings	

21. Psychiatric outcomes	Irritability	
21. Psychiatric outcomes	Irritable	
21. Psychiatric outcomes	Lethargy	
21. Psychiatric outcomes	Loneliness	
21. Psychiatric outcomes	Loss of sexual interest or pleasure	
21. Psychiatric outcomes	Many fears, easily scared (I have many fears)	
21. Psychiatric outcomes	Many worries (I worry a lot)	
21. Psychiatric outcomes	Mood and behaviour changes	
21. Psychiatric outcomes	Mood changes	
21. Psychiatric outcomes	Mood disorder	
21. Psychiatric outcomes	Mood swings	
21. Psychiatric outcomes	Nervous or clingy in new situations (I am nervous in new situations)	
21. Psychiatric outcomes	Nervousness or shakiness inside	
21. Psychiatric outcomes	Neurasthenia	
21. Psychiatric outcomes	Never feeling close to another person	
21. Psychiatric outcomes	Number of psychologic changes	
21. Psychiatric outcomes	Obsessive-compulsive symptoms	
21. Psychiatric outcomes	Obsessive-compulsive disorder	
21. Psychiatric outcomes	Often unhappy, downhearted (I am often unhappy)	
21. Psychiatric outcomes	Other people being aware of your private thoughts	
21. Psychiatric outcomes	Others not giving you proper credit for your achievements	
21. Psychiatric outcomes	Personality	
21. Psychiatric outcomes	Problems starting things	
21. Psychiatric outcomes	Psychologic status	
21. Psychiatric outcomes	Psychological/psychiatric symptoms	
21. Psychiatric outcomes	Psychosis	

21. Psychiatric outcomes	Restless, overactive (I am restless)	
21. Psychiatric outcomes	Sad	
21. Psychiatric outcomes	Sadness	
21. Psychiatric outcomes	Sees tasks through to the end (I finish the work I am doing)	
21. Psychiatric outcomes	Shouting or throwing things	
21. Psychiatric outcomes	Somatization disorder	
21. Psychiatric outcomes	Spells of terror or panic	
21. Psychiatric outcomes	Steals from home, school or elsewhere (I take things that are not mine)	
21. Psychiatric outcomes	Suddenly scared for no reason	
21. Psychiatric outcomes	Suicidal ideation	
21. Psychiatric outcomes	Temper outbursts that you could not control	
21. Psychiatric outcomes	Temper tantrums/hot tempers (get very angry)	
21. Psychiatric outcomes	The idea that someone else can control your thoughts	
21. Psychiatric outcomes	The idea that something is wrong with your mind	
21. Psychiatric outcomes	The idea that something serious is wrong with your body	
21. Psychiatric outcomes	The idea that you should be punished for your sins	
21. Psychiatric outcomes	Thinks things out before acting (I think before I do things)	
21. Psychiatric outcomes	Thoughts of death or dying	
21. Psychiatric outcomes	Thoughts of ending your life	
21. Psychiatric outcomes	Trouble getting your breath	
21. Psychiatric outcomes	Unwanted thoughts, words/ideas that won't leave your mind	
21. Psychiatric outcomes	Upset or distress abot current symptoms	
21. Psychiatric outcomes	Worried about sloppiness or carelessness	
21. Psychiatric outcomes	Worrying too much about things	
21. Psychiatric outcomes	Your feelings being easily hurt	134
22. Respiratory, thoracic and mediastinal outcomes	Abnormal 6MWT (6 - minute walk test)	

22. Respiratory, thoracic and mediastinal outcomes	Abnormal auscultatory findings: decreased breath sounds	
22. Respiratory, thoracic and mediastinal outcomes	Abnormal auscultatory findings: intermittent wheezing	
22. Respiratory, thoracic and mediastinal outcomes	Abnormal chest radiograph	
22. Respiratory, thoracic and mediastinal outcomes	Abnormal lung function	
22. Respiratory, thoracic and mediastinal outcomes	Abnormal pulmonary function tests	
22. Respiratory, thoracic and mediastinal outcomes	Abnormal respiratory function	
22. Respiratory, thoracic and mediastinal outcomes	Abnormal spirometry	
22. Respiratory, thoracic and mediastinal outcomes	Abnormal TLCO - lung diffusing capacity for carbon monoxide	
22. Respiratory, thoracic and mediastinal outcomes	Acute respiratory distress syndrome	
22. Respiratory, thoracic and mediastinal outcomes	Acute upper respiratory tract infection (AURI)	
22. Respiratory, thoracic and mediastinal outcomes	Breathlessness	
22. Respiratory, thoracic and mediastinal outcomes	Bronchial asthma	
22. Respiratory, thoracic and mediastinal outcomes	Bronchiolitis	
22. Respiratory, thoracic and mediastinal outcomes	Broncho-responsiveness	
22. Respiratory, thoracic and mediastinal outcomes	Changes in lung ventilation	

22. Respiratory, thoracic and mediastinal outcomes	Changes in other lung functions	
22. Respiratory, thoracic and mediastinal outcomes	Characteristics of resistance and reactance of lung airways	
22. Respiratory, thoracic and mediastinal outcomes	Chest pain	
22. Respiratory, thoracic and mediastinal outcomes	Chest pain/tightness	
22. Respiratory, thoracic and mediastinal outcomes	Chest radiograph changes	
22. Respiratory, thoracic and mediastinal outcomes	Chest tightness/pain	
22. Respiratory, thoracic and mediastinal outcomes	Chronic cough	
22. Respiratory, thoracic and mediastinal outcomes	Combined defects	
22. Respiratory, thoracic and mediastinal outcomes	Congested nose	
22. Respiratory, thoracic and mediastinal outcomes	Congestion	
22. Respiratory, thoracic and mediastinal outcomes	Consolidation	
22. Respiratory, thoracic and mediastinal outcomes	Correlation of the severity of the respiratory involvement during the acute infection with the long term respiratory status	
22. Respiratory, thoracic and mediastinal outcomes	Cough	
22. Respiratory, thoracic and mediastinal outcomes	Cough with expectoration	
22. Respiratory, thoracic and mediastinal outcomes	Cough/dyspnea/chest tightness	

22. Respiratory, thoracic and mediastinal outcomes	Coughing when lying down	
22. Respiratory, thoracic and mediastinal outcomes	CT abnormalities	
22. Respiratory, thoracic and mediastinal outcomes	Damage to the lungs	
22. Respiratory, thoracic and mediastinal outcomes	Difficulties breathing	
22. Respiratory, thoracic and mediastinal outcomes	Difficulty breathing	
22. Respiratory, thoracic and mediastinal outcomes	Difficulty breathing /chest tightness	
22. Respiratory, thoracic and mediastinal outcomes	Dry cough	
22. Respiratory, thoracic and mediastinal outcomes	Duration of oxygen	
22. Respiratory, thoracic and mediastinal outcomes	Dyspnea	
22. Respiratory, thoracic and mediastinal outcomes	Dyspnea at rest	
22. Respiratory, thoracic and mediastinal outcomes	Early effects of severe acute respiratory syndrome on lung function	
22. Respiratory, thoracic and mediastinal outcomes	Early effects of severe acute respiratory syndrome on respiratory symptoms	
22. Respiratory, thoracic and mediastinal outcomes	Elevated RV/TLC above 30%	
22. Respiratory, thoracic and mediastinal outcomes	Emphysema/Pulmonary bulla	
22. Respiratory, thoracic and mediastinal outcomes	Enhanced lung marking	

22. Respiratory, thoracic and mediastinal outcomes	Excess sputum	
22. Respiratory, thoracic and mediastinal outcomes	Exertional dyspnea	
22. Respiratory, thoracic and mediastinal outcomes	Exhaled breath profiles	
22. Respiratory, thoracic and mediastinal outcomes	Expectoration	
22. Respiratory, thoracic and mediastinal outcomes	FCV	
22. Respiratory, thoracic and mediastinal outcomes	FEF 25–75%	
22. Respiratory, thoracic and mediastinal outcomes	FEV1	
22. Respiratory, thoracic and mediastinal outcomes	FEV1/FVC	
22. Respiratory, thoracic and mediastinal outcomes	Fits of coughing	
22. Respiratory, thoracic and mediastinal outcomes	Ground-glass opacity	
22. Respiratory, thoracic and mediastinal outcomes	Hoarse voice	
22. Respiratory, thoracic and mediastinal outcomes	Hoarseness	
22. Respiratory, thoracic and mediastinal outcomes	Hyaline membrane disease	
22. Respiratory, thoracic and mediastinal outcomes	Hypoxemia	
22. Respiratory, thoracic and mediastinal outcomes	Impact of dyspnea symptoms on specific activities	

22. Respiratory, thoracic and mediastinal outcomes	Impaired pulmonary diffusion function	
22. Respiratory, thoracic and mediastinal outcomes	Inflammation absorption	
22. Respiratory, thoracic and mediastinal outcomes	Interstitial B-lines pattern	
22. Respiratory, thoracic and mediastinal outcomes	Late effects of severe acute respiratory syndrome on lung function	
22. Respiratory, thoracic and mediastinal outcomes	Late effects of severe acute respiratory syndrome on respiratory symptoms	
22. Respiratory, thoracic and mediastinal outcomes	Long term symptoms	
22. Respiratory, thoracic and mediastinal outcomes	Lung capacity	
22. Respiratory, thoracic and mediastinal outcomes	Lung function	
22. Respiratory, thoracic and mediastinal outcomes	Lung lesions	
22. Respiratory, thoracic and mediastinal outcomes	Lung tussie repair	
22. Respiratory, thoracic and mediastinal outcomes	Mean FVL Correlation	
22. Respiratory, thoracic and mediastinal outcomes	Mechanical ventilation	
22. Respiratory, thoracic and mediastinal outcomes	Meconium aspiration syndrome	
22. Respiratory, thoracic and mediastinal outcomes	Mild pneumonia	
22. Respiratory, thoracic and mediastinal outcomes	Mild shortness of breath	

22. Respiratory, thoracic and mediastinal outcomes	Mild-to-moderate obstructive disease	
22. Respiratory, thoracic and mediastinal outcomes	Moderate obstructive disease	
22. Respiratory, thoracic and mediastinal outcomes	Morphological changes in the lung	
22. Respiratory, thoracic and mediastinal outcomes	Morphological changes of lung parenchyma	
22. Respiratory, thoracic and mediastinal outcomes	Nasal Blockage	
22. Respiratory, thoracic and mediastinal outcomes	Nasal Congestion	
22. Respiratory, thoracic and mediastinal outcomes	Nasal congestion / rhinorrhea	
22. Respiratory, thoracic and mediastinal outcomes	Nasal congestion/ rhinorrhea	
22. Respiratory, thoracic and mediastinal outcomes	Nasal congestion/ rhinorrhoea	
22. Respiratory, thoracic and mediastinal outcomes	Nasal discharge	
22. Respiratory, thoracic and mediastinal outcomes	Need to blow nose	
22. Respiratory, thoracic and mediastinal outcomes	No obvious abnormality	
22. Respiratory, thoracic and mediastinal outcomes	Nodular shadowing	
22. Respiratory, thoracic and mediastinal outcomes	Non-specific interstitial pneumonia	
22. Respiratory, thoracic and mediastinal outcomes	Normal/Abnormal	

22. Respiratory, thoracic and mediastinal outcomes	Normalization	
22. Respiratory, thoracic and mediastinal outcomes	Nose symptoms	
22. Respiratory, thoracic and mediastinal outcomes	Obstructive or restrictive defect	
22. Respiratory, thoracic and mediastinal outcomes	Obstructive sleep apnea	
22. Respiratory, thoracic and mediastinal outcomes	Obstructive ventilatory defects	
22. Respiratory, thoracic and mediastinal outcomes	Ongoing supplemental oxygen requirement	
22. Respiratory, thoracic and mediastinal outcomes	Other Pulmonary Abnormalities	
22. Respiratory, thoracic and mediastinal outcomes	Pain on breathing	
22. Respiratory, thoracic and mediastinal outcomes	Pain when breathing	
22. Respiratory, thoracic and mediastinal outcomes	Pathological lung findings	
22. Respiratory, thoracic and mediastinal outcomes	Patterns of pulmonary microbiome	
22. Respiratory, thoracic and mediastinal outcomes	Perfusion defected percentage (QDP)	
22. Respiratory, thoracic and mediastinal outcomes	Perfusion defects	
22. Respiratory, thoracic and mediastinal outcomes	Perinatal asphyxia	
22. Respiratory, thoracic and mediastinal outcomes	Persistent cough	

22. Respiratory, thoracic and mediastinal outcomes	Persistent dyspnea	
22. Respiratory, thoracic and mediastinal outcomes	Pleural effusion	
22. Respiratory, thoracic and mediastinal outcomes	Pleural incrassation	
22. Respiratory, thoracic and mediastinal outcomes	Pleural pain	
22. Respiratory, thoracic and mediastinal outcomes	Pneumonia	
22. Respiratory, thoracic and mediastinal outcomes	Post-inflammation pulmonary fibrosis	
22. Respiratory, thoracic and mediastinal outcomes	Post-nasal discharge	
22. Respiratory, thoracic and mediastinal outcomes	Potential pulmonary sequelae	
22. Respiratory, thoracic and mediastinal outcomes	Pulmonary abnormalities	
22. Respiratory, thoracic and mediastinal outcomes	Pulmonary fibrosis	
22. Respiratory, thoracic and mediastinal outcomes	Pulmonary Function	
22. Respiratory, thoracic and mediastinal outcomes	Pulmonary function changes	
22. Respiratory, thoracic and mediastinal outcomes	QDP Exclusive	
22. Respiratory, thoracic and mediastinal outcomes	QDP Total	
22. Respiratory, thoracic and mediastinal outcomes	Radiologic changes	

22. Respiratory, thoracic and mediastinal outcomes	Resistance R5, R20, R5-R20 and reactance X5, X20, X inspiratory-X expiratory	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory distress	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory failure after COVID-19	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory function	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory function recovery	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory insuffeciency	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory problems	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory sequelae	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory sequelae of COVID 19 infection in children, by clinical examination and laboratory investigations during 1 year follow up period	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory support	
22. Respiratory, thoracic and mediastinal outcomes	Respiratory symptoms	
22. Respiratory, thoracic and mediastinal outcomes	Restrictive lung disease	
22. Respiratory, thoracic and mediastinal outcomes	Restrictive/obstructive lung disease	
22. Respiratory, thoracic and mediastinal outcomes	Rhinitis	

22. Respiratory, thoracic and mediastinal outcomes	Rhinorrhoea	
22. Respiratory, thoracic and mediastinal outcomes	Risk factors for pulmonary sequelae	
22. Respiratory, thoracic and mediastinal outcomes	Runny nose	
22. Respiratory, thoracic and mediastinal outcomes	Severe acute respiratory syndrome	
22. Respiratory, thoracic and mediastinal outcomes	Shortness of breadth	
22. Respiratory, thoracic and mediastinal outcomes	Shortness of breath	
22. Respiratory, thoracic and mediastinal outcomes	Shortness of breath (at rest)	
22. Respiratory, thoracic and mediastinal outcomes	Shortness of breath (with physical activities)	
22. Respiratory, thoracic and mediastinal outcomes	Shortness of breath with noisy breathing	
22. Respiratory, thoracic and mediastinal outcomes	Sneezing	
22. Respiratory, thoracic and mediastinal outcomes	Sore throat	
22. Respiratory, thoracic and mediastinal outcomes	SpO2	
22. Respiratory, thoracic and mediastinal outcomes	SPO2 Equal and more than 92	
22. Respiratory, thoracic and mediastinal outcomes	SPO2 Less than 92	
22. Respiratory, thoracic and mediastinal outcomes	Stuffy nose	

22. Respiratory, thoracic and mediastinal outcomes	Stuffy running nose	
22. Respiratory, thoracic and mediastinal outcomes	Subpleural multiple consolidations	
22. Respiratory, thoracic and mediastinal outcomes	Swollen glands	
22. Respiratory, thoracic and mediastinal outcomes	Tachypnea	
22. Respiratory, thoracic and mediastinal outcomes	Thick nasal discharge	
22. Respiratory, thoracic and mediastinal outcomes	Thoracic pain complaints	
22. Respiratory, thoracic and mediastinal outcomes	Throat pain	
22. Respiratory, thoracic and mediastinal outcomes	Throat symptoms	
22. Respiratory, thoracic and mediastinal outcomes	Throat/chest pain	
22. Respiratory, thoracic and mediastinal outcomes	To correlate FOT indices	
22. Respiratory, thoracic and mediastinal outcomes	Transient tachypnea of newborn	
22. Respiratory, thoracic and mediastinal outcomes	Trouble breathing	
22. Respiratory, thoracic and mediastinal outcomes	Unusual chest pain	
22. Respiratory, thoracic and mediastinal outcomes	Unusually hoarse voice	
22. Respiratory, thoracic and mediastinal outcomes	Varying degrees of usual interstitial pneumonia	

22. Respiratory, thoracic and mediastinal outcomes	VDP Exclusive	
22. Respiratory, thoracic and mediastinal outcomes	VDP FVL	
22. Respiratory, thoracic and mediastinal outcomes	VDP FVL Exclusive	
22. Respiratory, thoracic and mediastinal outcomes	VDP Total	
22. Respiratory, thoracic and mediastinal outcomes	Ventilation and perfusion of the lung	
22. Respiratory, thoracic and mediastinal outcomes	Ventilation defected percentage (VDP)	
22. Respiratory, thoracic and mediastinal outcomes	Ventilation defects	
22. Respiratory, thoracic and mediastinal outcomes	Ventilation/Perfusion match (VQM defect)	
22. Respiratory, thoracic and mediastinal outcomes	Ventilation/Perfusion mismatch (VQM defect)	
22. Respiratory, thoracic and mediastinal outcomes	Viral upper respiratory infection	
22. Respiratory, thoracic and mediastinal outcomes	VQM Defect	
22. Respiratory, thoracic and mediastinal outcomes	VQM Defect, FVL	
22. Respiratory, thoracic and mediastinal outcomes	VQM Non-defect	
22. Respiratory, thoracic and mediastinal outcomes	VQM Non-defect, FVL	
22. Respiratory, thoracic and mediastinal outcomes	Wheezing	180

23. Skin and subcutaneous tissue outcomes	Blisters	
23. Skin and subcutaneous tissue outcomes	Correlation between cutaneous manifestations in recovered patient of COVID 19 therapeutic regime used during treatment period	
23. Skin and subcutaneous tissue outcomes	Correlation between cutaneous manifestations in recovered patient of COVID 19 with disease severity	
23. Skin and subcutaneous tissue outcomes	Correlations between demographic parameter and skin manifestations in recovered patient of COVID-19	
23. Skin and subcutaneous tissue outcomes	Covid toe	
23. Skin and subcutaneous tissue outcomes	Cutaneous rash	
23. Skin and subcutaneous tissue outcomes	Dermatitis	
23. Skin and subcutaneous tissue outcomes	Dermatological changes	
23. Skin and subcutaneous tissue outcomes	Dermatological symptoms	
23. Skin and subcutaneous tissue outcomes	Dry skin	
23. Skin and subcutaneous tissue outcomes	Edema	
23. Skin and subcutaneous tissue outcomes	Hair	
23. Skin and subcutaneous tissue outcomes	Hair loss	
23. Skin and subcutaneous tissue outcomes	Hives	
23. Skin and subcutaneous tissue outcomes	Hyperhidrosis	

23. Skin and subcutaneous tissue outcomes	Itching skin	
23. Skin and subcutaneous tissue outcomes	Itchy skin	
23. Skin and subcutaneous tissue outcomes	Lumps or rashes (purple/pink) on toes	
23. Skin and subcutaneous tissue outcomes	Mottled feet	
23. Skin and subcutaneous tissue outcomes	Plantar wart	
23. Skin and subcutaneous tissue outcomes	Problems with teeth or gums	
23. Skin and subcutaneous tissue outcomes	Psoriasis flare	
23. Skin and subcutaneous tissue outcomes	Raised welts on skin or swelling	
23. Skin and subcutaneous tissue outcomes	Raised, red, itchy welts on the skin/sudden swelling of the face or lips	
23. Skin and subcutaneous tissue outcomes	Rash	
23. Skin and subcutaneous tissue outcomes	Rashes	
23. Skin and subcutaneous tissue outcomes	Red or purple sores or blisters on feet	
23. Skin and subcutaneous tissue outcomes	Red welts	
23. Skin and subcutaneous tissue outcomes	Red/purple sores/blisters on feet, including toes	
23. Skin and subcutaneous tissue outcomes	Redness skin	

23. Skin and subcutaneous tissue outcomes	Skin irritation/lesions	
23. Skin and subcutaneous tissue outcomes	Skin lesions	
23. Skin and subcutaneous tissue outcomes	Skin rash	
23. Skin and subcutaneous tissue outcomes	Skin rash - If yes, tick all body areas that apply: Face, Trunk (stomach or back), Arms, Legs, Buttocks,Toes, Fingers, Accompanied by itch	
23. Skin and subcutaneous tissue outcomes	Skin rashes (Face, Trunk, Arms, Legs, Buttocks, Toes, Fingers, Accompanied by itch)	
23. Skin and subcutaneous tissue outcomes	Subcutaneous nodules	
23. Skin and subcutaneous tissue outcomes	Sweatiness	
23. Skin and subcutaneous tissue outcomes	Swelling	
23. Skin and subcutaneous tissue outcomes	Swelling of body	
23. Skin and subcutaneous tissue outcomes	Swollen toes and/or fingers	
23. Skin and subcutaneous tissue outcomes	Urticaria	41
24. Vascular outcomes	Bleeding	
24. Vascular outcomes	Bleeding (If yes, specify bleeding site)	
24. Vascular outcomes	Epistaxis	
24. Vascular outcomes	Gangrene	
24. Vascular outcomes	Hemorrhage	
24. Vascular outcomes	Peripheral vascular disease	
24. Vascular outcomes	Pulmonary Embolism	

24. Vascular outcomes	Pulmonary embolism after COVID-19	
24. Vascular outcomes	Sinus vein thrombosis	
24. Vascular outcomes	Thrombosis	
24. Vascular outcomes	Vasculitis	
24. Vascular outcomes	Vasoactive agents use	
24. Vascular outcomes	Vasomotor complaints	
24. Vascular outcomes	Venous thromboembolism	14
25. Physical functioning	Cannot fully move or control movement	
25. Physical functioning	Decreased activity level	
25. Physical functioning	Decreased physical strength	
25. Physical functioning	Early effects of severe acute respiratory syndrome on exercise capacity	
25. Physical functioning	Exercise capacity	
25. Physical functioning	Exercise intolerance	
25. Physical functioning	Exercise tolerance	
25. Physical functioning	Feeling exhausted after walking	
25. Physical functioning	Functional secondary outcomes	
25. Physical functioning	Impairment in daily activities	
25. Physical functioning	Late effects of severe acute respiratory syndrome on exercise capacity	
25. Physical functioning	Lower limb muscle endurance	
25. Physical functioning	Mild limitations in daily functioning	
25. Physical functioning	Movement disorders	
25. Physical functioning	Muscle strength	
25. Physical functioning	No limitations in daily functioning	
25. Physical functioning	Number of functional limitations	
25. Physical functioning	Overall physical function recovery	
25. Physical functioning	Physical activity	

25. Physical functioning	Physical function	
25. Physical functioning	Physical score	
25. Physical functioning	Physical strength	
25. Physical functioning	Physical symptoms	
25. Physical functioning	Post-excertional malaise	
25. Physical functioning	Reduced physical performance	
25. Physical functioning	Severe limitations in daily functioning	
25. Physical functioning	Shortness of breath after activity	
25. Physical functioning	Shortness of breath at rest	
25. Physical functioning	Some/lots of mobility problems	
25. Physical functioning	Some/lots of problems with usual activities	
25. Physical functioning	Some/lots of self-care problems	
25. Physical functioning	Walking intolerance	32
26. Social functioning	Considerate of other people's feelings (I try to be nice to other people)	
26. Social functioning	Feeling close to other people	
26. Social functioning	Generally liked by other children (Other people my age generally like me)	
26. Social functioning	Generally obedient... (I usually do as I am told)	
26. Social functioning	Gets on better with adults than with other children (I get on better with adults than with people my age)	
26. Social functioning	Has at least one good friend (I have one good friend or more)	
26. Social functioning	Helpful if someone is hurt (I am helpful is someone is hurt...)	
26. Social functioning	Kind to younger children (I am kind to younger children)	
26. Social functioning	Often fights with other children... (I fight a lot)	
26. Social functioning	Often lies or cheats (I am often accused of lying or cheating)	
26. Social functioning	Often volunteers to help others (I often volunteer to help others)	

26. Social functioning	Picked on or bullied by other children (Other children or young people pick on me)	
26. Social functioning	Rather solitary, tends to play alone (I am usually on my own)	
26. Social functioning	Relationships	
26. Social functioning	Shares readily with other children (I usually share with others)	
26. Social functioning	Spending time with friends in person	
26. Social functioning	Spending time with friends remotely	17
27. Role functioning	Absence at school/kindergarten after recovering from COVID-19 because of the above symptoms?	
27. Role functioning	Attending school/nursery	
27. Role functioning	Reduced productivity	3
28. Emotional functioning/wellbeing	A bit/very worried, sad/unhappy	
28. Emotional functioning/wellbeing	Everyday was full of things that interest the child (All the time, Most of the time, A little more than half of the time, A little less than half of the time A bit of the time, At no point in time)	
28. Emotional functioning/wellbeing	Feeling calm and relaxed (All the time, Most of the time, A little more than half of the time, A little less than half of the time A bit of the time, At no point in time)	
28. Emotional functioning/wellbeing	Feeling optimistic about the future	
28. Emotional functioning/wellbeing	Feeling well rested (All the time, Most of the time, A little more than half of the time, A little less than half of the time A bit of the time, At no point in time)	
28. Emotional functioning/wellbeing	Full of energy (All the time, Most of the time, A little more than half of the time, A little less than half of the time A bit of the time, At no point in time)	
28. Emotional functioning/wellbeing	Happiness/good mood (All the time, Most of the time, A little more than half of the time, A little less than half of the time A bit of the time, At no point in time)	

28. Emotional functioning/wellbeing	Wellbeing	8
29. Cognitive functioning	Affected memory	
29. Cognitive functioning	Attention or memory deficit	
29. Cognitive functioning	Brain fog	
29. Cognitive functioning	Cognitive disturbances	
29. Cognitive functioning	Cognitive dysfunction	
29. Cognitive functioning	Cognitive function impairment	
29. Cognitive functioning	Cognitive impairment/'brain fog'	
29. Cognitive functioning	Cognitive score	
29. Cognitive functioning	Communication score	
29. Cognitive functioning	Concentration difficulties	
29. Cognitive functioning	Concentration impairment/concentration deficit	
29. Cognitive functioning	Concentration problems	
29. Cognitive functioning	Confusion	
29. Cognitive functioning	Confusion, disorientation, or drowsiness	
29. Cognitive functioning	Confusion/lack of concentration	
29. Cognitive functioning	Difficult to find the right word	
29. Cognitive functioning	Difficulties concentrating	
29. Cognitive functioning	Difficulties managing school	
29. Cognitive functioning	Difficulty concentrating	
29. Cognitive functioning	Disorientation	
29. Cognitive functioning	Forgetfulness	
29. Cognitive functioning	Impaired attention	
29. Cognitive functioning	learning difficulties	
29. Cognitive functioning	Memory impairment	
29. Cognitive functioning	Memory loss	

29. Cognitive functioning	Memory problems	
29. Cognitive functioning	Problems speaking or communicating	
29. Cognitive functioning	Problems with concentration	
29. Cognitive functioning	Problems with memory	
29. Cognitive functioning	Reduced concentration	
29. Cognitive functioning	Short-term memory loss	
29. Cognitive functioning	Social-emotional score	
29. Cognitive functioning	Speech and language disorders	
29. Cognitive functioning	Speech disturbances	
29. Cognitive functioning	Speech/language abnormalities	
29. Cognitive functioning	States of confusion	
29. Cognitive functioning	Thinking clearly	
29. Cognitive functioning	Trouble concentrating	
29. Cognitive functioning	Trouble forming words	
29. Cognitive functioning	Trouble remembering things	
29. Cognitive functioning	Your mind going blank	41
30. Global quality of life	Early effects of severe acute respiratory syndrome on HRQoL	
30. Global quality of life	Emotional Functioning	
30. Global quality of life	Health Related Quality of Life	
30. Global quality of life	Health-related quality of life (HRQoL) of patients diagnosed with COVID-19	
30. Global quality of life	Health-related quality of life and social impact	
30. Global quality of life	Late effects of severe acute respiratory syndrome on HRQoL	
30. Global quality of life	Physical Functioning	
30. Global quality of life	QoL at time of survey	
30. Global quality of life	QoL Before COVID-19	
30. Global quality of life	Quality of life	

30. Global quality of life	Quality of life and social impact	
30. Global quality of life	Quality of life/functioning	
30. Global quality of life	School Functioning	
30. Global quality of life	Social Functioning	14
31. Perceived health status	Health after COVID-19	
31. Perceived health status	Health before COVID-19	
31. Perceived health status	Health status before and after COVID-19	
31. Perceived health status	Self-rated health	4
32. Delivery of care		
33. Personal circumstances	Disability	
33. Personal circumstances	Life events	
33. Personal circumstances	Life events explaining the mentioned changes	
33. Personal circumstances	Spending time outside	
33. Personal circumstances	Spending time watching TV, playing video/computer games, or using social media for educational purposes, including school/nursery work	
33. Personal circumstances	Spending time watching TV, playing video/computer games, or using social media for non-educational purposes	6
34. Economic	Index of multiple deprivation	1
35. Hospital		
36. Need for further intervention	Admission to the ICU	
36. Need for further intervention	Change in Child SARS-CoV-2 Treatment Record	
36. Need for further intervention	Contacts to the general practitioner	
36. Need for further intervention	Diagnoses	
36. Need for further intervention	Duration of PICU hospitalization	
36. Need for further intervention	Duration of ward admission	
36. Need for further intervention	Frequency of family doctor visits after recovering from COVID-19	
36. Need for further intervention	Frequency of specialist visits after recovering from COVID-19	

36. Need for further intervention	Hospital admission after the Covid-19 (how many times, reason, name of hospital)	
36. Need for further intervention	Hospital readmission	
36. Need for further intervention	Hospitalization after SARS-CoV-2 infection	
36. Need for further intervention	Hospitalization/Rehospitalization	
36. Need for further intervention	Hospitalizations	
36. Need for further intervention	Increase in primary health care use	
36. Need for further intervention	Medical resource utilization for patients diagnosed with COVID-19	
36. Need for further intervention	Need for hospital care	
36. Need for further intervention	Number of GP visits	
36. Need for further intervention	Pediatric intensive care unit hospitalization	
36. Need for further intervention	Prescribed drugs	
36. Need for further intervention	Required a referral to a pediatric cardiologist for unspecified reasons	
36. Need for further intervention	Required physical therapy	
36. Need for further intervention	Studies performed after recovering from COVID-19	
36. Need for further intervention	Visit to other health facility after the Covid-19 (how many times, reason)	23
37. Societal/carer burden	Caregiver SARS-CoV-2 Vaccination Status	
37. Societal/carer burden	Caregiver Symptoms	
37. Societal/carer burden	Change in Caregiver SARS-CoV-2 Treatment Record	
37. Societal/carer burden	Help request because of Covid-19 consequences	4
38. Adverse events/effects	Episode of post-tussive vomiting	
38. Adverse events/effects	Adverse events	2

*Dodd S, Clarke M, Becker L, Mavergames C, Fish R, Williamson PR. A taxonomy has been developed for outcomes in medical research to help improve knowledge discovery. J Clin Epidemiol. 2018;96:84-92. doi:10.1016/j.jclinepi.2017.12.020

4. THE LIST OF OUTCOMES PRESENTED TO THE DELPHI PARTICIPANTS.

Domain name	Outcome	Lay definition
Mortality/survival	Survival	How long does someone live
Physiological/clinical	Cardiovascular functioning, symptoms, and conditions	New onset or worsening of problems affecting the heart (e.g. irregular heartbeat, palpitations, pounding or racing heartbeat, resting heartbeat changes, pericarditis/myocarditis (heart inflammation)); problems with the blood vessels (i.e., veins or arteries), changes in blood pressure
Physiological/clinical	Endocrine and metabolic functioning, symptoms, and conditions	New onset or worsening of problems related to the glands (type of body organ) that make hormones, hormonal balance (e.g. diabetes, thyroid problems, adrenal gland or steroid problems, changes in body weight, bone mineral problems), menstrual cycle, early onset of puberty
Physiological/clinical	Hearing-related functioning, symptoms, and conditions	New onset or worsening of problems with hearing (e.g., hearing loss, ringing or buzzing in the ears, increased sensitivity to sounds)
Physiological/clinical	Gastrointestinal functioning, symptoms, and conditions	New onset or worsening of problems with swallowing, stomach aches, nausea (feeling the need to vomit), vomiting, heartburn/reflux (stomach acid coming back up into the mouth and causing an unpleasant, sour taste), diarrhoea, constipation, gas, indigestion, lack of pleasure while eating (some children describe this as “food and eating is yuck”)
Physiological/clinical	Pain	New onset or worsening discomfort in the body that can include sharp or burning pain, dull ache, or stinging or throbbing, including pain that comes and goes, or is persistent, or chronic (ongoing) pain; increased sensitivity to pain (feeling pain even upon minor stimuli which have not caused pain before), inability to control pain with usual painkillers
Physiological/clinical	Fatigue or Exhaustion	New onset or worsening of feeling exhausted, having too little energy, or needing more rest, including fatigue not relieved by rest
Physiological/clinical	Sleep-related functioning, symptoms, and conditions	New onset or worsening of problems with falling or staying asleep, need for sleep medications/aids, excessive sleeping, or lack of refreshing sleep/poor sleep quality, increased nightmares and/or sleepwalking

Physiological/clinical	Muscle and joint symptoms and conditions	New onset or worsening of joint or muscle problems, such as muscle weakness or joint stiffness or swelling/inflammation
Physiological/clinical	Taste- and/or smell-related functioning, symptoms, and conditions	New onset or worsening problems with altered or reduced/loss of taste or smell (e.g., familiar things smell or taste bad or different, tasting or smelling things that are not there)
Physiological/clinical	Neuro-cognitive system functioning, symptoms, and conditions	New onset or worsening of dizziness/lightheadedness, tics (involuntary movements caused by spasm-like contractions of muscles, most commonly involving the face, mouth, eyes, head, neck or shoulders; vocal tics are sounds uttered unintentionally), fainting, headache, migraine, abnormal movements, tremors/shaking, seizures/fits, muscle twitching, tingling feelings, decreased sensation, inability to move part of the body, lack of coordination, speech difficulty; Problems with memory, communication, concentration, having "brain fog", understanding instructions, including interpretation of words; Abnormal child development (e.g. learning new skills, such as crawling/walking and talking, developmental regression)
Physiological/clinical	Mental / Psychological functioning, symptoms, and conditions	New onset or worsening problems with emotions and mood, including anxiety/worrying, panic attacks, separation anxiety, fear, aggression, irritability, anger, excessive crying, easily getting upset, feeling of guilt, depression, suicidal thoughts, or post-traumatic stress symptoms (having flashbacks to a stressful event), obsessions (intrusive unwanted thoughts) and compulsions (repetative actions or behaviours linked to obsessions)
Physiological/clinical	Kidney and urinary-related functioning, symptoms, and conditions	New onset or worsening problems with kidney function or need for dialysis or problems with urination (i.e., wee/pee) including infections, burning or stinging, higher frequency or urgency (i.e. feeling of needing), incontinence (inability to control urination/“wetting yourself”)
Physiological/clinical	Respiratory functioning, symptoms, and conditions	New onset or worsening problems with lungs or breathing (e.g., shortness of breath/shortness of air/not getting enough air, chest tightness or coughing/wheezing, problems with breathing through the nose including blocked and runny nose), sinusitis (infection of the sinuses (air-filled spaces in the bones of your face around the nose))
Physiological/clinical	Skin, hair, dental and/or nail-related functioning, symptoms, and conditions	New onset or worsening problems with ulcers, skin rash and/or peeling, itch, red spots or lumps on toes (COVID toes), hair thinning/loss, changes in nails and teeth

Physiological/clinical	Post-exertion symptoms	New onset or worsening of different symptoms following physical or mental activities or emotions that could previously be tolerated (e.g. thinking, moving, socialising), which that can last for a prolonged duration (multiple days/weeks)
Physiological/clinical	Vision-related functioning, symptoms, and conditions	New onset or worsening of problems with vision (e.g., problems seeing or blurred vision, increased sensitivity to light, colour misperception, loss of vision), dry eyes or feeling of a grit/sand in eyes
Physiological/clinical	Fever/body temperature changes	New onset or worsening of problems related to the body temperature without a known cause (e.g. fever that comes and goes, prolonged low-grade fever, chills or shivers, feeling too cold or too hot)
Life impact	Satisfaction with life, or personal enjoyment	New onset or worsening of problems with satisfaction with life or personal enjoyment, loss of being the person who you were before COVID-19, feeling "left out"/"missing out", feeling that "the world is moving, while you are stuck"
Life impact	Physical functioning, symptoms, and conditions	New onset or worsening problems with daily physical abilities (activities), including arm/leg shaking or unsteadiness, mobility, walking, dressing, playing or eating, growth
Life impact	Social role-functioning and relationships problems	New onset or worsening problems with connecting with others, including family members and friends, maintaining and creating new friendships and personal/romantic relationship, social activities
Life impact	Work/occupational and study changes	New onset or worsening problems with being able to resume usual level of work, study, attendance, less engagement/ participation in extracurricular activities
Life impact	Stigma	New onset or worsening problems with fear or experiences of being discriminated against, bullied, excluded from activities, ignored, including by employer/school/nursery/university, medical professionals, social groups, family/friends/neighbours, or others
Resource use	Healthcare resource utilisation	Seeing more healthcare professionals (e.g., doctor, physiotherapist, psychologist), taking new medications, returning to the hospital or emergency care, including complementary/alternative medicine (e.g., acupuncturists, naturopaths), medical devices/technology
Resource use	Family/carer burden	Increasing/developing a burden on caregiver/family or friends/classmates/colleagues/teachers; impact of sickness on other people in your life, including relationships between the carers

5. FULL DETAILS OF DELPHI PARTICIPANTS.

	Round 1 ***n* = 214**	**Round 2** **n=154**
Stakeholder group, *n*		
Children and young people (≤18 years old) who have experience of living with Long COVID	26	21
Family and carers of children and young people (≤18 years old) with Long COVID	115	76
Health professionals who have experience treating children and young people (≤18 years old) with Long COVID	37	32
Researchers studying Long COVID in children and young people (≤18 years old)	36	25
Other	*participants reclassified after R1 review and analysed within appropriate groups*	
Gender, n		
Male	47	34
Female	166	119
Non-binary	1	1
Other	0	0

Prefer not to answer	0	0
Age group, *n*		
2-5	1	1
6-11	5	2
12-18	21	19
18-29	5	2
30-39	35	31
40-49	94	67
50-59	45	27
60-69	7	4
70-79	1	1
>=80	0	0
Countries, *n*		

Argentina	2	2
Australia	7	5
Belarus	1	1
Belgium	1	1
Canada	5	1
Chile	2	2
Croatia	2	1
Cyprus	1	1
Czech Republic	1	1
Egypt	1	1
France	5	4
Germany	2	1
Greece	2	2

Indonesia	1	0
Ireland	3	2
Israel	1	1
Italy	6	5
Japan	1	0
Jordan	1	1
Lithuania	1	1
Malaysia	1	1
Netherlands	10	10
New Zealand	4	3
Norway	2	1
Panama	1	0
Peru	2	2

Poland	1	1
Republic of Korea	1	1
Romania	3	3
Russia	9	4
Spain	3	1
Sweden	1	0
Switzerland	1	0
Syria	1	1
Ukraine	1	0
United Kingdom	108	81
United States of America	19	12
Ethnicity, *n*		
White	180	130

South Asian	5	4
Hispanic/Latino/Spanish	8	6
East Asian/Pacific Islander	5	2
Indigenous peoples	0	0
Black	1	1
Middle Eastern/North African	6	5
Other	Mixed Asian = 1 Turkish = 1 Mixed - English/Pakistani = 1 British Indian = 1 Indian and West Indian =1 Jewish = 1 Mix: White British and South Asian = 1 This is a continuum. I identify with several =1	Turkish = 1 British Indian = 1 Indian and West Indian =1 Mixed - English/Pakistani = 1 Jewish = 1 Mix: White British and South Asian = 1

6. ATTRITION BETWEEN ROUNDS ONE AND TWO.

Stakeholder	Number registered n (% of total registrations)	Completed** R1 n (% of registered)	Number of participants invited to R2 n (% of completed R1)	Completed** R2 n (% of completed R1 and invited to R2)
CHILDREN AND YOUNG PEOPLE (≤18 YEARS OLD) WHO HAVE EXPERIENCE OF LIVING WITH POST COVID CONDITION (ALSO KNOWN AS LONG COVID)	30 (12·9)	26 (11·4)	26 (100)	21 (9·8)
FAMILY AND CARERS OF CHILDREN AND YOUNG PEOPLE (≤18 YEARS OLD) WITH LONG COVID	124 (53·5)	115 (50·4)	115 (100)	76 (35·5)
HEALTH PROFESSIONALS WHO HAVE EXPERIENCE TREATING CHILDREN AND YOUNG PEOPLE (≤18 YEARS OLD) WITH LONG COVID	37 (15·9)	37 (16.2)	37 (100)	32 (15)
RESEARCHERS STUDYING LONG COVID IN CHILDREN AND YOUNG PEOPLE (≤18 YEARS OLD)	37 (15·9)	36 (15.8)	36 (100)	25 (11·7)

TOTAL	228 (98·3)	214 (93·9)	214 (100)	154 (72)

**232 total registrations with 1 deleted as duplicate and 3 withdrawn during R1*

**Completed = completed/rated >50% of outcomes

7. RESULTS FOLLOWING TWO ROUNDS OF DELPHI AND SELECTION OF OUTCOMES FOR THE CONSENSUS MEETING

Domain	**Outcome**	**Stakeholder groups voting results**																				
		Overall result	**Children and young people (≤18 years old) with Long COVID and their family and carers**						**Result**	**Health professionals working with children and young people (≤18 years old) with Long COVID**						**Result**	**Researchers studying Long COVID in children and young people (≤18 years old)**						**Result**
			Round 1(n=141)			**Round 2(n=97)**				**Round 1(n=37)**			**Round 2(n=32)**				**Round 1(n=36)**			**Round 2(n=25)**			
			% 1-3	% 4-6	% 7-9	% 1-3	% 4-6	% 7-9		% 1-3	% 4-6	% 7-9	% 1-3	% 4-6	% 7-9		% 1-3	% 4-6	% 7-9	% 1-3	% 4-6	% 7-9	
Mortality/survival	Survival	**Discuss**	3·2	23·8	73	3·2	21·3	75·5	Medium	19·4	22·2	58·3	15·6	25	59·4	Medium	5·7	11·4	82·9	4	8	88	In
Physiological/clinical	Cardiovascular functioning; symptoms; and conditions	**In**	5·3	9·8	85	2·1	9·6	88·3	In	10·8	18·9	70·3	9·4	6·3	84·4	In	8·3	13·9	77·8	4	8	88	In
	Endocrine and metabolic functioning; symptoms;	**Out**	6·2	17·2	76·6	3·2	20·4	76·3	Medium	10·8	48·6	40·5	6·3	56·3	37·5	Out	13·9	47·2	38·9	16	56	28	Out

	and conditions																					
	Hearing-related functioning; symptoms; and conditions	**Out**	23·3	38·8	38	22·2	51·1	26·7	Out	29·7	43·2	27	34·4	53·1	12·5	Out	25·7	45·7	28·6	28	56	16	Out
	Gastrointestinal functioning; symptoms; and conditions	**Discuss**	2·2	21·3	76·5	0	15·8	84·2	In	8·1	27	64·9	6·3	12·5	81·3	In	11·1	50	38·9	16	40	44	Out
	Pain	**Discuss**	1·4	15·9	82·6	1	10·3	88·7	In	5·4	27	67·6	3·1	9·4	87·5	In	11·1	27·8	61·1	4	28	68	Medium
	Fatigue or Exhaustion	**In**	0·7	3·6	95·7	0	2·1	97.9	In	2·7	10·8	86·5	0	6·3	93·8	In	0	19·4	80·6	0	8	92	In
	Sleep-related functioning; symptoms; and conditions	**Discuss**	0·7	17·4	81·9	0	13·5	86·5	In	2·7	24·3	73	0	15·6	84·4	In	2·8	38·9	58·3	4	24	72	Medium
	Muscle and joint symptoms and conditions	**Discuss**	3·6	23·7	72·7	0	19·8	80·2	In	5·4	37·8	56·8	3·1	25	71·9	Medium	5·6	38·9	55·6	8	36	56	Medium
	Taste- and/or smell-related functioning; symptoms; and	**Out**	27·1	33·8	39·1	28	47·3	24·7	Out	16·2	35·1	48·6	21·9	40·6	37·5	Out	0	50	50	0	60	40	Out

	conditions																					
	Neuro-cognitive system functioning; symptoms; and conditions	**In**	1·5	10·9	87·6	0	5·3	94.7	In	5·4	5·4	89·2	3·1	3·1	93·8	In	2·8	13·9	83·3	0	4	96	In
	Mental / Psychological functioning; symptoms; and conditions	**Discuss**	6·5	19·4	74·1	4·2	16·8	78·9	Medium	2·7	13·5	83·8	0	3·1	96·9	In	2·8	22·2	75	0	8	92	In
	Kidney and urinary-related functioning; symptoms; and conditions	**Out**	19·7	28·3	52	22·6	36·6	40·9	Out	29·7	45·9	24·3	25	53·1	21·9	Out	25·7	42·9	31·4	29·2	54·2	16·7	Out
	Respiratory functioning; symptoms; and conditions	**Discuss**	3·8	27·5	68·7	4·3	24·7	71	Medium	5·4	27	67·6	0	18·8	81·3	In	0	11·1	88·9	0	12	88	In
	Skin; hair; dental and/or nail-related functioning; symptoms; and conditions	**Out**	18·3	45	36·6	23·4	53·2	23·4	Out	24·3	48·6	27	25	65·6	9·4	Out	22·2	61·1	16·7	32	60	8	Out

	Post-exertion symptoms	**Discuss**	0·7	5·8	93·5	0	1	99	In	10·8	13·5	75·7	0	12·5	87·5	In	8·3	36·1	55·6	8	24	68	Medium
	Vision-related functioning; symptoms; and conditions	**Out**	10·7	35·1	54·2	12·9	38·7	48·4	Out	27	51·4	21·6	28·1	59·4	12·5	Out	27·8	44·4	27·8	28	60	12	Out
	Fever/body temperature changes	**Out**	8·2	35·8	56	9·5	36·8	53·7	Medium	21·6	54·1	24·3	12·5	75	12·5	Out	22·2	55·6	22·2	16	76	8	Out
Life impact	Satisfaction with life; or personal enjoyment	**Discuss**	3	14·1	83	0	10·3	89·7	In	5·4	27	67·6	0	25	75	Medium	0	37·1	62·9	0	26·9	73·1	Medium
	Physical functioning; symptoms; and conditions	**In**	0·7	3·7	95·6	0	2·1	97·9	In	0	10·8	89·2	0	9·4	90·6	In	2·9	8·6	88·6	0	8	92	In
	Social role-functioning and relationships problems	**Discuss**	5·3	28·6	66·2	1	32	67	Medium	2·8	22·2	75	0	12·9	87·1	In	0	31·4	68·6	4	32	64	Medium
	Work/occupational and study changes	**Discuss**	2·3	14·3	83·5	0	12·2	87·8	In	2·8	16·7	80·6	0	12·9	87·1	In	2·9	25·7	71·4	0	24	76	Medium
	Stigma	**Out**	9·2	41·2	49·6	7·2	41·2	51·5	Mediu	5·7	57·1	37·1	6·5	61·3	32·3	Out	17·1	48·6	34·3	16	68	16	Out

									m														
Resource use	Healthcare resource utilisation	**Query discuss at end**	2·9	18·4	78·7	2	20·4	77·6	Medium	0	36·1	63·9	0	37·5	62·5	Medium	8·6	17·1	74·3	7·7	19·2	73·1	Medium
	Family/carer burden	**Query discuss at end**	1·5	29·6	68·9	0	21·9	78·1	Medium	2·8	22·2	75	0	28·1	71·9	Medium	0	31·4	68·6	0	24	76	Medium

Total	
In	**4**
Out	**8**
Discuss	**11**
Query discuss at end	**2**

8. Delphi process and Consensus meeting results

Domain	Outcome	Outcome description	% Children and young people/Family and carers of children and young people (≤18 years old) with Long COVID voting 7-9 in R2 of online Delphi	% HCPs voting 7-9 in R2 of online Delphi	Researchers voting 7-9 in R2 of online Delphi	% Children and young people/ Family and carers of children and young people (≤18 years old) with Long COVID voting 7-9 in consensus meeting	% HCPs/ Researchers voting 7-9 in consensus meeting	Result
Physiological/clinical outcomes	**Fatigue or Exhaustion**	New onset or worsening of feeling exhausted, having too little energy, or needing more rest, including fatigue not relieved by rest	97·9	93·8	92	N/A	N/A	Included in the COS following Delphi survey
	Neuro-cognitive system functioning, symptoms, and conditions	New onset or worsening of dizziness/lightheadedness, tics (involuntary movements caused by spasm-like contractions of muscles, most commonly involving the face, mouth, eyes, head,	94·7	93·8	96	N/A	N/A	Included in the COS following Delphi survey

		neck or shoulders; vocal tics are sounds uttered unintentionally), fainting, headache, migraine, abnormal movements, tremors/shaking, seizures/fits, muscle twitching, tingling feelings, decreased sensation, inability to move part of the body, lack of coordination, speech difficulty; Problems with memory, communication, concentration, having "brain fog", understanding instructions, including interpretation of words; Abnormal child development (e.g. learning new skills, such as crawling/walking and talking, developmental regression)						
	Cardiovascular functioning,	New onset or worsening of	88·3	84·4	88	N/A	N/A	Included in the COS

	symptoms, and conditions	problems affecting the heart (e.g. irregular heartbeat, palpitations, pounding or racing heartbeat, resting heartbeat changes, pericarditis/myocarditis (heart inflammation)); problems with the blood vessels (i.e., veins or arteries), changes in blood pressure						following Delphi survey
Life impact outcomes	**Physical functioning, symptoms, and conditions**	New onset or worsening problems with daily physical abilities (activities), including arm/leg shaking or unsteadiness, mobility, walking, dressing, playing or eating, growth	97·9	90·6	92	N/A	N/A	Included in the COS following Delphi survey
Physiological/clinical outcomes	**Post-exertion symptoms**	New onset or worsening of different symptoms following physical or mental activities or emotions that could previously be tolerated (e.g. thinking, moving, socialising), which	99	87·5	68	100	84	Included in the COS following discussion at the consensus meeting

		that can last for a prolonged duration (multiple days/weeks)						
	Gastrointestinal functioning; symptoms; and conditions	New onset or worsening of problems with swallowing, stomach aches, nausea (feeling the need to vomit), vomiting, heartburn/reflux (stomach acid coming back up into the mouth and causing an unpleasant, sour taste), diarrhoea, constipation, gas, indigestion, lack of pleasure while eating (some children describe this as "food and eating is yuck")	84·2	81·3	44	100	84	Included in the COS following discussion at the consensus meeting
Life impact outcomes	**Work/occupational and study changes**	New onset or worsening problems with being able to resume usual level of work, study, attendance, less engagement/ participation in	87·8	87·1	76	100	91	Included in the COS following discussion at the consensus meeting

		extracurricular activities						
Physiological/clinical outcomes	**Endocrine and metabolic functioning, symptoms, and conditions**	New onset or worsening of problems related to the glands (type of body organ) that make hormones, hormonal balance (e.g. diabetes, thyroid problems, adrenal gland or steroid problems, changes in body weight, bone mineral problems), menstrual cycle, early onset of puberty	76·3	37·5	28	N/A	N/A	Excluded following Delphi survey
	Hearing-related functioning, symptoms, and conditions	New onset or worsening of problems with hearing (e.g., hearing loss, ringing or buzzing in the ears, increased sensitivity to sounds)	26·7	12·5	16	N/A	N/A	Excluded following Delphi survey
	Taste- and/or smell-related functioning, symptoms, and conditions	New onset or worsening problems with altered or reduced/loss of taste or smell (e.g., familiar things	24·7	37·5	40	N/A	N/A	Excluded following Delphi survey

		smell or taste bad or different, tasting or smelling things that are not there)						
	Kidney and urinary-related functioning, symptoms, and conditions	New onset or worsening problems with kidney function or need for dialysis or problems with urination (i.e., wee/pee) including infections, burning or stinging, higher frequency or urgency (i.e. feeling of needing), incontinence (inability to control urination/"wetting yourself")	40·9	21·9	16·7	N/A	N/A	Excluded following Delphi survey
	Skin, hair, dental and/or nail-related functioning, symptoms, and conditions	New onset or worsening problems with ulcers, skin rash and/or peeling, itch, red spots or lumps on toes (COVID toes), hair thinning/loss, changes in nails and teeth	23·4	9·4	8	N/A	N/A	Excluded following Delphi survey
	Vision-related functioning,	New onset or worsening of problems with vision (e.g.,	48·4	12·5	12	N/A	N/A	Excluded following

	symptoms, and conditions*	problems seeing or blurred vision, increased sensitivity to light, colour misperception, loss of vision), dry eyes or feeling of a grit/sand in eyes						Delphi survey
	Fever/body temperature changes	New onset or worsening of problems related to the body temperature without a known cause (e.g. fever that comes and goes, prolonged low-grade fever, chills or shivers, feeling too cold or too hot)	53·7	12·5	8	N/A	N/A	Excluded following Delphi survey
Life impact outcomes	**Stigma**	New onset or worsening problems with fear or experiences of being discriminated against, bullied, excluded from activities, ignored, including by employer/school/nursery/university, medical professionals, social groups,	51·5	32·3	16	N/A	N/A	Excluded following Delphi survey

		family/friends/neighbours, or others						
Mortality outcomes	**Survival**	How long does someone live	75·5	59·4	88	27	8	Excluded following discussion at the consensus meeting
Physiological/clinical outcomes	**Sleep-related functioning; symptoms; and conditions**	New onset or worsening of problems with falling or staying asleep, need for sleep medications/aids, excessive sleeping, or lack of refreshing sleep/poor sleep quality, increased nightmares and/or sleepwalking	86·5	84·4	72	91	75	Excluded following discussion at the consensus meeting
	Muscle and joint symptoms and conditions	New onset or worsening of joint or muscle problems, such as	80·2	71·9	56	72	34	Excluded following discussion at the

		muscle weakness or joint stiffness or swelling/inflammation						consensus meeting
	Mental / Psychological functioning	New onset or worsening problems with emotions and mood, including anxiety/worrying, panic attacks, separation anxiety, fear, aggression, irritability, anger, excessive crying, easily getting upset, feeling of guilt, depression, suicidal thoughts, or post-traumatic stress symptoms (having flashbacks to a stressful event), obsessions (intrusive unwanted thoughts) and compulsions (repetative actions or behaviours linked to obsessions)	78·9	96·9	92	10	59	Excluded following discussion at the consensus meeting
	Respiratory functioning	New onset or worsening problems with lungs or breathing (e.g., shortness of	71	81·3	88	45	66	Excluded following discussion at the

		breath/shortness of air/not getting enough air, chest tightness or coughing/wheezing, problems with breathing through the nose including blocked and runny nose), sinusitis (infection of the sinuses (air-filled spaces in the bones of your face around the nose))						consensus meeting
	Pain	New onset or worsening discomfort in the body that can include sharp or burning pain, dull ache, or stinging or throbbing, including pain that comes and goes, or is persistent, or chronic (ongoing) pain; increased sensitivity to pain (feeling pain even upon minor stimuli which have not caused pain before), inability to control pain with usual painkillers	88·7	87·5	68	80	75	Excluded following discussion at the consensus meeting

Life impact outcomes	**Satisfaction with life; or personal enjoyment**	New onset or worsening of problems with satisfaction with life or personal enjoyment, loss of being the person who you were before COVID-19, feeling "left out"/"missing out", feeling that "the world is moving, while you are stuck"	89·7	75	73·1	63	34	Excluded following discussion at the consensus meeting
	Social role-functioning and relationships problems	New onset or worsening problems with connecting with others, including family members and friends, maintaining and creating new friendships and personal/romantic relationship, social activities	67	87·1	64	27	18	Excluded following discussion at the consensus meeting
Resource Use Outcomes	**Family/carer burden**	Increasing/developing a burden on caregiver/family or friends/classmates/colleagues/teachers; impact of sickness on other people in your life, including	78·1	71·9	76	100	34	Excluded following discussion at the consensus meeting

		relationships between the carers						
	Healthcare resource utilisation	Seeing more healthcare professionals (e.g., doctor, physiotherapist, psychologist), taking new medications, returning to the hospital or emergency care, including complementary/alternative medicine (e.g., acupuncturists, naturopaths), medical devices/technology	77·6	62·5	73·1	44	8	Excluded following discussions at the consensus meeting

9. PC-COS Children Project Steering Committee Group Authors

Asiah Kassim[1], Jennifer R. Chevinsky[2], Karen Choong[3], Rae Duncan[4], Susanna Esposito[5], Rebecca Foster[6], Alla Guekht[7], Allison Jaure[8], Carrie Mackenzie[9], Vivienne Matthies-Bonn[10], Karen Matvienko-Sikar[11], Lorraine McCloud[12], Donna C McParland[12], Victor Daniel Miron[13], Srinivas Murrhy[14], Sarah O Connel[12], Margaret O'Hara[15], Anna Ogonowska-Slodownik[16], Jana Pavare[17], Paula Robertson[18], Jeremy Rossman[19], Oana Sandulescu[20], Sharon H. Saydah[21], Jochen Schmitt[22], Malcolm "Calum" G. Semple[23,24], Roz Shafran[25], Ausra Snipaitiene[26], Arne Søraas[27], Terence Stephenson[28], Lola Tulen[29], Gonzalo Valenzuela Galaz[30], Kees van den Wijngaard[29], David Vickers[31], Daniel Christian Vilser[32], Michaela Waak[33], Julie Wells[12], Elizabeth Whittaker[34], Michelle Winer[12], Alan Asmanov[35], Pasquale Comberiati[36]

1 Kuala Lumpur Women and Children Hospital, Kuala Lumpur, Malaysia

2 CDC COVID-19 Emergency Response, USA

3 McMaster University, Hamilton, Canada

4 Newcastle's Freeman Hospital, Newcastle upon Tyne, UK

5 University of Parma, Parma, Italy

6 Sherwood Forest Hospitals Foundation Trust, Nottinghamshire, UK

7 Moscow Research and Clinical Centre for Neuropsychiatry, Moscow, Russia

8 The University of Sydney, Sydney, Australia

9 Sheffield Children's NHS Foundation Trust, Sheffield, UK

10 Long Covid kinderen, the Netherlands

11 University of Cork, Cork, Ireland

12 Long Covid Kids

13 Carol Davila University of Medicine and Pharmacy, Bucharest, Romania

14 University of British Columbia, Vancouver, Canada

15 Long Covid Support, London, UK

16 Faculty of Rehabilitation, Jozef Pilsudski University of Physical Education in Warsaw, Warsaw, Poland

17 Riga Stradins University, Riga, Latvia

18 Paediatric Emergency Department at Eric Williams Medical Complex, Trinidad and Tobago

19 University of Kent, Canterbury, UK

20 Department of Infectious Diseases, Faculty of Medicine, Carol Davila University of Medicine and Pharmacy, Bucharest, Roman ia and National Institute for Infectious Diseases "Prof. Dr. Matei Balş", Bucharest, Romania

21 CDC/DDID/NCIRD/DVD; CDC COVID-19 Response, USA

22 University of Dresden, Dresden, Germany

23 University of Liverpool, Liverpool, UK

24 Alder Hey Children's Hospital, Liverpool, UK

25 UCL GOS Institute of Child Health, London, UK

26 Lithuanian University of Health Sciences Pediatric Department, Kaunas, Lithuania

27 Oslo University Hospital, Oslo, Norway

28 University College London, London, UK

29 National Institute for Public Health and the Environment, Bilthoven, the Netherlands

30 Department of Paediatric Infectious Diseases and Immunology, Pontifical Catholic University of Chile, Santiago, Chile.

31 Cambridgeshire Community Services NHS Trust, Cambridgeshire, UK

32 Hospital for Pediatrics and Adolescent Medicine, Jena University Hospital, Jena, Germany

33 The University of Queensland, Brisbane, Australia

34 Imperial College London, London, UK

35 The Research and Clinical Institute for Pediatrics named after Academician Yuri Veltischev of the Pirogov Russian National Research Medical University, Moscow, Russia

36 Department of Clinical and Experimental Medicine, Section of Pediatrics, University of Pisa, Italy

10. PC-COS CHILDREN PROJECT STEERING COMMITTEE (TABLE)

Name, Middle name	Surname	Institution	Country	Expertise
EUROPEAN REGION				
Daniel	Munblit	Division of Care in Long Term Conditions, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London/Department of Paediatrics and Paediatric Infectious Diseases, Institute of Child's Health,	UK/Russia	Allergy, Paediatrics, COS development

		Sechenov First Moscow State Medical University (Sechenov University)/Research and Clinical Center for Neuropsychiatry		
Anastasia	Chernyavskaya	Department of Paediatrics and Paediatric Rheumatology, Sechenov First Moscow State Medical University (Sechenov University)/National Medical Research Center for Children's Health	Russia	Paediatrics
Nina	Seylanova	Independent researcher	UK	Critical Care, COS development
Olalekan	Aiyegbusi	University of Birmingham	UK	Outcomes Methodology
Anbarasu	Anbu	Alder Hey Children's NHS Foundation Trust	UK	Lead for CYP Long Covid and ME/CFS service at Alder Hey Children's NHS Foundation Trust Hub
Christian	Apfelbacher	University of Magdeburg	Germany	Epidemiology, COS development
Liat	Ashkenazi-Hoffnung	Schneider Children's Medical Center of Israel	Israel	Pediatric Infectious Diseases
Caroline	Brackel	Amsterdam University Medical Centers/Department of Pediatrics, Tergooi Hospital	The Netherlands	Paediatric Pulmonology
Danilo	Buonsenso	Università Cattolica del Sacro Cuore/Department of Woman and Child Health and Public Health, Fondazione Policlinico Universitario A. Gemelli IRCCS	Italy	Paediatrics, Infectious Diseases
Pasquale	Comberiati	Department of Clinical and Experimental Medicine, Section of Pediatrics, University of Pisa	Italy	Paediatrics, Allergy
Daniele	Dona'	Department for Women's and Children's Health, University of Padua	Italy	Pediatric Infectious Diseases Consultant, co-leader of the Clinical Working Group of the VERDI project (101045989), which is funded by the European Union

Audrey	DunnGalvin	University of Cork	Ireland	Psychology
Jon	Genuneit	Pediatric Epidemiology, Department of Pediatrics, Medical Faculty, Leipzig University	Germany	Immunology
Helen	Goss	Long Covid Kids	UK	Family member of a person with living experience of Long COVID
Sarah E.	Hughes	Institute of Applied Health Research, University of Birmingham	UK	Outcomes Methodology
Christina	Jones	University of Surrey	UK	Adherence, Allergy, Asthma, Behaviour change, Diabetes, Evidence synthesis, Health services research, Long term conditions, Physical and psychological health comorbidities, Psychological interventions, Research methods
Sammie	McFarland	Long Covid Kids	UK	Family member of a person with living experience of Long COVID
Timothy R	Nicholson	King's College London	UK	Neuropsychiatry
Terry	Segal	University College London Hospitals NHS Foundation Trust	UK	Adolescence, paediatric endocrinology (growth and puberty), chronic fatigue syndrome, obesity, anorexia nervosa (medical aspects), chronic medically unexplained symptoms
Louise	Sigfrid	University of Oxford	UK	Public Health, Infectious diseases
Claire	Thorne	Population, Policy and Practice Dept, University College London GOS Institute of Child Health	UK	Infectious diseases epidemiology
Susanne	Vijverberg	Amsterdam University Medical Centers	The Netherlands	Paediatric asthma
John O.	Warner	Imperial College London	UK	Allergy, Respiratory, Pediatrics

Paula R	Williamson	University of Liverpool	UK	Methodology, COS development
Sarah O	Connell	Long Covid Kids	UK	Family member of a person with living experience of Long COVID
Rae	Duncan	Newcastle's Freeman Hospital	UK	Cardiology, LCK (PPI)
Susanna	Esposito	University of Parma	Italy	Paediatrics, Infectious Diseases
Rebecca	Foster	Sherwood Forest Hospitals Foundation Trust	UK	Paediatrics
Alla	Guekht	Moscow Research and Clinical Centre for Neuropsychiatry	Russia	Neurology
Carrie	Mackenzie	Sheffield Children's NHS Foundation Trust	UK	Paediatrics
Vivienne	Matthies-Bonn	Long Covid kinderen	the Netherlands	Family member of a person with living experience of Long COVID
Karen	Matvienko-Sikar	University of Cork	Ireland	COS development
Lorraine	McCloud	Long Covid Kids	UK	Family member of a person with living experience of Long COVID
Donna C	McParland	Long Covid Kids	UK	Family member of a person with living experience of Long COVID
Victor Daniel	Miron	Carol Davila University of Medicine and Pharmacy	Romania	Paediatrics, Infectious Diseases
Margaret	O'Hara	Long Covid Support	UK	Patient and Public Involvement in Research
Anna	Ogonowska-Slodownik	Faculty of Rehabilitation, Jozef Pilsudski University of Physical Education in Warsaw	Poland	Physiotherapy and physical education
Jana	Pavare	Riga Stradins University	Latvia	Paediatrics, Infectious Diseases
Jeremy	Rossman	University of Kent	UK	Virology, Public Health

Oana	Sandulescu	Department of Infectious Diseases, Faculty of Medicine, Carol Davila University of Medicine and Pharmacy	Romania	Infectious Diseases
Jochen	Schmitt	University of Dresden	Germany	Methodology, COS development
Malcolm "Calum" G.	Semple	University of Liverpool/Alder Hey Children's Hospital	UK	Infectious Diseases
Roz	Shafran	UCL GOS Institute of Child Health	UK	Population, Policy & Practice Dept
Ausra	Snipaitiene	Lithuanian University of Health Sciences Pediatric Department	Lithuania	Paediatrics, Rheumatology
Arne	Søraas	Oslo University Hospital	Norway	Bacteriology
Terence	Stephenson	University College London	UK	Paediatrics
Lola	Tulen	National Institute for Public Health and the Environment	the Netherlands	Epidemiology
Kees	van den Wijngaard	National Institute for Public Health and the Environment	the Netherlands	Epidemiology
David	Vickers	Cambridgeshire Community Services NHS Trust	UK	Paediatrics
Daniel Christian	Vilser	Hospital for Pediatrics and Adolescent Medicine, Jena University Hospital	Germany	Pediatric Cardiology, Pediatric Emergency Medicine
Julie	Wells	Long Covid Kids	UK	Family member of a person with living experience of Long COVID
Elizabeth	Whittaker	Imperial College London	UK	Paediatrics, Infectious Diseases
Alan	Asmanov	The Research and Clinical Institute for Pediatrics named after Academician Yuri Veltischev of the Pirogov Russian National Research Medical University	Russia	Pediatrics, ENT
REGION OF THE AMERICAS				

Dale M.	Needham	Outcomes After Critical Illness and Surgery (OACIS) Research Group, Johns Hopkins University/Pulmonary and Critical Care Medicine, Department of Medicine, Johns Hopkins University School of Medicine/Physical Medicine and Rehabilitation, Johns Hopkins University School of Medicine	USA	Critical Care, Physical Medicine and Rehabilitation
Nikita	Nekliudov	Institute for Health Metrics and Evaluation, University of Washington	USA	Health Services Research
Carlos	Oliveira	Yale University School of Medicine, Department of Pediatrics, Section of Infectious Diseases/Yale University School of Public Health, Department of Biostatistics, Division of Health Informatics/Yale New Haven Children's Hospital	USA	Paediatric infectious diseases
Laura	Malone	Kennedy Krieger Institute/Johns Hopkins University	USA	Paediatric long COVID
Jennifer R.	Chevinsky	CDC COVID-19 Emergency Response	USA	Epidemiology, Population Health, Preventive Medicine
Karen	Choong	McMaster University	Canada	Paediatrics
Sharon H.	Saydah	CDC/DDID/NCIRD/DVD; CDC COVID-19 Response	USA	Epidemiology
Michelle	Winer	Long Covid Kids	USA	Family member of a person with living experience of Long COVID
Srinivas	Murthy	University of British Columbia	Canada	Critical Care, Paediatrics, Infectious Diseases
Paula	Robertson	Paediatric Emergency Department at Eric Williams Medical Complex	Trinidad and Tobago	Paediatrics
Gonzalo	Valenzuela Galaz	Pontifical Catholic University of Chile	Chile	Paediatrics, Infectious Diseases
WESTERN PACIFIC REGION				
Asiah	Kassim	Kuala Lumpur Women and Children Hospital	Malaysia	Paediatrics

Allison	Jaure	The University of Sydney	Australia	Chronic Disease, COS development
Michaela	Waak	The University of Queensland	Australia	Paediatrics, Neurology, Paediatric intensive care/Retrieval medicine
EASTERN MEDITERRANEAN REGION				
Ali Akbar	Asadi-Pooya	Epilepsy Research Center, Shiraz University of Medical Sciences/Jefferson comprehensive epilepsy center, Thomas Jefferson University	Iran/USA	Neurological/cognitive problems in long COVID
WHO				
Wouter	de Groote	WHO - Rehabilitation Team	Switzerland	Global Health, Rehabilitation Medicine
Krutika	Kuppalli	WHO	Switzerland	Infectious Diseases, Global Health
Nicoline	Schiess	WHO - Brain Health Team	Switzerland	Global health, Neurology
Wilson Milton	Were	WHO	Switzerland	Infectious Diseases, Global Health, Epidemiology
Janet Victoria	Diaz	WHO	Switzerland	Critical Care, Pulmonary Medicine, Global Health

Appendix 2

PC-COS Children 'What to measure' Consensus meeting report

THE POST-COVID CORE OUTCOME SET (PC-COS) FOR CHILDREN AND YOUNG PEOPLE

PC-COS CHILDREN

Meeting date and time: 28th April 2023

Location: Online (Zoom)

Contents

1 Summary

Following a two-round online Delphi survey an online consensus meeting was held on the 28th April 2023 to discuss outcomes where, according to the pre-agreed definition of consensus, consensus for inclusion in, or exclusion from, the core outcome set (COS) had not been reached. This report summarises these discussions and the resulting core outcome set.

2 Pre-Meeting for children and young people (≤18 years old) with Long COVID and their family and carers

Participants were invited to attend one of the pre-meeting sessions on the 26th April 2023 (10:00-10:30 AM or 5:00-5:30 PM, UK time). This session was aiming to provide information on core outcome sets and what to expect at the meeting and to offer an opportunity to meet the PC-COS Children team and to ask any outstanding questions.

3 Consensus meeting participants

Thirty-nine participants, including 9 non-voting members of the study team, four observers, one facilitator and 25 members of stakeholder groups, who had completed both rounds of the online Delphi survey, attended the online meeting. Twenty-three participants of the meeting were voting (12 health professionals/researchers, 11 children and young people (≤18 years old) with Long COVID and their family and carers). (Table 1)

Some participants were unable to attend for the entire meeting or dropped 'in' and 'out' as a result of internet connection. The final number of voting participants for each outcome is included in this report.

In the online Delphi survey, the results in Round 2 were presented for three stakeholder groups:

(a) Health professionals working with children and young people *(≤18 years old)* with Long COVID;
(b) Researchers studying Long COVID in children and young people *(≤18 years old)*;
(c) Children and young people (≤18 years old) with Long COVID and their family and carers.

All were invited to express their interest in attending the online consensus meeting on completion of Delphi survey. An additional online poll was distributed between potential meeting participants to vote for the most convenient date and time of the consensus meeting, which was scheduled for the slot preferred by most participants. Potentially interested participants were informed that the consensus meeting will be undertaken in English.

For feasibility purposes a decision was made prior to the meeting to have two voting groups only: (a) Children and young people (≤18 years old) with Long COVID and their family and carers; and (b) Health professionals/researchers. Similar approach has previously been implemented for the consensus meeting of the PC-COS adult project.

Table 1. Consensus meeting participants

	N (%)	Voting (%)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old)	**14 (100)**	**12 (100)**
Delphi stakeholder group		
Health professionals working with children and young people (≤18 years old) with Long COVID	6 (43)	6 (50)
Researchers studying Long COVID in children and young people (≤18 years old)	8 (57)	6 (50)
Country of residence		
Malaysia	1 (7)	1 (8)
Germany	1 (7)	1 (8)
Lithuania	1 (7)	1 (8)
Italy	2 (14)	2 (17)
Norway	1 (7)	1 (8)
Romania	1 (7)	1 (8)
UK	4 (29)	3 (25)
USA	3 (21)	2 (17)
Children and young people (≤18 years old) with Long COVID and their family and carers	**11 (100)**	**11 (100)**
Country of residence		
Ireland	2 (18)	2 (18)
UK	8 (73)	8 (73)
USA	1 (9)	1 (9)

4 Outcomes

Twenty-five outcomes were rated in Round 2 of the online Delphi survey. The pre-agreed definition of consensus (Appendix 1) was applied to ratings submitted in Round 2 for each of the three stakeholder groups: (a) Children and young people (≤18 years old) with Long COVID; (b) Health professionals who have experience treating children and young people (≤18 years old) with Long COVID; (c) Researchers studying Long COVID in children and young people (≤18 years old).

As a result of the Delphi survey, four outcomes met a priori definition for "consensus in" to be included in the core outcome set and eight met the definition of "consensus out" and were excluded from the core outcome set. During the consensus meeting 13 outcomes were discussed: 11 outcomes with no consensus but at least one group voted "in" and two outcomes with no "in" or "out" votes.

At the consensus meeting the outcomes for discussion were presented along with the outcomes from the same domain, already included in the COS. Meeting participants were then invited to provide comments on outcomes and their value for the COS. After outcome discussion, participants were asked to anonymously rate each outcome using the 1-9 Likert scale (1 "not that important" – 9 "critically important"). Voting was organised by the study team using Zoom Video Communications Inc (Zoom) online polling mode. The discussion and rating of outcomes was facilitated by an experienced independent facilitator.

4.1 Selection of outcomes for consensus meeting discussion

Outcomes that reached the definition of consensus after Round 2 of the Delphi survey were presented prior to the voting. (Appendix 2)

Eleven outcomes with at least one group voted "in" (but not fulfilling the criteria of the consensus 'in') were presented for discussion at the consensus meeting. Two outcomes with no "in" or "out" votes after Round 2 of the Delphi survey ("Healthcare resource utilisation", "Family/carer burden") were presented at the end of the voting process.

4.2 Outcomes discussed in the consensus meeting

4.2.1 Mortality outcomes

One outcome "survival" was prioritised for discussion in the mortality domain.

Survival

During the meeting participants were mainly acknowledging the great importance of survival outcome, but as mortality rate among paediatric population with post-COVID-19 condition is known to be very low, the general agreement was that "survival" is not critical enough to be included in the core outcome set.

Outcome of discussion and rating:

Outcome: Survival	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=11)	4 (36)	4 (36)	3 (27)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=13)	8 (66)	3 (25)	1 (8)
Result	**Outcome not included in COS**		

4.2.2 Physiological/clinical outcomes Mortality outcomes

The physiological/clinical domain included seven outcomes:

- Post-exertion symptoms
- Mental / Psychological functioning; symptoms; and conditions
- Respiratory functioning; symptoms; and conditions

- Pain
- Sleep-related functioning; symptoms; and conditions
- Gastrointestinal functioning; symptoms; and conditions
- Muscle and joint symptoms and conditions

Post-exertion symptoms

All participants (11/11, 100%) representing the "children and young people (≤18 years old) with Long COVID and their family and carers" group were in favour of this outcome inclusion in the core outcome set, highlighting great importance of this feature for children and young people with post-COVID-19 condition. Parents of the child(-ren) with Long COVID believe that post-exertion symptoms are hard to recognise by general practitioners, so they are convinced that it is crucial to include this outcome in the core outcome set. It was also commented that this outcome is often named by the family members as the one substantially associated with reduction in quality of life. Health professionals/ researchers were providing similar feedback and during voting most of them suggested that this outcome is critical (5/12 voted "9", 5/12 voted "8"), with 17% (2/12) considering the outcome important, but not critical enough to be included in the COS.

Outcome: Post-exertion symptoms	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=11)	0	0	11 (100)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	0	2 (17)	10 (84)
Result	**Outcome included in COS**		

Mental/Physiological functioning symptoms; and conditions

Stakeholders from both groups, including health professionals, researchers and representatives from "Children and young people (≤18 years old) with Long COVID and their family and carers", have expressed their concerns about the challenges associated with distinguishing whether a child was already, prior to COVID infection, experiencing mental health issues or mental health issues are the consequence of Long COVID condition. This fact limits the possibility of including the mental/physiological functioning symptoms and conditions in the core outcome set. It was also highlighted by one of the participants from the "Children and young people (≤18 years old) with Long COVID and their family and carers" group, that a significant number of parents are troubled and hesitant to discuss mental problems of their child with healthcare providers, as they and their children are often not understood and the symptoms of their children are often attributed to mental health diseases. Overall, representatives of this stakeholder group was supportive of this view and although acknowledged importance of this outcome, they felt that it is not critical enough to be assessed in every study, particularly considering potential stigmatisation of children and young people.

Outcome: Mental/Physiological functioning symptoms; and conditions	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=10)	3 (30)	6 (60)	1 (10)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	0	5 (42)	7 (59)
Result	**Outcome not included in COS**		

Respiratory functioning; symptoms; and conditions

Health professionals and researchers acknowledged the significance of respiratory symptoms and outcomes in children who have experienced COVID-19. They noted that while children generally experience milder symptoms of COVID-19 compared to adults, the aftermath can manifest in significant respiratory symptoms. On the other hand, carers provided a more intimate and personal account, reflecting the lingering challenges faced by their children. One carer recounted how their child, even two years post-infection, still struggles with breathlessness during routine activities such as dressing or climbing stairs. Another carer brought up the issue of chest tightness and the sensation of not getting enough air, which many children reportedly experience. They raised questions about how this symptom relates to Post-Exertional Malaise (PEM), a term often associated with other post-viral syndromes. From a medical perspective, a health professional clarified that PEM encompasses any physical or mental symptom resulting from exertion, not solely respiratory issues. However, the distinction between direct respiratory issues and symptoms that arise due to exertion remained a topic of concern for carers.

It was also noted that even after employing multiple examination methods, major findings are often absent. However, children still report feelings of chest tightness and breathlessness following minor physical activity or emotional stress. Consequently, parents find it challenging to differentiate between symptoms of respiratory function and post-exertional malaise, which can be attributed to various physical or mental issues. Given that most parents lack medical training, they struggle to discern between these two categories of symptoms. As a result, not all members from the group "Children and young people (≤18 years old) with Long COVID and their family and carers" are in favour of including respiratory functioning symptoms and conditions in the COS.

Outcome: Respiratory functioning; symptoms; and conditions	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=11)	1 (9)	5 (45)	5 (45)

Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	0	4 (34)	8 (66)
Result	**Outcome not included in COS**		

Pain

Carers predominantly voiced concerns about the chronic pains their children experienced following a COVID-19 infection. A recurring sentiment was that pain, particularly chronic pain, is a crucial outcome that often goes dismissed by some medical professionals. One carer highlighted the importance of recognising pain as an outcome, especially as it might be linked to other symptoms such as anxiety. Another shared a personal experience where their son suffered from a persistent headache for 18 months, and a consultant suggested the cause might be superficial – like having a 'top knot' – or even attention-seeking. Such experiences of having genuine pain symptoms dismissed were distressing for parents.

Carers also attested to the prevalence of pain in children with post-COVID-19 condition. They described it as widespread, manifesting in various forms such as migraines, muscle pain, abdominal pain, and musculoskeletal pain. Another carer noted that while pain is common in paediatric long COVID, it's a broad symptom that might not be unique to the condition. Thus, while it is essential to recognise, they expressed uncertainty about whether it should be prioritised as a critical outcome. However, the overall sentiment was that pain was both common and a significant concern for those with post-COVID-19 condition. That is why for most of the parents this outcome is critical. Health professionals and researchers were reiterating that several conditions could cause pain, and the outcome did not reach the threshold of 80% necessary for inclusion into COS.

Outcome: Pain	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=10)	0	2 (20)	8 (80)

Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	2 (17)	1 (8)	9 (75)
Result	**Outcome not included in COS**		

Sleep-related functioning; symptoms; and conditions

Almost all participants from the "children and young people (≤18 years old) with Long COVID and their family and carers" group believe that sleep-related functioning should be definitely included in the COS. Carers voiced significant concerns regarding their children's sleep disturbances post-COVID-19. One carer described their child's severe insomnia, noting the cyclical nature of the condition where increased fatigue exacerbated the insomnia. Another carer stressed the critical importance of assessing sleep due to its profound influence on various domains of a child's life. They pointed out that disturbances in sleep could impact cognitive function, pain, daily life functioning, and fatigue. As such, without a thorough assessment of sleep, it becomes challenging to understand or address other related domains effectively. This sentiment was echoed by another carer who reinforced the idea that sleep disturbances are a common symptom amongst children with the post-COVID-19 condition. A young participant raised an insightful question regarding the relationship between sleep and pain, pondering whether pain might be causing sleep disturbances or if a lack of sleep could intensify pain. This view has been reflected by the predominance (91%) of "children and young people (≤18 years old) with Long COVID and their family and carers" voting for inclusion into COS.

From a health professional and researcher's perspective, the importance of assessing sleep as an outcome was acknowledged. The professional pointed out that if sleep is chosen as a critical outcome, then the next step would be to determine the tools and methods to measure it effectively. Such an evaluation would not only consider the quantity of sleep but would also delve deeper to ascertain the reasons behind sleep disturbances, whether that be pain, breathing difficulties, or other factors.

However, although the outcome has been recognised as very important, it did not reach the necessary threshold as 75% of 'health professionals and researchers' voted this outcome as critical. Some concerns were raised suggesting that several factors may lead to sleep disturbance, making it difficult to measure this outcome.

Outcome: Sleep-related functioning, symptoms, and conditions	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=11)	0	1 (9)	10 (91)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	1 (8)	2 (16)	9 (75)
Result	**Outcome not included in the COS**		

Gastrointestinal functioning; symptoms; and conditions

Discussions were overall toned for "inclusion" of this outcome in the COS. One of the health professional-participants highlighted the recurrent observation of GI symptoms in their clinical practice, noting the often-elongated period it takes to establish a connection between these symptoms and a prior COVID-19 infection. One carer provided a personal perspective, sharing the struggles their daughter faced. Their child became intolerant to numerous foods following her bout with COVID-19, which, in turn, negatively affected her quality of life, energy levels, and appetite. This intolerance also necessitated the intake of multiple medications and supplements. Several other carers voiced concerns over GI dysfunctions being more prevalent in children than in adults. This was supported by statements highlighting the increase in children requiring feeding tubes or being diagnosed with conditions like coeliac disease. A sentiment that gained traction was that GI issues seem to be more widespread in children with long COVID than in their adult counterparts, even though adults are not entirely immune to these symptoms. Furthering this dialogue, another health professional concurred with the high incidence of GI symptoms they observed in their clinic. Another carer expressed that the vast majority of children encounter

GI challenges at some stage in their long COVID trajectory, whether that manifests as nausea, new “food allergies”, persistent stomach aches, or digestion issues.

Health professionals chimed in on the significance of these symptoms, suggesting that chronic GI symptoms may be more specific to children than other broader health challenges. There was also a reference to emerging evidence supporting the notion of viral persistence in the GI tracts of children post-COVID.

All representatives of the “Children and young people (≤18 years old) with Long COVID and their family and carers” (12/12, 100%) considered this outcome critical, while 10/12, 84% health professionals and researchers voted for inclusion of the outcome in the COS.

Outcome: Gastrointestinal functioning; symptoms; and conditions	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=11)	0	0	11 (100)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	0	2 (16)	10 (84)
Result	**Outcome included in COS**		

Muscle and joint symptoms and conditions

From the carers' perspective, muscle and joint symptoms were prevalent, though some believed they weren't as common as headaches. The distinction between muscle/joint symptoms and fatigue was emphasised by a health professional who noted that some parents often conflate muscle/joint problems with fatigue and/or post-exertional malaise. There was a shared understanding among the carers that the pain experienced in the joints was

distinct. This was not due to deconditioning, a term they were often confronted with to explain away the symptoms. It was not linked to PEM either. Instead, the pain was consistent, and it typically manifested in similar joints among many children. However, there was some debate about its prevalence and its significance as a primary outcome. A few carers provided personal experiences: one mentioned their daughter faced the se symptoms daily, hampering her participation in activities and diminishing her overall quality of life. Another carer raised the possibility of exploring the connection between muscle pains, “hypermobility", and “connective tissue disorders”. For many, muscle pain and weakness seemed to be an everyday reality, affecting various body parts from the calves to the neck.

Healthcare professionals and researchers flagged it as a relatively frequently observed symptom in children with post-COVID condition. A distinction was made between various types of pain, from joint pain to muscle fatigue, and it was emphasised that not including pain as an outcome could be an oversight.

In summary, although the consensus meeting showcased a collective recognition of muscle and joint symptoms post-COVID in children and young people; neither “Children and young people (≤18 years old) with Long COVID and their family and carers” or “health professionals/researchers” voted the outcome as critical enough to be included in the COS.

Outcome: Muscle and joint symptoms and conditions	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=11)	0	3 (27)	8 (72)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	3 (25)	5 (42)	4 (34)
Result	**Outcome not included in COS**		

4.2.3 Life impact outcomes

The life impact domain includes three outcomes:

- Work/occupational and study changes
- Satisfaction with life; or personal enjoyment
- Social role-functioning and relationships problems (voted "out" according to the Delphi 2nd round)

Work/occupational and study changes

Almost all participants from each stakeholder group (100% – family and children, 91% – healthcare and researchers) agreed that this outcome should definitely be included in the core outcome set. During the consensus meeting it was noted by one researcher that in most of the studies this aspect is deprived of attention and that could explain why the difference between Long COVID and non-COVID children was not detected, so the lack of this outcome in most of the studies contributes to the misunderstanding of Long COVID.

Long COVID causes a range of issues that affect not only children, but also those who care for them. The majority of these children are unable to attend school and have to have a reduced timetable and have online learning. This makes it difficult for them to grasp knowledge, perform well academically, and socially engage with their peers. During consensus meeting a special attention was paid to extracurricular activity: due to their chronic condition children could not participate in any of the sports and activities that they used to enjoy before they experienced COVID-19 infection, which is a major concern for carers. The inability of children to attend school has an impact on the entire family, as parents have to stay home and take "days off work" in order to take care of their child. Thus, this outcome concerns the children and their parents, so almost all of the voting participants suggested that this outcome is critical and should be included in the final COS.

Outcome: Work/occupational and study changes	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=9)	0	0	9 (100)

Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	0	1 (8)	11 (91)
Result	**Outcome included in COS**		

Satisfaction with life; or personal enjoyment

Parents of children with Long COVID believe that due to the Long COVID the satisfaction with life of children has been changed. Due to the inability to attend school, to do extracurricular activities and lack of social engagement children can not live their life like before and escape from reflections on their condition. From the carer perspective, there was a deep sense of the profound impact post-COVID conditions had on the affected children's lives. A parent shared the drastic transformation their daughter underwent post-infection: from being a sporty, academic individual to becoming housebound and dependent on a wheelchair for more extended mobility. Such drastic changes, they pointed out, severely affected the child's identity and consequently, her quality of life and her overall life satisfaction. Drawing a poignant contrast, the parent highlighted how their child, while alive, wasn't truly living and enjoying her life. A young person further emphasised this outcome's importance, highlighting the emotional and social toll. Missing school, losing the opportunity to socialise with friends, and not being able to partake in previously enjoyed activities was a source of significant distress. The participant voiced concerns about the potential cascading effect on mental and psychological well-being and asserted the outcome's inclusion.

However, “health professionals/researchers” displayed some reservations. One researcher pondered whether aspects like socialisation, school attendance, and sports, which directly influence life satisfaction, were adequately covered under another outcome ("life impact and functioning"). They questioned if the outcome of "satisfaction with life" might be seen as a mere consequence of these daily impacts, akin to how mental health was perceived in previous discussions. Drawing parallels, they alluded to concerns about how addressing "satisfaction with life" might mirror earlier challenges faced when discussing mental health. Another health professional interjected with a contrasting viewpoint, advocating for the inclusion of this outcome. While acknowledging concerns related to the mental health outcome, they argued that "satisfaction with life" offered a less contentious avenue to delve into the emotional well-being of the children, which could be more readily embraced by patients and their families.

In essence, the meeting accentuated the multifaceted implications of post-COVID-19 condition on children's lives, from their physical abilities to their emotional well-being. While there was a shared acknowledgment of the profound effects, the best approach to measure and address these impacts remained a point of discussion and did not reach the required threshold for inclusion in any of the stakeholder groups.

Satisfaction with life, or personal enjoyment	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=11)	2 (18)	2 (18)	7 (63)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	3 (25)	5 (42)	4 (34)
Result	**Outcome not included in COS**		

Social functioning and relationships problems

One carer suggested that aspects of social functioning were inherently intertwined with school outcomes. Given that children's primary social sphere is often centred around school, they found it challenging to distinguish between the two outcomes and questioned the need for redundancy. Echoing a similar sentiment, a health professional drew parallels between this outcome and school functioning. They pointed out that tangible aspects like school and sports attendance offer a more objective measurement framework, unlike the more abstract concept of general satisfaction. In their view, this general satisfaction was largely a by-product of the more tangible metrics like school attendance and the quality of relationships.

Another carer believed that the essence of "Social functioning and relationships problems" had already been encompassed in a previous core outcome. They raised an interesting perspective that while some individuals might become more insular post-COVID, it doesn't necessarily equate to unhappiness

or dissatisfaction. Their stance was that if individuals feel contented with their life, then by extension, they are likely satisfied with their current level of social functioning.

There was a general agreement from the participants from both stakeholder groups that this outcome is similar to “Satisfaction with life; or personal enjoyment”. The participants gravitated towards the idea that the outcome of "Social functioning and relationships problems" might be too interwoven with other outcomes, particularly those related to school. The challenge lay in discerning its unique value amid other outcomes that seemingly encompass its core elements.

Social role-functioning and relationships problems	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=11)	1 (9)	7 (63)	3 (27)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=11)	4 (36)	5 (45)	2 (18)
Result	**Outcome not included in COS**		

4.2.4 Resource use outcomes

This domain included two outcomes with no groups – no groups voted “in” or “out”:

- Healthcare resource utilisation
- Family/carer burden

Healthcare resource utilisation

A young person with lived experience of long COVID shared their personal perspective, underscoring the significant role that healthcare plays in their daily life. From consistent doctor visits to taking medications, healthcare interactions have become an integral aspect of their existence. They emphasised the need to evaluate how healthcare resources are assisting children grappling with the condition. On the other hand, a health professional brought up the inherent challenges in measuring this outcome. They noted the extensive variability in healthcare experiences not only across different countries but even within individual countries. They highlighted that many factors, such as familial organisation and regional differences, contribute to this variability. Moreover, the treatment approach often differs based on the healthcare professional, making it a multifaceted issue. A carer, reflecting on their UK-based experience, expressed the intricate nature of healthcare resource utilisation. They shared that it took over 18 months for their child to receive an official diagnosis of long COVID. The carer attributed this delay not merely to capacity issues but also to the chronic nature of the condition. The advice they received was to avoid seeking appointments for chronic conditions that lacked treatments. This made the process cumbersome and highlighted the complexities involved. Another carer emphasised the importance of monitoring healthcare resource utilisation due to the inconsistent experiences of families. They argued that the treatment received and access to it widely differed, indicating a lack of a standardised care pathway. They strongly believed that geographic location or place of residence shouldn't dictate the quality or access to care, insisting on the need for a comprehensive understanding of standard healthcare and its effectiveness.

There was a strong agreement between participants representing both stakeholder groups that although this outcome is important it is not critical enough to be included in the COS, particularly as it may vary across geographies, from one medical centre to another.

Outcome: Healthcare resource utilisation	**% rating 1-3**	**% rating 4-6**	**%rating 7-9**
Children and young people (≤18 years old) with Long COVID and their family and carers (n=9)	1 (11)	4 (44)	4 (44)

Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	2 (16)	9 (75)	1 (8)
Result	**Outcome not included in COS**		

Family/carer burden

All representatives from the "Children and young people (≤18 years old) with Long COVID and their family and carers" group found this outcome critical and viewed the carer burden as underestimated. Many carers shared personal testimonies on the multifaceted challenges they face as they support their children with long COVID. One carer articulated that the effects are not just emotional and psychological but also economic, affecting a broad spectrum of households. They pointed out that parents of children with long COVID often grapple with the capacity to maintain their jobs, thus intensifying the overarching burden. They felt that this burden was considerably underestimated and merited some form of measurement to understand its true magnitude.

Echoing this sentiment, another carer mentioned that the ramifications had forced them to change jobs and curtail their working hours, impacting their home circumstances and finances. The implication was clear: having a child with long COVID invariably alters a family's dynamics, from its emotional fabric to its economic stability. While a health professional acknowledged the gravity of the situation, stating the need to assist these families, the narratives of carers were profound. One self-employed carer revealed a substantial cutback in their work hours to support their child with long COVID. Another carer expressed their inability to continue working at all, illustrating the drastic shift in their financial state since their children fell chronically ill with the condition.

As for voting, the health professionals and researchers agreed that the burden on families and caregivers is very important, but the outcome is not too critical to be included in the COS.

Outcome: Family/carer burden	% rating 1-3	% rating 4-6	%rating 7-9
Children and young people (≤18 years old) with Long COVID and their family and carers (n=8)	0	0	8 (100)
Health professionals working with children and young people (≤18 years old) with Long COVID/ Researchers studying Long COVID in children and young people (≤18 years old) (n=12)	2 (17)	6 (50)	4 (34)
Result	**Outcome not included in COS**		

5 Discussion

Four outcomes were included in the core outcome set after the two round online Delphi survey and work/occupational and study changes, post-exertion symptoms, gastrointestinal functioning; symptoms; and conditions were added at the consensus meeting.

Table 2. Outcomes included in the Core Outcome Set

Domain	Outcome	Outcome description
Physiological/ Clinical Outcomes	**Cardiovascular functioning; symptoms; and conditions**	New onset or worsening of problems affecting the heart (e.g. pounding or racing heart) and the blood vessels (e.g., veins or arteries)
	Fatigue or Exhaustion	New onset or worsening in severity or duration of feeling exhausted, having too little energy, or needing more rest

	Neuro-cognitive system functioning; symptoms, and conditions	New onset or worsening of dizziness/lightheadedness, tics (involuntary movements caused by spasm-like contractions of muscles, most commonly involving the face, mouth, eyes, head, neck or shoulders; vocal tics are sounds uttered unintentionally), fainting, headache, migraine, abnormal movements, tremors/shaking, seizures/fits, muscle twitching, tingling feelings, decreased sensation, inability to move part of the body, lack of coordination, speech difficulty; Problems with memory, communication, concentration, having "brain fog", understanding instructions, including interpretation of words; Abnormal child development (e.g. learning new skills, such as crawling/walking and talking, developmental regression)
	Post-exertion symptoms	New onset or worsening of different symptoms following physical or mental activities or emotions that could previously be tolerated (e.g. thinking, moving, socialising), which that can last for a prolonged duration (multiple days/weeks)
	Gastrointestinal functioning; symptoms; and conditions	New onset or worsening of problems with swallowing, stomach aches, nausea (feeling the need to vomit), vomiting, heartburn/reflux (stomach acid coming back up into the mouth and causing an unpleasant, sour taste), diarrhoea, constipation, gas, indigestion, lack of pleasure while eating (some children describe this as “food and eating is yuck”)
Life Impact Outcomes	**Physical functioning; symptoms; and conditions**	New onset or worsening problems with physical abilities, including muscle strength, arm/leg shaking or unsteadiness, walking, dressing, or eating
	Work/occupational and study changes	New onset or worsening problems with being able to resume usual level of work, study, attendance, less engagement/ participation in extracurricular activities

References

1. Tong A, Baumgart A, Evangelidis N, et al. Core Outcome Measures for Trials in People With Coronavirus Disease 2019: Respiratory Failure, Multiorgan Failure, Shortness of Breath, and Recovery. *Crit Care Med*. 2021;49(3):503-516. doi:10.1097/CCM.0000000000004817

Appendix 1

Pre-defined definition of consensus applied in the consensus meeting

Consensus classification	Description	Definition
Consensus in	Consensus that outcome should be included in the core outcome set	80% or more of participants in each group rating the outcome 7-9
Consensus out	Consensus that outcome should not be included in the core outcomes set	50% or fewer in each group scoring 7-9
No consensus	Uncertainty about importance of outcome	Anything else

Appendix 2

Delphi process and Consensus meeting results

Domain	Outcome	Outcome description	% Children and young people/Family and carers of children and young people (≤18 years old) with Long COVID voting 7-9 in R2 of online Delphi	% HCPs voting 7-9 in R2 of online Delphi	Researchers voting 7-9 in R2 of online Delphi	% Children and young people/ Family and carers of children and young people (≤18 years old) with Long COVID voting 7-9 in consensus meeting	% HCPs/ Researchers voting 7-9 in consensus meeting	Result
Physiological/ clinical outcomes	**Fatigue or Exhaustion**	New onset or worsening of feeling exhausted, having too little energy, or needing more rest, including fatigue not relieved by rest	97·9	93·8	92	N/A	N/A	Included in the COS following Delphi survey
	Neuro-cognitive system functioning, symptoms, and conditions	New onset or worsening of dizziness/lightheadedness, tics (involuntary movements caused by spasm-like contractions of muscles, most commonly involving the face, mouth, eyes, head, neck or shoulders; vocal tics are sounds uttered unintentionally), fainting, headache, migraine, abnormal movements, tremors/shaking, seizures/fits, muscle twitching, tingling	94·7	93·8	96	N/A	N/A	Included in the COS following Delphi survey

		feelings, decreased sensation, inability to move part of the body, lack of coordination, speech difficulty; Problems with memory, communication, concentration, having "brain fog", understanding instructions, including interpretation of words; Abnormal child development (e.g. learning new skills, such as crawling/walking and talking, developmental regression)						
	Cardiovascular functioning, symptoms, and conditions	New onset or worsening of problems affecting the heart (e.g. irregular heartbeat, palpitations, pounding or racing heartbeat, resting heartbeat changes, pericarditis/myocarditis (heart inflammation)); problems with the blood vessels (i.e., veins or arteries), changes in blood pressure	88·3	84·4	88	N/A	N/A	Included in the COS following Delphi survey
Life impact outcomes	**Physical functioning, symptoms, and conditions**	New onset or worsening problems with daily physical abilities (activities), including arm/leg shaking or unsteadiness, mobility, walking,	97·9	90·6	92	N/A	N/A	Included in the COS following Delphi survey

		dressing, playing or eating, growth						
Physiological/ clinical outcomes	**Post-exertion symptoms**	New onset or worsening of different symptoms following physical or mental activities or emotions that could previously be tolerated (e.g. thinking, moving, socialising), which that can last for a prolonged duration (multiple days/weeks)	99	87·5	68	100	84	Included in the COS following discussion at the consensus meeting
	Gastrointestinal functioning; symptoms; and conditions	New onset or worsening of problems with swallowing, stomach aches, nausea (feeling the need to vomit), vomiting, heartburn/reflux (stomach acid coming back up into the mouth and causing an unpleasant, sour taste), diarrhoea, constipation, gas, indigestion, lack of pleasure while eating (some children describe this as “food and eating is yuck”)	84·2	81·3	44	100	84	Included in the COS following discussion at the consensus meeting
Life impact outcomes	**Work/occupational and study changes**	New onset or worsening problems with being able to resume usual level of work, study, attendance, less engagement/ participation in extracurricular activities	87·8	87·1	76	100	91	Included in the COS following discussion at the consensus meeting

Physiological/ clinical outcomes	**Endocrine and metabolic functioning, symptoms, and conditions**	New onset or worsening of problems related to the glands (type of body organ) that make hormones, hormonal balance (e.g. diabetes, thyroid problems, adrenal gland or steroid problems, changes in body weight, bone mineral problems), menstrual cycle, early onset of puberty	76·3	37·5	28	N/A	N/A	Excluded following Delphi survey
	Hearing-related functioning, symptoms, and conditions	New onset or worsening of problems with hearing (e.g., hearing loss, ringing or buzzing in the ears, increased sensitivity to sounds)	26·7	12·5	16	N/A	N/A	Excluded following Delphi survey
	Taste- and/or smell-related functioning, symptoms, and conditions	New onset or worsening problems with altered or reduced/loss of taste or smell (e.g., familiar things smell or taste bad or different, tasting or smelling things that are not there)	24·7	37·5	40	N/A	N/A	Excluded following Delphi survey
	Kidney and urinary-related functioning, symptoms, and conditions	New onset or worsening problems with kidney function or need for dialysis or problems with urination (i.e., wee/pee) including infections, burning or stinging, higher frequency or urgency (i.e. feeling of needing),	40·9	21·9	16·7	N/A	N/A	Excluded following Delphi survey

		incontinence (inability to control urination/"wetting yourself")						
	Skin, hair, dental and/or nail-related functioning, symptoms, and conditions	New onset or worsening problems with ulcers, skin rash and/or peeling, itch, red spots or lumps on toes (COVID toes), hair thinning/loss, changes in nails and teeth	23·4	9·4	8	N/A	N/A	Excluded following Delphi survey
	Vision-related functioning, symptoms, and conditions*	New onset or worsening of problems with vision (e.g., problems seeing or blurred vision, increased sensitivity to light, colour misperception, loss of vision), dry eyes or feeling of a grit/sand in eyes	48·4	12·5	12	N/A	N/A	Excluded following Delphi survey
	Fever/body temperature changes	New onset or worsening of problems related to the body temperature without a known cause (e.g. fever that comes and goes, prolonged low-grade fever, chills or shivers, feeling too cold or too hot)	53·7	12·5	8	N/A	N/A	Excluded following Delphi survey

Life impact outcomes	**Stigma**	New onset or worsening problems with fear or experiences of being discriminated against, bullied, excluded from activities, ignored, including by employer/school/nursery/university, medical professionals, social groups, family/friends/neighbours, or others	51·5	32·3	16	N/A	N/A	Excluded following Delphi survey
Mortality outcomes	**Survival**	How long does someone live	75·5	59·4	88	27	8	Excluded following discussion at the consensus meeting
Physiological/ clinical outcomes	**Sleep-related functioning; symptoms; and conditions**	New onset or worsening of problems with falling or staying asleep, need for sleep medications/aids, excessive sleeping, or lack of refreshing sleep/poor sleep quality, increased nightmares and/or sleepwalking	86·5	84·4	72	91	75	Excluded following discussion at the consensus meeting
	Muscle and joint symptoms and conditions	New onset or worsening of joint or muscle problems, such as muscle weakness or joint stiffness or swelling/inflammation	80·2	71·9	56	72	34	Excluded following discussion at the consensus meeting
	Mental / Psychological functioning	New onset or worsening problems with emotions and mood, including	78·9	96·9	92	10	59	Excluded following discussion at

		anxiety/worrying, panic attacks, separation anxiety, fear, aggression, irritability, anger, excessive crying, easily getting upset, feeling of guilt, depression, suicidal thoughts, or post-traumatic stress symptoms (having flashbacks to a stressful event), obsessions (intrusive unwanted thoughts) and compulsions (repetative actions or behaviours linked to obsessions)						the consensus meeting
	Respiratory functioning	New onset or worsening problems with lungs or breathing (e.g., shortness of breath/shortness of air/not getting enough air, chest tightness or coughing/wheezing, problems with breathing through the nose including blocked and runny nose), sinusitis (infection of the sinuses (air-filled spaces in the bones of your face around the nose))	71	81·3	88	45	66	Excluded following discussion at the consensus meeting
	Pain	New onset or worsening discomfort in the body that can include sharp or burning pain, dull ache, or stinging or	88·7	87·5	68	80	75	Excluded following discussion at the consensus meeting

		throbbing, including pain that comes and goes, or is persistent, or chronic (ongoing) pain; increased sensitivity to pain (feeling pain even upon minor stimuli which have not caused pain before), inability to control pain with usual painkillers						
Life impact outcomes	**Satisfaction with life; or personal enjoyment**	New onset or worsening of problems with satisfaction with life or personal enjoyment, loss of being the person who you were before COVID-19, feeling "left out"/"missing out", feeling that "the world is moving, while you are stuck"	89·7	75	73·1	63	34	Excluded following discussion at the consensus meeting
	Social role-functioning and relationships problems	New onset or worsening problems with connecting with others, including family members and friends, maintaining and creating new friendships and personal/romantic relationship, social activities	67	87·1	64	27	18	Excluded following discussion at the consensus meeting
Resource Use Outcomes	**Family/carer burden**	Increasing/developing a burden on caregiver/family or friends/classmates/colleagues/teachers; impact of sickness on other people in your life, including relationships between the carers	78·1	71·9	76	100	34	Excluded following discussion at the consensus meeting

	Healthcare resource utilisation	Seeing more healthcare professionals (e.g., doctor, physiotherapist, psychologist), taking new medications, returning to the hospital or emergency care, including complementary/alternative medicine (e.g., acupuncturists, naturopaths), medical devices/technology	77·6	62·5	73·1	44	8	Excluded following discussions at the consensus meeting

Appendix 3

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1. Outcome measure instrument selection methods

The outcome measurement instruments were selected from those used in published and ongoing studies and research protocols for post-COVID-19 condition in children for each outcome domain. The literature set was collected and evaluated in a systematic review conducted by a comprehensive search of Medline, Embase, the WHO COVID-19 Research Database (from inception until December 29, 2021). Clinical trial protocols were identified from two clinical trial registries (ICTRP database and ClinicalTrials.gov). Additional search was performed on June 1, 2023 to screen for recent evidence. All articles and protocols were evaluated independently by two researchers (NS, AC, AM, ND, AA, LX, PB, PR, KA). After data extraction outcome measurement instruments were categorised by the core group into 3 types: scales/questionnaires, laboratory tests and clinical assessment tools. Instruments requiring trained personnel, additional software, clinical facilities, or not pertaining to "core outcomes" were excluded by core group pre-Delphi.

A list of remaining instruments was anonymously reviewed by a group of independent international experts - 11 healthcare professionals and researchers. They provided feedback on each instrument and suggested potential additions, which were assessed for feasibility and applicability by the core group. Approved new instruments were presented in the second round for further review. Experts were reminded to evaluate each instrument's feasibility and suitability, specifically for diverse settings and the paediatric population. In the second round, each expert received an anonymised feedback-incorporated list of instruments. After reviewing the comments from the first round, they had the liberty to modify their initial selection or retain it. Each expert indicated their preference for each instrument's inclusion in the consensus workshop. Instruments that garnered "include" or "maybe" responses from more than half of the experts were forwarded to the consensus workshop.

2. Example instrument card*

THE POST-COVID CORE OUTCOME SET (PC-COS)
FOR CHILDREN AND YOUNG PEOPLE

PC-COS CHILDREN

INSTRUMENT CARD

Outcome 1: Cardiovascular functioning, symptoms, and conditions

Description: New onset or worsening of problems affecting the heart (e.g. irregular heartbeat, palpitations, pounding or racing heartbeat, resting heartbeat changes, pericarditis/myocarditis
(heart inflammation)); problems with the blood vessels (i.e., veins or arteries), changes in blood pressure.

GENERAL INSTRUCTIONS

As a first step of this project **seven outcomes** were selected as the most critical for children and young people with Long Covid, forming a Core Outcome Set.

Now we need to decide on the most appropriate instruments to be used for the assessment of each of these outcomes.

Please thoroughly review the list of prioritised instruments provided. For each instrument, you will find a summary and expert feedback regarding its appropriateness for assessing Long Covid in children and young people.

Prioritise: As you review each instrument, consider which one you believe is the most suitable for assessing each outcome in children and young people with Long Covid. This selection should be made considering the instrument's feasibility (i.e., can be used in all settings) and suitability for the paediatric population.

Consideration of Expert Feedback: Read through the feedback provided by a group of eleven international experts. However, please note that it is entirely up to you to decide which of the instruments you prioritise over the others, and we will have a chance to discuss this at the meeting.

Keep the balance: Strive to strike a balance between an instrument's reliability and feasibility for research and clinical practice. The most effective tools will both provide reliable outcomes and be practical to use in a variety of settings.

Voting at the workshop: During the workshop, you will have the opportunity to discuss and vote for the most appropriate instrument for each outcome ranking them. The goal of this process is to reach a consensus on the best tools for assessing long Covid outcomes in children and young people.

Contents

Full instrument samples were provided for every instrument for consensus workshop participants' review

Instruments Summary Information

Outcome 1: Cardiovascular functioning, symptoms, and conditions

Description: New onset or worsening of problems affecting the heart (e.g. irregular heartbeat, palpitations, pounding or racing heartbeat, resting heartbeat changes, pericarditis/myocarditis (heart inflammation)); problems with the blood vessels (i.e., veins or arteries), changes in blood pressure.

Instrument	Link	Time to complete	N of items	Age group	Validation in children	Languages	Cost
PedsQL™ Cardiac Module	https://drive.google.com/file/d/1hjmQtxVmC42mg4d11668W_ROjTPUk-n_/view	3-5 minutes	Toddlers (age 2-4): 23 items Young Children (ages 5-7): 25 items Children, Teens, Young Adults and Adults: 27 items	Self reported and Parent-reported: Toddlers (2-4 years) Young Child (5-7 years Child (8-12 years) Adolescent (13-18 years) Young Adult (18-25 years) Self-reported only: Adults (>26 years)	Yes	Available in multiple languages (100+)	Free and commercial licence available
Symptom Burden Questionnaire for Long COVID (Circulation scale)	https://drive.google.com/file/d/1pKHaHjqDW9NqyfIIIJEE_khAkJbEfL5Z/view	1-2 minutes (Circulation scale)	4 items (Circulation scale)	Adults 18+	No	US English Chinese, Arabic, Japanese	Free and commercial licence available
Malmo POTS score (MAPS)	https://drive.google.com/file/d/1W02IQPmeFdscWUEWyDw8hYASwU_Es44R/view	5 minutes	12 items	Adults 18+	No	English, Swedish	Free
The information provided in the table is accurate to the best of our knowledge							

Experts review *(Experts were asked to select instruments that should be discussed at the meeting from a long list of instruments. Only instruments that will be discussed at the meeting are presented)*

Measurement instruments	Decision after two rounds of revision

	1	2	3	4	5	6	7	8	9	10	11
PedsQL™ Cardiac Module	Include	Include	Maybe	Include	Include	Include	Include	Include	Include	Include	Include
Symptom Burden Questionnaire for Long COVID (Circulation scale)	*Unvoted*	Maybe	Include	Maybe	Include	Maybe	Maybe	Include	Include	Include	*Unvoted*
Postural orthostatic tachycardia syndrome (POTS)	*Unvoted*	Exclude	Maybe	Exclude	Maybe	Include	Maybe	Exclude	Maybe	Include	Include

Summary of additional comments from the experts

PedsQL™ Cardiac Module	Some experts express difficulties in understanding the module and indicate potential issues with its accessibility. Yet, others appreciate the PedsQL, a well-validated and widely used questionnaire set, often favoured in most studies due to its generic quality of life assessment, which may be more appropriate than other cardiac-specific measures. Experts also acknowledge the scale's beneficial features, like ability to use in a paper format, existence of age-specific questions, and the inclusion of cognitive scores. Despite this, some criticise its relevance to specific outcomes, suggesting that several questions may not pertain to the interest outcomes, and others may make assumptions such as “past surgery”. Its applicability for younger children was also raised as a concern, with its current format may require in-person interactions for accurate rating.
Symptom Burden Questionnaire for Long COVID (Circulation scale)	Experts have expressed mixed views about the given scale. The scale was originally developed for adults, and while some believe it's adaptable for children, others note that it would require modification and validation for paediatric populations. The clarity in defining degrees of severity, such as mild, moderate, and severe, was considered not easy to implement. Despite being in development, some experts appreciate the scale's design, finding it comprehensive and potentially superior to other outcome measures if certain sections were removed. However, they caution that it's not fully validated yet, and its reliance on a 7-day recall period might be insufficient given the fluctuating nature of many symptoms. It's also viewed as a feasible tool that captures relevant aspects of Long COVID, yet it notably lacks a focus on chest pain. Adaptation of this tool for younger people is currently underway.
Postural orthostatic tachycardia syndrome (POTS)	Some experts believe that this instrument is not ideal for children, particularly younger ones, implying that it may be more suitable for older children or adults. Others point out that it also incorporates questions for several non-cardiac issues, suggesting it may be too broad in scope. There is a consensus that some of the questions are too specific to POTS or that they are replicated in other questionnaires, making it less unique or potentially redundant. Despite these criticisms, some experts found the questionnaire straightforward, and believe that the content is appropriate and relevant, though there are reservations regarding the psychometrics of the scale.

3. List of unique outcome measures for COS outcomes

COS outcome	Outcome Measure	Result
Cardiovascular functioning, symptoms and conditions	PedsQL™ Cardiac Module	Excluded following discussions at consensus meeting
	Symptom Burden Questionnaire for Long COVID (Circulation scale)	Excluded following discussions at consensus meeting
	Malmo POTS score (MAPS)	Excluded following discussions at consensus meeting
	ADHD Cardiac screening questionnaire	Excluded following expert Delphi process*
	Paediatric Sudden Cardiac Arrest Signal questions	Excluded following expert Delphi process*
	SCL-90 Scale	Excluded by core group prior to expert Delphi (not feasible)
	ISARIC COVID-19 Health and Wellbeing Follow-Up Survey for Children	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Questionnaire (adapted for children from the adult WHO CRF for post-COVID-19 conditions) by Vanesa Seery et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9892252/bin/mmc2.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Telephone follow-up using standardised clinical proforma by Cara J Bossley et al. (https://assets.researchsquare.com/files/rs-1001103/v1/1c14f9553af8d1d272de0e35.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Telephone interview using original questionnaire by Ali A Asadi-Pooya et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8414448/bin/12519_2021_457_MOESM2_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Self-reported data through a mobile application by Erika Molteni et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8443448/bin/mmc1.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Ellinor Sterky et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8444740/bin/APA-110-2578-s001.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original survey for paediatricians by Giuseppe Fabio Parisi et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8467017/table/children-08-00769-t001/?report=objectonly)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Ieva Roge et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8586002/bin/Data_Sheet_2.PDF)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original online survey for the children's parent/guardian by Maria Zavala et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8767867/bin/ciab991_suppl_Supplementary_Data.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Roxane Dumont et al. (https://static-content.springer.com/esm/art%3A10.1038%2Fs41467-022-34616-	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)

	8/MediaObjects/41467_2022_34616_MOESM1_ESM.pdf)	
	Original online questionnaire by Adriana Prato et al. (12887_2023_4035_MOESM1_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Limor Adler et al. (https://bmjopen.bmj.com/content/bmjopen/suppl/2023/02/21/bmjopen-2022-064155.DC1/bmjopen-2022-064155supp001_data_supplement.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	B-type natriuretic peptide	Excluded by core group prior to expert Delphi (laboratory investigation)
	Blood tests - Troponin	Excluded by core group prior to expert Delphi (laboratory investigation)
	Pro-BNP	Excluded by core group prior to expert Delphi (laboratory investigation)
	Troponin I	Excluded by core group prior to expert Delphi (laboratory investigation)
	Troponin T	Excluded by core group prior to expert Delphi (laboratory investigation)
	12-lead electrocardiogram	Excluded by core group prior to expert Delphi (clinical investigation)
	24 hours ambulatory ECG recording	Excluded by core group prior to expert Delphi (clinical investigation)
	24hr ECG	Excluded by core group prior to expert Delphi (clinical investigation)
	6MWT	Excluded by core group prior to expert Delphi (clinical investigation)
	Angiogram	Excluded by core group prior to expert Delphi (clinical investigation)
	Blood pressure	Excluded by core group prior to expert Delphi (clinical investigation)
	Cardiac examination	Excluded by core group prior to expert Delphi (clinical investigation)
	Cardiac MRI	Excluded by core group prior to expert Delphi (clinical investigation)
	Cardiac ultrasound	Excluded by core group prior to expert Delphi (clinical investigation)
	Cardiopulmonary exercise test	Excluded by core group prior to expert Delphi (clinical investigation)
	CT-pulmonary angiograms	Excluded by core group prior to expert Delphi (clinical investigation)
	Detailed echocardiography	Excluded by core group prior to expert Delphi (clinical investigation)

	Doppler Ultrasound (Baseline blood flow measurements in the brachial artery)	Excluded by core group prior to expert Delphi (clinical investigation)
	Doppler Ultrasound (Flow-mediated vasodilation (VMF) in the brachial artery)	Excluded by core group prior to expert Delphi (clinical investigation)
	ECG	Excluded by core group prior to expert Delphi (clinical investigation)
	Echocardiogram	Excluded by core group prior to expert Delphi (clinical investigation)
	Echocardiographical M mode - LateraL E/E‘ ratio	Excluded by core group prior to expert Delphi (clinical investigation)
	Echocardiographical M mode - Left atrial to aortic ratio	Excluded by core group prior to expert Delphi (clinical investigation)
	Echocardiographical M mode - Left ventricular ejection fraction	Excluded by core group prior to expert Delphi (clinical investigation)
	Echocardiographical M mode - Left ventricular end diastolic diameter	Excluded by core group prior to expert Delphi (clinical investigation)
	Echocardiographical M mode - Left ventricular posterior wall diameter	Excluded by core group prior to expert Delphi (clinical investigation)
	Echocardiographical M mode - Mitral septal E/E‘, M/S ratio	Excluded by core group prior to expert Delphi (clinical investigation)
	Electrocardiogram Conduction block	Excluded by core group prior to expert Delphi (clinical investigation)
	Electrocardiogram including arrhythmia	Excluded by core group prior to expert Delphi (clinical investigation)
	Electrocardiogram ST-T change	Excluded by core group prior to expert Delphi (clinical investigation)
	Exercise stress test	Excluded by core group prior to expert Delphi (clinical investigation)
	Heart rate	Excluded by core group prior to expert Delphi (clinical investigation)
	Holter	Excluded by core group prior to expert Delphi (clinical investigation)
	Medical imaging of the heart	Excluded by core group prior to expert Delphi (clinical investigation)
	Non-contrast cardiac MRI	Excluded by core group prior to expert Delphi (clinical investigation)
	Oscillometric BP device	Excluded by core group prior to expert Delphi (clinical investigation)
	Peripheral vascular examination	Excluded by core group prior to expert Delphi (clinical investigation)
	Stress test using treadmill ergometry	Excluded by core group prior to expert Delphi (clinical investigation)

	Tissue Doppler	Excluded by core group prior to expert Delphi (clinical investigation)
Gastrointestinal functioning, symptoms, and conditions	PedsQL™ Gastrointestinal Symptoms Scales	Included in the COMS as a measurement instrument for "Gastrointestinal functioning, symptoms, and conditions"
	Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS)	Excluded following discussions at consensus meeting
	Symptom Burden Questionnaire for Long COVID (Stomach and Digestion Scale)	Excluded following discussions at consensus meeting
	EAT-10 score	Excluded following expert Delphi process*
	Section within the SCL-90 scale	Excluded following expert Delphi process*
	Original questionnaire by Mostafa M. Khodeir et al. (http://www.plosone.org/article/fetchSingleRepresentation.action?uri=info:doi/10.1371/journal.pone.0260259.s002)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Telephone follow-up using standardised clinical proforma by Cara J Bossley et al. (https://assets.researchsquare.com/files/rs-1001103/v1/1c14f9553af8d1d272de0e35.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Luise Borch et al. (https://static-content.springer.com/esm/art%3A10.1007%2Fs00431-021-04345-z/MediaObjects/431_2021_4345_MOESM1_ESM.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Telephone interview using original questionnaire by Ali A Asadi-Pooya et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8414448/bin/12519_2021_457_MOESM2_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Self-reported data through a mobile application by Erika Molteni et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8443448/bin/mmc1.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original survey for paediatricians by Giuseppe Fabio Parisi et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8467017/table/children-08-00769-t001/?report=objectonly)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Ieva Roge et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8586002/bin/Data_Sheet_2.PDF)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original online survey for the children's parent/guardian by Maria Zavala et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8767867/bin/ciab991_suppl_Supplementary_Data.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	CLoCk Questionnaire by Terence Stephenson et al. (https://www.thelancet.com/cms/10.1016/S2352-4642(22)00022-0/attachment/15f4036a-7343-461f-9399-85fcb36b5042/mmc1.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Roxane Dumont et al. (https://static-content.springer.com/esm/art%3A10.1038%2Fs41467-022-34616-8/MediaObjects/41467_2022_34616_MOESM1_ESM.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)

	Original online questionnaire by Adriana Prato et al. (12887_2023_4035_MOESM1_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Questionnaire (adapted for children from the adult WHO CRF for post-COVID-19 conditions) by Vanesa Seery et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9892252/bin/mmc2.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Measuring stomach reflux symptom by Visual Analog Score (VAS)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	ISARIC COVID-19 Health and Wellbeing Follow-Up Survey for Children	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Blood analysis	Excluded by core group prior to expert Delphi (laboratory investigation)
	Albumin	Excluded by core group prior to expert Delphi (laboratory investigation)
	Triglycerides	Excluded by core group prior to expert Delphi (laboratory investigation)
	Total cholesterol	Excluded by core group prior to expert Delphi (laboratory investigation)
	Total Bilirubin	Excluded by core group prior to expert Delphi (laboratory investigation)
	Stool Sample (faeces or rectal swab)	Excluded by core group prior to expert Delphi (laboratory investigation)
	Alkaline phosphatase (ALP)	Excluded by core group prior to expert Delphi (laboratory investigation)
	Metagenomic sequencing on rectal swabs/stools	Excluded by core group prior to expert Delphi (laboratory investigation)
	Amilase	Excluded by core group prior to expert Delphi (laboratory investigation)
	Alanine Aminotransferase (ALT)	Excluded by core group prior to expert Delphi (laboratory investigation)
	Aspartate Aminotransferase (AST)	Excluded by core group prior to expert Delphi (laboratory investigation)
	Bilirubin	Excluded by core group prior to expert Delphi (laboratory investigation)
	Gamma-glutamyl Transferase (GGT)	Excluded by core group prior to expert Delphi (laboratory investigation)
	Lactate Dehydrogenase (LDH)	Excluded by core group prior to expert Delphi (laboratory investigation)
	Faecal routine test	Excluded by core group prior to expert Delphi (laboratory investigation)
	Lipase	Excluded by core group prior to expert Delphi (laboratory investigation)

	Volume-Viscosity Swallowing Test (V-VST)	Excluded by core group prior to expert Delphi (clinical investigation)
	Abdominal examination	Excluded by core group prior to expert Delphi (clinical investigation)
	Abdominal ultrasound	Excluded by core group prior to expert Delphi (clinical investigation)
Fatigue or Exhaustion	PedsQL™ Multidimensional Fatigue Scale	Included in the COMS as a measurement instrument for "Fatigue or Exhaustion"
	Chalder fatigue questionnaire	Excluded following discussions at consensus meeting
	PROMIS Paediatric Fatigue	Excluded following discussions at consensus meeting
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	Excluded following discussions at consensus meeting
	Multidimensional Fatigue Inventory, MFI-20	Excluded following expert Delphi process*
	Fried Frailty phenotype	Excluded following expert Delphi process*
	Bell's Functionality Score	Excluded following expert Delphi process*
	ISARIC COVID-19 Health and Wellbeing Follow-Up Survey for Children	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Modified Rankin scale (mRS)	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	pedsFACIT-F	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	Question verbally on the phone, "In the last month, have you felt tired for a great part of the day?"	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Limor Adler et al. (https://bmjopen.bmj.com/content/bmjopen/suppl/2023/02/21/bmjopen-2022-064155.DC1/bmjopen-2022-064155supp001_data_supplement.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original online questionnaire by Adriana Prato et al. (12887_2023_4035_MOESM1_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	CLoCk Questionnaire by Terence Stephenson et al. (https://www.thelancet.com/cms/10.1016/S2352-4642(22)00022-0/attachment/15f4036a-7343-461f-9399-85fcb36b5042/mmc1.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Mostafa M. Khodeir et al. (http://www.plosone.org/article/fetchSingleRepresentation.action?uri=info:doi/10.1371/journal.pone.0260259.s002)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Telephone follow-up using standardised clinical proforma by Cara J Bossley et al. (https://assets.researchsquare.com/files/rs-1001103/v1/1c14f9553af8d1d272de0e35.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Luise Borch et al. (https://static-content.springer.com/esm/art%3A10.1007%2Fs00431-021-04345-z/MediaObjects/431_2021_4345_MOESM1_ESM.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)

	Standardised clinic proforma by Daniela Say et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8057863/bin/mmc1.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Telephone interview using original questionnaire by Ali A Asadi-Pooya et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8414448/bin/12519_2021_457_MOESM2_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Self-reported data through a mobile application by Erika Molteni et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8443448/bin/mmc1.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	An original questionnaire by Ellinor Sterky et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8444740/bin/APA-110-2578-s001.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original survey for paediatricians by Giuseppe Fabio Parisi et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8467017/table/children-08-00769-t001/?report=objectonly)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Ieva Roge et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8586002/bin/Data_Sheet_2.PDF)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Questionnaire (adapted for children from the adult WHO CRF for post-COVID-19 conditions) by Vanesa Seery et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9892252/bin/mmc2.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Roxane Dumont et al. (https://static-content.springer.com/esm/art%3A10.1038%2Fs41467-022-34616-8/MediaObjects/41467_2022_34616_MOESM1_ESM.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
Post-exertion symptoms	CDC symptom inventory for CFS	Excluded following discussions at consensus meeting
	PEM items from DePaul Symptom Questionnaire	Excluded following discussions at consensus meeting
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	Excluded following discussions at consensus meeting
	ISARIC COVID-19 Health and Wellbeing Follow-Up Survey for Children	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Roxane Dumont et al. (https://static-content.springer.com/esm/art%3A10.1038%2Fs41467-022-34616-8/MediaObjects/41467_2022_34616_MOESM1_ESM.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
Neuro-cognitive system functioning, symptoms, and condition	Peds QL Cognitive Functioning Scale	Included in the COMS as a measurement instrument for "Neuro-cognitive system functioning, symptoms, and conditions"
	PROMIS Pediatric Cognitive Function - Short Form 7a	Excluded following discussions at consensus meeting
	Symptom Burden Questionnaire for Long COVID (Memory, Thinking & Communication scale, movement scale, muscles and joints, pain scales)	Excluded following discussions at consensus meeting
	Addenbrooke's Cognitive Examination (ACE-III)	Excluded following expert Delphi process*

	ASQ assessment (for infants born >29 weeks gestation)	Excluded following expert Delphi process*
	Bayley-IV neurological examination	Excluded following expert Delphi process*
	Chalder fatigue scale	Excluded following expert Delphi process*
	From Body Vigilance Scale (BVS)	Excluded following expert Delphi process*
	Functional Independence measure (FIM)	Excluded following expert Delphi process*
	IQCODE	Excluded following expert Delphi process*
	Short Blessed Test	Excluded following expert Delphi process*
	Vanderbilt ADHD assessment	Excluded following expert Delphi process*
	NIH Toolbox	Excluded following expert Delphi process*
	ISARIC COVID-19 Health and Wellbeing Follow-Up Survey for Children	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	MentalPlus® (a scale of assessment and cognitive rehabilitation)	Excluded by core group prior to expert Delphi (not applicable in low-resource settings)
	Modified Rankin scale (mRS)	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	Montreal Cognitive Assessment	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	SCL-90 scale	Excluded by core group prior to expert Delphi (not feasible)
	SDQ (Hyperactivity scale)	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWS)	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	Original questionnaire by Limor Adler et al. (https://bmjopen.bmj.com/content/bmjopen/suppl/2023/02/21/bmjopen-2022-064155.DC1/bmjopen-2022-064155supp001_data_supplement.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Roxane Dumont et al. (https://static-content.springer.com/esm/art%3A10.1038%2Fs41467-022-34616-8/MediaObjects/41467_2022_34616_MOESM1_ESM.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Mostafa M. Khodeir et al. (http://www.plosone.org/article/fetchSingleRepresentation.action?uri=info:doi/10.1371/journal.pone.0260259.s002)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Telephone follow-up using standardised clinical proforma by Cara J Bossley et al. (https://assets.researchsquare.com/files/rs-1001103/v1/1c14f9553af8d1d272de0e35.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Luise Borch et al. (https://static-content.springer.com/esm/art%3A10.1007%2Fs00431-021-04345-z/MediaObjects/431_2021_4345_MOESM1_ESM.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)

	Telephone interview using original questionnaire by Ali A Asadi-Pooya et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8414448/bin/12519_2021_457_MOESM2_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Self-reported data through a mobile application by Erika Molteni et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8443448/bin/mmc1.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	An original questionnaire by Ellinor Sterky et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8444740/bin/APA-110-2578-s001.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Ieva Roge et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8586002/bin/Data_Sheet_2.PDF)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original online survey for the children's parent/guardian by Maria Zavala et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8767867/bin/ciab991_suppl_Supplementary_Data.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	CLoCk Questionnaire by Terence Stephenson et al. (https://www.thelancet.com/cms/10.1016/S2352-4642(22)00022-0/attachment/15f4036a-7343-461f-9399-85fcb36b5042/mmc1.pdf)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original online questionnaire by Adriana Prato et al. (12887_2023_4035_MOESM1_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Questionnaire (adapted for children from the adult WHO CRF for post-COVID-19 conditions) by Vanesa Seery et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9892252/bin/mmc2.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	NSE, S100B, neurofilament proteins in blood	Excluded by core group prior to expert Delphi (laboratory investigation)
	Attention Bias test of automatic biases towards disease-associated words	Excluded by core group prior to expert Delphi (requires trained personnel)
	Function Acquisition Speed Test	Excluded by core group prior to expert Delphi (requires trained personnel)
	Hopkins Verbal Learning Test-Revised (HVLT-R)	Excluded by core group prior to expert Delphi (requires trained personnel)
	Behavior Rating Inventory of Executive Function 2nd Edition (BRIEF-2)	Excluded by core group prior to expert Delphi (requires trained personnel)
	California Verbal Learning Test Children's Version (CVLT-C)	Excluded by core group prior to expert Delphi (requires trained personnel)
	Child and Adolescent Memory Profile List (ChAMP) List	Excluded by core group prior to expert Delphi (requires trained personnel)
	Conners Comprehensive Behavior Rating Scale (Conners CBRS)	Excluded by core group prior to expert Delphi (not feasible)

	Conners Early Childhood (Conners EC)	Excluded by core group prior to expert Delphi (not feasible)
	Delis Kaplan Executive Functioning System Verbal Fluency (D-KEFS)	Excluded by core group prior to expert Delphi (requires trained personnel)
	MVP Verbal Subtest and Reliable Digit Span	Excluded by core group prior to expert Delphi (requires trained personnel)
	NEPSY-II Auditory Attention	Excluded by core group prior to expert Delphi (requires trained personnel)
	Oral Symbol Digits Modalities Test (SDMT)	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	Test of Everyday Attention of Children Score (TEA-Ch Score)	Excluded by core group prior to expert Delphi (requires trained personnel)
	Wechsler Intelligence Scale for Children 5th Edition Digit Span (WISC-V)	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	Digit Span forward and backward test	Excluded by core group prior to expert Delphi (requires trained personnel)
	The Babinski reflex	Excluded by core group prior to expert Delphi (clinical investigation)
	Hoffman's sign	Excluded by core group prior to expert Delphi (clinical investigation)
	Brain fMRI during resting state and a fatigue-provoking test	Excluded by core group prior to expert Delphi (clinical investigation)
	Neurological examination	Excluded by core group prior to expert Delphi (clinical investigation)
Physical functioning, symptoms, and conditions	EQ5D (family of instruments)	Included in the COMS as a measurement instrument for "Physical functioning, symptoms, and conditions"
	PROMIS Early Childhood Parent Report Physical Activity 7a	Excluded following discussions at consensus meeting
	PROMIS Pediatric Physical Activity – Short Form 8a	Excluded following discussions at consensus meeting
	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	Excluded following discussions at consensus meeting
	Barthel Index	Excluded following expert Delphi process*
	Basic Activity of Daily Living (BADL)	Excluded following expert Delphi process*
	Clinical Frailty Scale (CFS)	Excluded following expert Delphi process*
	Duke Activity Status Index (DASI)	Excluded following expert Delphi process*
	Fried Frailty phenotype	Excluded following expert Delphi process*
	Functional Independence Measure (WeeFIM or FIM)	Excluded following expert Delphi process*
	International Physical Activity Questionnaires Short Form (IPAQ-SF)	Excluded following expert Delphi process*
	Post COVID-19 Functional Status Scale (Scale 0-64 points)	Excluded following expert Delphi process*

	PROMIS Pediatric Physical Activity – Short Form 4a	Excluded following expert Delphi process*
	Bell's Functionality Score	Excluded following expert Delphi process*
	The motor skills module activity questionnaire (MOMO) (Available in German only)	Excluded following expert Delphi process*
	Global Physical Activity Questionnaire (GPAQ)	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	Growth indices	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	ISARIC COVID-19 Health and Wellbeing Follow-Up Survey for Children	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Functional Status Scale (FSS)	Excluded by core group prior to expert Delphi (requires trained personnel)
	Medical Outcome Study Short Form (MOS SF)-36 Score	Excluded by core group prior to expert Delphi (not suitable for the purpose of this COS)
	Short Physical Performance Battery (SPPB)	Excluded by core group prior to expert Delphi (clinical investigation)
	Telephone follow-up using standardised clinical proforma by Cara J Bossley et al. (https://assets.researchsquare.com/files/rs-1001103/v1/1c14f9553af8d1d272de0e35.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Telephone interview using original questionnaire by Ali A Asadi-Pooya et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8414448/bin/12519_2021_457_MOESM2_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	An original questionnaire by Ellinor Sterky et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8444740/bin/APA-110-2578-s001.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Ieva Roge et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8586002/bin/Data_Sheet_2.PDF)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original online questionnaire by Adriana Prato et al. (12887_2023_4035_MOESM1_ESM.docx)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Pulse oximetry (SpO2) at rest, before 6-minute walk test	Excluded by core group prior to expert Delphi (clinical investigation)
	Pulse oximetry (SpO2) during exercise, at the end of 6-minute walk test	Excluded by core group prior to expert Delphi (clinical investigation)
	Incremental Cardiopulmonary exercise test (Dyspnea during exercise, 10-point categorical Borg scale)	Excluded by core group prior to expert Delphi (clinical investigation)
	Incremental Cardiopulmonary exercise test (Inspiratory capacity during exercise, L and % of predicted)	Excluded by core group prior to expert Delphi (clinical investigation)
	Incremental Cardiopulmonary exercise test (Minute-ventilation/carbon dioxide output during exercise (L/L))	Excluded by core group prior to expert Delphi (clinical investigation)

	Incremental Cardiopulmonary exercise test (Oxygen uptake at peak exercise (% of predicted))	Excluded by core group prior to expert Delphi (clinical investigation)
	Incremental Shuttle Walk Test (SWT)	Excluded by core group prior to expert Delphi (clinical investigation)
	Berg Balance Test	Excluded by core group prior to expert Delphi (clinical investigation)
	Standardised stadiometer (calculating standard deviation, growth curves, and growth speed)	Excluded by core group prior to expert Delphi (clinical investigation)
	Actigraph (3D accelerometer) model G-Walk during the 10 metre gait test	Excluded by core group prior to expert Delphi (clinical investigation)
	Actigraph (3D accelerometer) model G-Walk during the 6-minute walk test	Excluded by core group prior to expert Delphi (clinical investigation)
	Actigraph (3D accelerometer) model G-Walk used during the "timed up and go" test	Excluded by core group prior to expert Delphi (clinical investigation)
	Musculoskeletal ultrasound	Excluded by core group prior to expert Delphi (clinical investigation)
	ActivPAL	Excluded by core group prior to expert Delphi (clinical investigation)
	Six-minute walk test	Excluded by core group prior to expert Delphi (clinical investigation)
Work/ occupational and study changes	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	Excluded following discussions at consensus meeting
	WHO DAS 2 Children and Youth 36-Item Version	Excluded following discussions at consensus meeting
	Work Productivity and Activity Impairment Questionnaire: General Health V2.0 (WPAI:GH)	Excluded following expert Delphi process*
	ISARIC COVID-19 Health and Wellbeing Follow-Up Survey for Children	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Original questionnaire by Ieva Roge et al. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8586002/bin/Data_Sheet_2.PDF)	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)
	Number of absent days from school/work due to illness	Excluded by core group prior to expert Delphi (non-validated questionnaire/CRF)

*- Did not meet a priori predefined criteria (“include” or “maybe” responses from more than half of the experts)

4. Full details of expert Delphi participants

Name	Surname	Gender	Institution	Country	Stakeholder group (HCP/Researcher)	Primary expertise related to Long COVID

Ali Akbar	Asadi-Pooya	Male	Epilepsy Research Center, Shiraz University of Medical Sciences; Jefferson comprehensive epilepsy center, Thomas Jefferson University	Iran/USA	Health professional/Researcher	Neurological/cognitive problems in long COVID
Dr Anbarasu Theodore	Anbu	Male	Alder Hey Children's NHS Foundation Trust	United Kingdom	Health professional, Paediatrician	Lead for CYP Long Covid and ME/CFS service at Alder Hey Children's NHS Foundation Trust Hub
Carlos R.	Oliveira	Male	Yale University School of Medicine	USA	Health professional/Researcher	Diagnosis and treatment of paediatric Long COVID patients.
Danilo	Buonsenso	Male	Fondazione Policlinico Universitario A. Gemelli IRCCS	Italy	Health professional/Researcher	Paediatric infectious diseases
Sarah	Hughes	Female	University of Birmingham	United Kingdom	Researcher	Outcome measure development (patient-reported outcomes
Laura	Malone	Female	Kennedy Krieger Institute & Johns Hopkins	USA	Health professional/Researcher	Paediatric long COVID
Liat	Ashkenazi-Hoffnung	Female	Schneider Children's Medical Center	Israel	Health professional	Pediatric Infectious Diseases
Olalekan Lee	Aiyegbusi	Male	University of Birmingham	United Kingdom	Researcher	Patient and public involvement lead for the NIHR-funded TLC Study. Conducted reviews of long COVID literature and was involved in the development of the SBQ a PRO measure for assessing symptoms of long COVID
Daniele	Dona'	Male	Department for Women's and Children's Health, University of Padua	Italy	Researcher	Pediatric Infectious Diseases Consultant, co-leader of the Clinical Working Group of the VERDI project (101045989), which is funded by the European Union.
Claire	Thorne	Female	Population, Policy and Practice Dept, University College London GOS	United Kingdom	Researcher	Infectious diseases epidemiology

			Institute of Child Health			
Terry	Segal	Female	University College London Hospitals NHS Foundation Trust	United Kingdom	Health professional/Researcher	Adolescence, paediatric endocrinology (growth and puberty), chronic fatigue syndrome, obesity, anorexia nervosa (medical aspects), chronic medically unexplained symptoms

5. Results following expert Delphi

Outcome 1: Cardiovascular functioning, symptoms, and conditions

Measurement instruments	Round of expert Delphi	Expert voting										
		1	2	3	4	5	6	7	8	9	10	11
PedsQL™ Cardiac Module	Round 1	Maybe	Include	Exclude	Maybe	Include	Include	Include	Include	Maybe	Include	Include
	Round 2	Include	Include	Maybe	Include	Include	Include	Include	Include	Include	Include	Include
ADHD Cardiac screening questionnaire	Round 1	Exclude	Exclude	Maybe	Maybe	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude	Exclude
	Round 2	Exclude	Exclude	Maybe	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
Paediatric Sudden Cardiac Arrest Signal questions	Round 1	Exclude	Exclude	Maybe	Exclude	Maybe	Maybe	Maybe	Exclude	Exclude	Exclude	Maybe
	Round 2	Exclude	Exclude	Maybe	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe
Symptom Burden Questionnaire for Long COVID (Circulation scale)	Round 1	NEWLY SUGGESTED										

	Round 2	*Unvoted*	Maybe	Include	Maybe	Include	Maybe	Maybe	Include	Include	Include	*Unvoted*
Malmo POTS score (MAPS)	Round 1	NEWLY SUGGESTED										
	Round 2	*Unvoted*	Exclude	Maybe	Exclude	Maybe	Include	Maybe	Exclude	Maybe	Include	Include

Measurement instruments	**Summary of additional comments from the experts in rounds 1/2**
PedsQL™ Cardiac Module	Some experts express difficulties in understanding the module and indicate potential issues with its accessibility. Yet, others appreciate the PedsQL, a well-validated and widely used questionnaire set, often favoured in most studies due to its generic quality of life assessment, which may be more appropriate than other cardiac-specific measures. Experts also acknowledge the scale's beneficial features, like ability to use in a paper format, existence of age-specific questions, and the inclusion of cognitive scores. Despite this, some criticise its relevance to specific outcomes, suggesting that several questions may not pertain to the interest outcomes, and others may make assumptions such as "past surgery". Its applicability for younger children was also raised as a concern, with its current format may require in-person interactions for accurate rating.
ADHD Cardiac screening questionnaire	Overall, experts have mixed opinions on the ADHD Cardiac screening questionnaire. Some believe it is not ideal for follow-up visits and has questions that are unrelated to Long COVID. However, others find the first questions on intolerance, ECG, and fainting to be good. The relevance of the questions for family history is disputed. The questionnaire is considered short and simple, but there are concerns about its applicability to the paediatric population and the potential distress caused by some of the sensitive questions. Additionally, experts mention that the questionnaire focuses more on congenital and sudden death screenings rather than long COVID.
Paediatric Sudden Cardiac Arrest Signal questions	There are mixed opinions among experts regarding the appropriateness of the Paediatric Sudden Cardiac Arrest Signal questions for follow-up visits. Some experts believe that only the first part of the questionnaire is suitable. The focus on family history is a concern for several experts, as it may increase anxiety without providing any useful information. Overall, experts suggest modifying the questionnaire to include only the first five questions and rewording them for improved clarity.
Symptom Burden Questionnaire for Long COVID (Circulation scale)	Experts have expressed mixed views about the given scale. The scale was originally developed for adults, and while some believe it's adaptable for children, others note that it would require modification and validation for paediatric populations. The clarity in defining degrees of severity, such as mild, moderate, and severe, was considered not easy to implement. Despite being in development, some experts appreciate the scale's design, finding it comprehensive and potentially superior to other outcome measures if certain sections were removed. However, they caution that it's not fully validated yet, and its reliance on a 7-day recall period might be insufficient given the fluctuating nature of many symptoms. It's also viewed as a feasible tool that captures relevant aspects of Long COVID, yet it notably lacks a focus on chest pain. Adaptation of this tool for younger people is currently underway.

Malmo POTS score (MAPS)	Some experts believe that this instrument is not ideal for children, particularly younger ones, implying that it may be more suitable for older children or adults. Others point out that it also incorporates questions for several non-cardiac issues, suggesting it may be too broad in scope. There is a consensus that some of the questions are too specific to POTS or that they are replicated in other questionnaires, making it less unique or potentially redundant. Despite these criticisms, some experts found the questionnaire straightforward, and believe that the content is appropriate and relevant, though there are reservations regarding the psychometrics of the scale.

Outcome 2: Gastrointestinal functioning, symptoms, and conditions

Measurement instruments	**Round of expert Delphi**	**Expert voting**										
		1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
EAT-10 score	Round 1	Exclude	Include	Exclude	Maybe	Include	Include	Exclude	Include	Exclude	Exclude	Include
	Round 2	Exclude	Exclude	Exclude	Exclude	Maybe	Include	Exclude	Exclude	Exclude	Exclude	*Unvoted*
Section within the SCL-90 scale	Round 1	Exclude	Exclude	Exclude	Exclude	Include	*Unvoted*	Maybe	Exclude	Maybe	Maybe	Exclude
	Round 2	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
PedsQL™ Gastrointestinal Symptoms Scales	Round 1	Maybe	Maybe	Include	Maybe	Maybe	Include	Include	Include	Include	Include	Include
	Round 2	Include	Include	Include	Include	Include	Include	Include	Include	Maybe	Include	Include
Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS)	Round 1	Exclude	Include	Maybe	Maybe	Maybe	Include	Include	Exclude	Exclude	Include	Include

	Round 2	Exclude	Include	Include	Maybe	Maybe	Include	Exclude	Exclude	Maybe	Include	Include
Symptom Burden Questionnaire for Long COVID (Stomach and Digestion Scale)	Round 1	NEWLY SUGGESTED										
	Round 2	*Unvoted*	Maybe	Include	Exclude	Include	Exclude	Maybe	Include	Include	Maybe	*Unvoted*

Measurement instruments	**Summary of additional comments from the experts in rounds 1/2**
EAT-10 score	Overall, experts have varying opinions on the EAT-10 score questionnaire. Some believe that there are too many questions, many of which are irrelevant or unrelated to swallowing. Others find the questionnaire easy to complete and relevant, especially for monitoring purposes. There is also a recognition that difficulty swallowing is an important symptom to assess and that it is not covered by other tools. However, there is a consensus among experts that the questionnaire may be too long and that it may not accurately capture the symptoms commonly seen in paediatric patients. Overall, the relevance and usefulness of the EAT-10 score questionnaire seem to depend on the specific focus on swallowing difficulties and the individual needs of the patient population being assessed.
Section within the SCL-90 scale	Experts have differing opinions on the usefulness and appropriateness of the Section within the SCL-90 scale. Some experts feel that the section has too many questions and is too long, making it potentially burdensome for respondents, especially younger children. They also note that the section includes items that are not relevant to the specific outcomes of interest. Some experts point out that the scale was originally designed for psychiatric patients, which may reduce compliance and limit its applicability to other groups. Additionally, extracting individual items from the scale is seen as problematic, as the psychometric properties pertain to the scale as a whole, rather than individual items.
PedsQL™ Gastrointestinal Symptoms Scales	Some experts believe that it may lack specific relevance to the gastrointestinal (GI) implications of COVID and propose the development of a new scale, others praise its broad coverage of GI symptoms, especially in a paediatric setting, and its use of validated questionnaires, making it a go-to for most studies. The scale's length and accessibility of its questions are points of contention, with critics citing it as potentially too long or unclear. Despite these criticisms, the scale's comprehensive range of questions and its previous validation across a variety of paediatric GI conditions are applauded. Some suggest that the scale may even be redundant if a COVID symptom questionnaire is available, while others see its generality and age specificity as strengths. It is also recognised for covering symptoms included in COS and its development and validation within a paediatric population.
Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS)	Mixed views were expressed, some experts believe that it is a comprehensive tool, specifically designed for functional gastrointestinal disorders, covering a broad range of symptoms and suitable for all ages, including follow-up visits. It is particularly noted for its potential applicability to populations experiencing Functional GI symptoms as seen in Chronic Fatigue Syndrome and Long Covid. Some experts appreciate its detailed nature, despite its length, and believe it could be feasibly completed periodically for continued monitoring. However, concerns are raised about its length - 83 questions - and redundancy, particularly when compared with the PedsQL GIS questionnaire that covers similar questions anyway. Critics also highlight weak temporal stability in items

	evaluating the impact of symptoms on school and social/family activities. A significant limitation flagged is that it has not been fully validated in children yet. Therefore, there is debate about its usage versus other tools like the PedsQL which is valid ated in children.
Symptom Burden Questionnaire for Long COVID (Stomach and Digestion Scale)	The scale has received mixed expert feedback. While it is recognised for its strengths, particularly its suitability for asse ssing gastrointestinal issues and its comprehensive coverage of major symptoms, it also raises concerns. Primary among them is the lack of clarity in defining symptom severity levels like mild, moderate, and severe. Also, experts pointed out the need for valida tion and adaptation for use in children and adolescents, as its primary development was for adults. Adaptation for younger age groups (11-17 years) is just under development, some professionals still express reservations about its usage in paediatrics, suggesting re liance on previously used, validated tools.

Outcomes 3 and 4: Fatigue or Exhaustion AND Post-exertion symptoms

Measurement instruments	**Round of expert Delphi**	**Expert voting**										
		1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
Chalder fatigue questionnaire	Round 1	Maybe	Maybe	Maybe	Exclude	Maybe	Exclude	Exclude	Include	Include	Include	Maybe
	Round 2	Maybe	Maybe	Maybe	Exclude	Exclude	Exclude	Exclude	Include	Include	Include	Exclude
Fried Frailty phenotype	Round 1	Exclude	Exclude	Maybe	Maybe	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
CDC symptom inventory for CFS	Round 1	Include	Maybe	Exclude	Maybe	Maybe	Maybe	Maybe	Include	Maybe	Include	Maybe

	Round 2	Maybe	Maybe	Exclude	Maybe	Exclude	Exclude	Exclude	Include	Maybe	Include	Maybe
PEM items from DePaul Symptom Questionnaire	Round 1	Maybe	Exclude	Include	Maybe	Exclude	Include	Include	Exclude	Include	Maybe	Exclude
	Round 2	Maybe	Exclude	Include	Maybe	Maybe	Maybe	Exclude	Exclude	Include	Exclude	Maybe
PROMIS Paediatric Fatigue	Round 1	Maybe	Include	Include	Maybe	Include	Maybe	Maybe	Include	Maybe	Exclude	*Unvoted*
	Round 2	Include	Include	Include	Maybe	Maybe	Maybe	Include	Include	Maybe	Exclude	Include
PedsQL™ Multidimensional Fatigue Scale	Round 1	Exclude	Include	*Unvoted*	Maybe	Maybe	Include	Include	Include	Include	Maybe	*Unvoted*
	Round 2	Maybe	Include	Exclude	Include	Maybe	Include	Include	Include	Include	Include	Maybe
Multidimensional Fatigue Inventory, MFI-20	Round 1	NEWLY SUGGESTED										
	Round 2	Maybe	Exclude	Include	Exclude	Exclude	Exclude	Maybe	Exclude	Maybe	Exclude	Maybe
Symptom Burden Questionnaire for Long COVID (Fatigue scale)	Round 1	NEWLY SUGGESTED										
	Round 2	Exclude	Maybe	Include	Exclude	Include	Include	Maybe	Include	Include	Maybe	*Unvoted*
Bell's Functionality Score	Round 1	NEWLY SUGGESTED										

	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Include	Maybe	Include	Maybe

Measurement instruments	Summary of additional comments from the experts in rounds 1/2
Chalder fatigue questionnaire	The Chalder Fatigue Questionnaire has elicited varied opinions among experts. Some highlight the presence of unrelated questions, notably on memory, while others question its applicability in children, given its predominant use in adult populations. Additionally, it appears to elicit cognitive issues, with responses ranging from appreciation for its succinctness to critique for its potential controversy. The scale's validation in paediatric populations also raises questions. Further, some experts cast doubt on the scale due to controversy surrounding Chalder's work, particularly in relation to cognitive behavioural therapy for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, which may not adequately capture long COVID population. However, others appreciate its simplicity, shortness, and its established use in conditions like Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. They argue that controversies related to the authors should not discount its use. It is also noted that the scale's age range is 18-65, questioning its content validity and highlighting the lack of validation in paediatric populations.
Fried Frailty phenotype	Experts agree that the Fried Frailty phenotype is suitable for adults, specifically focused on assessing frailty in older adults. However, it is not appropriate for children. The Fried Frailty phenotype was initially developed for cardiac patients and is mostly focused on the adult population. It requires tests and equipment that may not be feasible or suitable for use in children and adolescents. It is suggested that alternative measures, such as the Physical Activity Questionnaire for Children (PAQ-C) and Adolescents (PAQ-A), may be more useful in assessing frailty in this population.
CDC symptom inventory for CFS	Instrument has been viewed as a robust but relatively complicated tool. Experts appreciate its good internal consistency, excellent convergent validity, and its specificity for Chronic Fatigue Syndrome symptoms, finding it somewhat comparable to the Long Covid scale. However, they have raised concerns about its lengthy and intricate scoring process, which they perceive to be a challenge in quantifying symptoms. Additionally, the scale is criticised for its breadth, spanning multiple domains rather than being narrowly focused. It was also noted that the instrument has not been developed specifically for paediatrics, limiting its applicability in younger populations. It has also not been validated for Primary Care Clinics, which can pose questions about its reliability and validity in these settings. Lastly, if only specific components, such as Fatigue and Exhaustion data, are to be extracted from the general inventory, it could increase the administration burden and potentially affect its reliability and validity.
PEM items from DePaul Symptom Questionnaire	The key concerns highlighted include the length and complexity of the DSQ, with 91 sections deemed time-consuming, and possibly leading to low compliance due to the high burden on patients. Some experts also noted its potential limitations when applying it to children. However, many expressed appreciation for the DSQ's extensive coverage of symptoms beyond fatigue, and its detailed assessment of frequency and severity over a longer period (3 months) than other instruments. Experts seem interested in the potential utility of the DSQ's paediatric version (DSQ-Ped), which is currently being validated. While it's noted that the questionnaire might be better adapted for a wider age range, the DSQ could be a suitable patient-reported outcome (PRO) tool, particularly if a paediatric version becomes available. There's also the possibility of extracting individual items from the questionnaire, though there are concerns about how this might impact scoring, reliability, and validity. The consensus seems to be that the DSQ's use requires further discussion, and decisions should be made based on the similarity of the assessed factors.

PROMIS Paediatric Fatigue	Most experts appreciate its combination of information acquisition and feasibility, citing it as a validated measure that's short, specific to paediatrics, and widely used in practice. The scale's specific focus on fatigue was recognized as advantageous by some, given that it doesn't encompass aspects outside its targeted domain. However, several experts expressed concern about the scale's lack of attention to cognitive fatigue, key components in the broader concept of fatigue. These limitations suggest that the PROMIS Paediatric Fatigue scale might best be used in conjunction with other instruments to ensure comprehensive fatigue assessment.
PedsQL™ Multidimensional Fatigue Scale	Experts found this instrument as a generally valid and useful tool, especially for assessing fatigue in children over 8 years old. Although the scale, featuring a relatively large set of 45 questions, may appear extensive, it provides a detailed analysis of various aspects of fatigue, including cognitive fatigue. This factor is crucial when evaluating children in certain populations. While the quality of life (QOL) aspect is not directly linked with the Core Outcome Set, it is still considered feasible and beneficial, as it is regularly used in clinical practice. Overall, the scale is recognised for its focus on fatigue but needs to be understood within its limitations.
Multidimensional Fatigue Inventory, MFI-20	Experts have varying opinions on the Multidimensional Fatigue Inventory (MFI-20) in relation to its applicability to children. It is generally agreed that the MFI-20 is not completely suitable for children and young people, as it has only been validated in adults. Some experts find the item wording to be clear and easy to understand, while others believe the questions are too broad and may reflect symptoms other than fatigue.
Symptom Burden Questionnaire for Long COVID (Fatigue scale)	Experts suggest that the focus of the current version on adults raises issues concerning its applicability to younger populations, although it is noted to be adaptable to children in the future. There is ambiguity on how to define the intensity levels, such as mild, moderate, or severe. Yet, concerns are raised regarding its "7 day" time frame as an outcome measure given the fluctuating nature of Long COVID symptoms. Its lack of focus on function and Activities of Daily Living is another point of criticism.
Bell's Functionality Score	Experts do not consider Bell's Functionality Score to be appropriate for children and adolescents due to its complexity and difficulty for children to understand. They suggest that it might be more suitable for assessing physical functioning. The inclusion of work-related questions and irrelevant item wording also makes it unsuitable for the paediatric population. Overall, experts agree that Bell's Functionality Score is only suitable for adults and not children.

Outcome 5: Neuro-cognitive system functioning, symptoms, and conditions

Measurement instruments	Round of expert Delphi	Expert voting										
		1	2	3	4	5	6	7	8	9	10	11
Addenbrooke's Cognitive Examination (ACE-III)	Round 1	Maybe	Exclude	Maybe	Maybe	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
ASQ assessment (for infants born >29 weeks gestation)	Round 1	Exclude	Exclude	Exclude	Include	Include	Include	Maybe	Exclude	Exclude	Exclude	Include
	Round 2	Exclude	Exclude	Exclude	Exclude	Maybe	Maybe	Exclude	Exclude	Exclude	Exclude	Maybe
Bayley-IV neurological examination	Round 1	Maybe	Include	Exclude	Maybe	Exclude	Exclude	Include	Exclude	Exclude	Exclude	Include
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude	Exclude	Exclude	Maybe

Chalder fatigue scale	Round 1	Maybe	Maybe	Exclude	Exclude	Maybe	Maybe	Exclude	Maybe	Include	Include	Exclude
	Round 2	Maybe	Maybe	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Include	Include	Exclude
From Body Vigilance Scale (BVS)	Round 1	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude	Exclude	Maybe	Maybe	Maybe
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude	Exclude
Functional Independence measure (FIM)	Round 1	Exclude	Exclude	Maybe	Exclude	Exclude	Include	Exclude	Exclude	Include	Maybe	Maybe
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
IQCODE	Round 1	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude	Exclude	Exclude	Exclude	Exclude
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
Short Blessed Test	Round 1	Exclude	Exclude	Exclude	Exclude	Exclude	Include	Maybe	Exclude	Exclude	Exclude	Exclude
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
PROMIS Pediatric Cognitive Function - Short Form 7a	Round 1	Include	Include	Include	Include	Include	Include	Include	Include	Maybe	Maybe	Include
	Round 2	Include	Include	Include	Include	Include	Include	Include	Include	Include	Include	Include
Vanderbilt ADHD assessment	Round 1	NEWLY SUGGESTED										

	Round 2	Maybe	Maybe	*Unvoted*	Exclude	Exclude	Include	Exclude	Exclude	Maybe	Exclude	*Unvoted*
Peds QL Cognitive Functioning Scale	Round 1	NEWLY SUGGESTED										
	Round 2	Maybe	Include	*Unvoted*	Maybe	Include	Include	Include	Maybe	Include	Maybe	*Unvoted*
Symptom Burden Questionnaire for Long COVID (Memory, Thinking & Communication scale, movement scale, muscles and joints, pain scales)	Round 1	NEWLY SUGGESTED										
	Round 2	Exclude	Maybe	Include	Exclude	Include	Exclude	Maybe	Include	Include	Maybe	*Unvoted*
NIH Toolbox	Round 1	NEWLY SUGGESTED										
	Round 2	Exclude	Include	*Unvoted*	Exclude	Maybe	Exclude	Exclude	Include	*Unvoted*	Exclude	*Unvoted*

Measurement instruments	**Summary of additional comments from the experts in rounds 1/2**
Addenbrooke's Cognitive Examination (ACE-III)	The experts generally agree that the Addenbrooke's Cognitive Examination (ACE-III) is a good instrument for assessing cognitive abilities in adults. However, they also highlight that it is not suitable for use with children, as it contains questions that are not developmentally appropriate. The length of the examination is also seen as a drawback. Another point of agreement among the experts is that the ACE-III is not feasible for use in a post or online format. Additionally, they believe that it may not be relevant for assessing cognitive abilities in long COVID patients.
ASQ assessment (for infants born >29 weeks gestation)	Experts have provided mixed opinions on the ASQ assessment for infants born >29 weeks gestation. Some experts feel that the assessment is very age-specific and should be completed at 2 years of age. They also find it unclear and not suitable for older children, and that it may not be fully related to long covid. However, other experts believe that the ASQ assessment is standard, well-validated, simple, and easy to use. They suggest using other instruments for older children and adolescents. Additionally, as the ASQ was developed specifically for children with prematurity, some experts feel it may be relevant to all paediatric populations.

Bayley-IV neurological examination	Experts have differing opinions on this instrument. Some find it to be a good tool, but note that it can be very lengthy. It is important to note that the BSID-IV is mostly representative of the U.S. population, which may impact its applicability in other countries. Additionally, the BSID-IV requires specific equipment and must be conducted by a healthcare professional with specific training. This may make it less feasible for certain settings or individuals. There are also concerns about the suitability of the BSID-IV for long COVID patients, as it is primarily focused on developmental achievements and may not be relevant to their specific needs.
Chalder fatigue scale	Overall, experts have mixed opinions on the Chalder fatigue scale. It is seen as more applicable in adults and less applicable in children. It is mainly used to assess fatigue and may not be as suitable for assessing neuro-cognitive abilities or sleep. There is some controversy surrounding its validation, particularly in children. Some experts suggest that it may be more relevant for assessing fatigue than neuro-cognitive complaints but problematic in young children. It is considered a simple and easy-to-complete scale, but it may not be suitable for younger children who are still developing language skills. Additionally, word finding difficulties should not be confused with pre-existing language disorders or other developmental difficulties.
From Body Vigilance Scale (BVS)	Experts have mixed opinions on the From Body Vigilance Scale (BVS). Some feel that the scale has too many questions and is too specific, making it less applicable in children. They also express doubts about its relevance in measuring sensitivity and awareness of internal sensations in young people and children. Furthermore, some experts question the feasibility and validation of the scale in children. However, others believe that the tool is complex and requires further exploration to understand its effectiveness. Additionally, experts warn about the importance of considering developmental differences when using the BVS.
Functional Independence measure (FIM)	Experts have mixed opinions on the Functional Independence Measure (FIM) as a quantitative tool in paediatric rehabilitation. While some experts believe it is only appropriate for adults and the elderly, others feel it is too specific to gastrointestinal issues and not appropriate for younger children or long COVID patients. It appears to be a clinician-reported measure and may not reflect a change in performance. However, some experts find it useful and applicable to the most severe patients, and suggest assessing if the questions are age appropriate.
IQCODE	The experts' opinions on the IQCODE suggest that it is not suitable for use with children. They believe it is more applicable for severe neurocognitive problems typically found in elderly individuals with dementia. The questionnaire's focus on comparing the current condition with that of 10 years ago is not considered appropriate for paediatric use.
Short Blessed Test	Overall, experts tend to agree that the Short Blessed Test may not be suitable for children and adolescents. It is not considered appropriate for individuals with cognitive impairments, intellectual disabilities, or severe cognitive impairment or language difficulties. It may also not capture the full range of cognitive abilities in children and adolescents. Some experts also mention that the test is primarily designed for assessing dementia in adults and may not be appropriate for children, especially when considering developmental considerations. Additionally, it is noted that the test cannot be done by post or online.
PROMIS Pediatric Cognitive Function - Short Form 7a	Experts largely hold a positive view on the Pediatric Cognitive Function - Short Form 7a scale. They appreciate its design, emphasising its appropriateness for paediatric patients, especially in identifying symptoms commonly reported. Its brevity is highly commended, making it a manageable tool for children to complete, although there is a noted limitation for its applicability primarily to older children. Overall, the consensus among professionals suggests that it is a short, precise, and appropriate tool for assessing cognitive function in children.

Vanderbilt ADHD assessment	The experts have varying opinions on the Vanderbilt ADHD assessment for assessing symptoms such as brain fog. Some find the inattention questions relevant and helpful, while others feel that the instrument is not relevant or necessary for all patients. It is noted that the assessment is ADHD-specific and not useful for exploring other possible symptoms or conditions. Additionally, some experts express concerns about the length and potential worry it may cause for patients and parents. Overall, the assessment is seen as more suitable for parents of children aged 8-12 years and may not be relevant for Long COVID patients.
Peds QL Cognitive Functioning Scale	Experts were generally positive in their views on the PedsQL Cognitive Functioning Scale. Some view it as overly lengthy, while others see it as a relatively concise and validated tool. These contrasting perspectives could stem from difficulty in accessing the entirety of the questions, an issue noted by a few of the experts. Despite this, some experts regard it as a potentially better option than PROMIS, acknowledging its routine use and age-appropriate design. The scale's appropriateness for long COVID symptoms has been mentioned as well, highlighting its potential application in ongoing pandemic-related research. Despite these differing opinions, the common thread seems to be an appreciation for the scale's validation and frequent use in practice.
Symptom Burden Questionnaire for Long COVID (Memory, Thinking & Communication scale, movement scale, muscles and joints, pain scales)	The questionnaire is yet to be validated for use in paediatric populations. The simplicity, feasibility, and relevance of the questionnaire to the Long COVID population have been noted positively, although questions about its validation persist.
NIH Toolbox	The purpose and usage of the NIH Toolbox are considered unclear by some experts. However, it is regarded as a comprehensive and beneficial tool for adults and children aged three and above. It offers normative data for children as young as three years old, yet some of the tests and instruments necessitate assessment by an examiner, which poses a limitation. Concerns also arise regarding the lack of validation for the youngest children and the potential resource and access issues associated with acquiring electronic versions, which can be expensive. Nonetheless, it is widely utilised and has been validated in diverse conditions.

Outcome 6: Physical functioning, symptoms, and conditions

Measurement instruments	Round of expert Delphi	Expert voting										
		1	2	3	4	5	6	7	8	9	10	11
Barthel Index	Round 1	Include	Maybe	Exclude	Maybe	Exclude	Include	Include	Include	Maybe	Exclude	Exclude
	Round 2	Maybe	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude	Include	Exclude	Exclude	Exclude
Basic Activity of Daily Living (BADL)	Round 1	Exclude	Maybe	Exclude	Exclude	Exclude	Include	Exclude	Include	Exclude	*Unvoted*	Maybe
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude	Exclude
Clinical Frailty Scale (CFS)	Round 1	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe	Maybe	Exclude	Exclude	Exclude
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
Duke Activity Status Index (DASI)	Round 1	Exclude	Exclude	Exclude	Exclude	Exclude	Include	Maybe	Include	Maybe	Exclude	Exclude

	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe	Exclude	Exclude
EQ5DY instrument	Round 1	Exclude	Include	*Unvoted*	Include	Include	Include	Include	Exclude	Include	Include	Include
	Round 2	Maybe	Include	*Unvoted*	Include	Include	Include	Include	Exclude	Include	Include	Include
Fried Frailty phenotype	Round 1	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
Functional Independence Measure (WeeFIM or FIM)	Round 1	Exclude	Exclude	Exclude	Exclude	Exclude	Include	Maybe	Exclude	Maybe	Maybe	Include
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Maybe
International Physical Activity Questionnaires Short Form (IPAQ-SF)	Round 1	Exclude	Exclude	Exclude	Exclude	Maybe	Include	Include	Maybe	Maybe	Maybe	Maybe
	Round 2	Exclude	Exclude	Exclude	Exclude	Maybe	Maybe	Maybe	Maybe	Exclude	Exclude	Maybe
Post COVID-19 Functional Status Scale (Scale 0-64 points)	Round 1	Exclude	Maybe	Include	Exclude	Exclude	Include	Maybe	Include	Maybe	Exclude	Exclude
	Round 2	Exclude	Exclude	Maybe	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude
PROMIS Early Childhood Parent Report Physical Activity 7a	Round 1	Exclude	Include	Maybe	Maybe	Include	Exclude	Include	Include	*Unvoted*	Exclude	Include
	Round 2	Maybe	Include	Maybe	Maybe	Include	Exclude	Include	Include	Maybe	Exclude	Include

PROMIS Pediatric Physical Activity – Short Form 8a	Round 1	Exclude	Include	Exclude	Maybe	Include	Maybe	Include	Include	*Unvoted*	Exclude	Include
	Round 2	Maybe	Include	Exclude	Maybe	Maybe	Include	Include	Include	Exclude	Maybe	Include
PROMIS Pediatric Physical Activity – Short Form 4a	Round 1	Exclude	Exclude	Exclude	Maybe	Maybe	Exclude	Include	Include	*Unvoted*	Exclude	Include
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Exclude	Include	Exclude	Exclude	Include
Bell's Functionality Score	Round 1	NEWLY SUGGESTED										
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Include	Exclude	Include	Maybe	Include	Maybe
The motor skills module activity questionnaire (MOMO) (Available in German only)	Round 1	NEWLY SUGGESTED										
	Round 2	Exclude	Maybe	Exclude	Exclude	*Unvoted*	Exclude	Exclude	Exclude	Exclude	Exclude	*Unvoted*
Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	Round 1	NEWLY SUGGESTED										
	Round 2	Exclude	Maybe	Maybe	Exclude	Include	Exclude	Maybe	Exclude	Exclude	Maybe	*Unvoted*

Measurement instruments	**Summary of additional comments from the experts in rounds 1/2**
Barthel Index	The Barthel Index has received varied opinions from experts. While some experts believe that it can be adapted for use in children and appreciate its brevity and comprehensiveness, others argue that it is more suitable for older adults with severe dementia. It is particularly challenging to interpret the scale in younger children, but it might be possible for a family member to complete it on their behalf. Modifications may be necessary to make it more applicable for young children, including those experiencing Post COVID Condition (Long COVID). Additionally, the index primarily revolves around adults and assumes independence, which may not align with the developmental needs of younger children.

Basic Activity of Daily Living (BADL)	There are varying opinions among experts regarding the use of the Basic Activity of Daily Living (BADL) scale. Certain experts believe that it could be adapted for use with children, while others argue that the scale is more suitable for older adults. Furthermore, some experts express doubt about the practicality of using the BADL scale with children due to the need for direct observation.
Clinical Frailty Scale (CFS)	The Clinical Frailty Scale (CFS) is a tool that is primarily used in geriatrics and focused on older adults, particularly those with dementia. However, it is not appropriate for use with children or individuals with stable long-term disabilities or learning disabilities. Some experts suggest that the CFS may need tailoring for use with paediatric populations, as its rating system appears to be more focused on terminal illness.
Duke Activity Status Index (DASI)	Experts agree that the Duke Activity Status Index (DASI) is not fully suitable for the paediatric population as it is designed for adults and includes questions about sexual activity and work, which are not developmentally appropriate for children. However, some experts note that the DASI is short and may be used in the older population, but it has limited questions relevant to child daily functioning and may not capture all aspects of frailty in children.
EQ5DY instrument	The EQ5DY instrument is largely praised by experts as an effective, simple, and focused tool designed for the paediatric population. It is regarded as sufficient by itself, highlighted by its popularity and broad application in children's health economic analyses. The EQ5DY is noted for its validity in assessing children's health, with a specific proxy version available for young children. Its range of assessment is not limited to physical activity but extends to various facets like mobility, self-care, usual activities, and psychological states, such as feeling worried, sad, or unhappy. The tool's practicality and user-friendliness, particularly for children, are appreciated. A child-friendly version of the EQ-5D further underscores its suitability and adaptability for this demographic.
Fried Frailty phenotype	Experts agree that the Fried Frailty phenotype is suitable for adults, specifically focused on assessing frailty in older adults. However, it is not appropriate for children. The Fried Frailty phenotype was initially developed for cardiac patients and is mostly focused on the adult population. It requires tests and equipment that may not be feasible or suitable for use in children and adolescents. It is suggested that alternative measures, such as the Physical Activity Questionnaire for Children (PAQ-C) and Adolescents (PAQ-A), may be more useful in assessing frailty in this population.
Functional Independence Measure (WeeFIM or FIM)	Experts have expressed mixed opinions on the use of the Functional Independence Measure (WeeFIM or FIM) as a quantitative tool in paediatric rehabilitation. Some experts feel that the tool is too long and complicated, making it difficult to use in online or postal settings. They also believe that it may not be suitable for assessing self-care abilities in younger children and that the FIM may be too complicated for parents to understand and accurately complete.
International Physical Activity Questionnaires Short Form (IPAQ-SF)	Experts have varying opinions on the International Physical Activity Questionnaires Short Form (IPAQ-SF). Some experts feel that it may be too complex or detailed for younger children to accurately recall their activity levels. The consensus is that it is most applicable for older children and adolescents, with some experts suggesting it is suitable for older teens and potentially younger teens as well. However, there is concern that parents may struggle to estimate activity levels for younger children based on the wording of the questionnaire.
Post COVID-19 Functional Status Scale (Scale 0-64 points)	The experts had mixed opinions on the appropriateness of the Post COVID-19 Functional Status Scale for children. Some felt that it could be adapted for children and that it was the easiest and most appropriate option available. Others felt that the questions were too specific to adults and not suitable for children. Some experts mentioned that the scale was not developmentally appropriate for dependent children and that the responses were difficult to differentiate. Overall, the experts were unsure about its suitability for children.

PROMIS Early Childhood Parent Report Physical Activity 7a	General feedback is that an instrument has been explicitly designed for assessing physical activity in very young children. Experts note its potential utility, acknowledging it as a promising, albeit not flawless, tool for the younger age groups. Some have reservations, unsure if they would implement all three sections of the tool. Others advocate for its use in combination with additional assessments for older children. Overall, its focus on intense physical activity and its perceived suitability for the target population have garnered positive responses from the expert community.
PROMIS Pediatric Physical Activity – Short Form 8a	This tool has garnered a mix of opinions from experts. There is concern about the reference to strenuous exercises, as these could in themselves cause the symptoms being referred to, creating potential ambiguity. While there is some favour for the PROMIS scales, which offer a broad range of measurement, experts are hesitant to include all three due to potential interpretational issues among different populations. There is also concern about the 7-day recall period, as this might not capture the fluctuating nature of long COVID symptoms adequately, making it hard to observe systematic changes over time. There's a viewpoint that the scale may be more suited to older children. Some experts see the scale as a great tool for quantification, but there are also reservations regarding its relevance, with criticism that it might confuse strenuous physical activity with symptoms like sweating, which could cross into autonomic territory or yield false positives. Lastly, there's a note that the scale focuses predominantly on hard activity, which could be a limitation.
PROMIS Pediatric Physical Activity – Short Form 4a	The experts felt that the Pediatric Physical Activity - Short Form 4a is too short and less informative compared to other scales mentioned. They mentioned that it focuses on hard activity and does not consider post-exertional malaise. They also mentioned that for older children, a longer scale might be more appropriate.
Bell's Functionality Score	The experts generally agreed that Bell's Functionality Score is not suitable for children as it is primarily designed for adults. They also noted that the item wording is not relevant to the paediatric population. Some experts suggested that it could be adapted for children by replacing the reference to work with school. Overall, the experts felt that the scale is more appropriate for adults and would require modifications to be applicable to children.
The motor skills module activity questionnaire (MOMO) (Available in German only)	The experts had mixed opinions on The Motor Skills Module Activity Questionnaire (MOMO). Some found it to be an interesting tool that offers good coverage of both adults and children. However, others noted that it is only available in German, making it difficult for non-German speakers to evaluate. Additionally, some experts found it to be too long and challenging to complete, which may impact its feasibility in research studies or clinical settings. Overall, the lack of availability in additional languages was seen as a limitation of the questionnaire.
Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	Experts have expressed mixed views about the given scale. The scale was originally developed for adults, and while some believe it's adaptable for children, others note that it would require modification and validation for paediatric populations. The clarity in defining degrees of severity, such as mild, moderate, and severe, was considered not easy to implement. Despite being in development, some experts appreciate the scale's design, finding it comprehensive and potentially superior to other outcome measures if certain sections were removed. However, they caution that it's not fully validated yet, and its reliance on a 7-day recall period might be insufficient given the fluctuating nature of many symptoms. It's also viewed as a feasible tool that captures relevant aspects of Long COVID, yet it notably lacks a focus on chest pain. Adaptation of this tool for younger people is currently underway.

Outcome 7: Work/occupational and study changes

Measurement instruments	Round of expert	Expert voting

	Delphi	1	2	3	4	5	6	7	8	9	10	11
None	Round 1	**No scales/instruments reported in the reviewed evidence**										
Work Productivity and Activity Impairment Questionnaire: General Health V2.0 (WPAI:GH)	Round 1	NEWLY SUGGESTED										
	Round 2	Exclude	Exclude	Exclude	Exclude	Exclude	Include	Maybe	Include	Exclude	Exclude	Maybe
Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	Round 1	NEWLY SUGGESTED										
	Round 2	Exclude	Maybe	Include	Exclude	Include	Exclude	Maybe	Exclude	*Unvoted*	Maybe	*Unvoted*

Measurement instruments	Summary of additional comments from the experts in rounds 1/2
Work Productivity and Activity Impairment Questionnaire: General Health V2.0 (WPAI:GH)	Experts indicate that WPAI:GH instrument is focused on adults' activities and may not be appropriate for children. Some experts believe that the questions should be adapted to include school-related activities for paediatric use. However, others feel that with mild adaptations, the questionnaire can be used for older children. The ability of younger children to respond to some items requesting time estimates is questioned, indicating a need for more suitable questions for this age group.
Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	Experts have expressed mixed views about the given scale. The scale was originally developed for adults, and while some believe it's adaptable for children, others note that it would require modification and validation for paediatric populations. The clarity in defining degrees of severity, such as mild, moderate, and severe, was considered not easy to implement. Despite being in development, some experts appreciate the scale's design, finding it comprehensive and potentially superior to other outcome measures if certain sections were removed. However, they caution that it's not fully validated yet, and its reliance on a 7-day recall period might be insufficient given the fluctuating nature of many symptoms. It's also viewed as a feasible tool that captures relevant aspects of Long COVID, yet it notably lacks a focus on chest pain. Adaptation of this tool for younger people is currently underway.

6. Consensus workshop participants

	Total number (%)[3]	Voting participants (%)
Healthcare professionals/Researchers	**29 (100)**	**22 (100)**
Delphi stakeholder group:		

- Health professional (including those who also do research)[1]	16 (55)	11 (50)
- Researcher (without any clinical patient care duties)[2]	13 (45)	11 (50)
Country of residence		
Australia	2 (7)	1 (4·5)
Chile	2 (7)	1 (4·5)
Germany	1 (3·4)	1 (4·5)
Israel	1 (3·4)	1 (4·5)
Italy	1 (3·4)	1 (4·5)
Lithuania	1 (3·4)	0 (0)
Latvia	1 (3·4)	1 (4·5)
Malaysia	1 (3·4)	1 (4·5)
Netherlands	1 (3·4)	1 (4·5)
Poland	1 (3·4)	1 (4·5)
Romania	2 (7)	2 (9)
Switzerland	1 (3·4)	0 (0)
UK	9 (31)	7 (32)
USA	5 (17)	4 (18)
Children and young people (≤18 years old) with Long COVID and their family and carers	**9 (100)**	**8 (100)**
Delphi stakeholder Group:		
- Family/caregivers of CYP with Long COVID	9 (100)	8 (100)
Country of residence		
Ireland	1 (11)	1 (13)
Netherlands	1 (11)	1 (13)
UK	6 (66·6)	5 (63)
USA	1 (11)	1 (13)

[1] Health professionals who care for people with Long COVID/post COVID-19 condition
[2] Researchers who undertake research in Long COVID/post COVID-19 condition
[3] One observer did not provide information on their stakeholder group and country of residence

7. Consensus workshop voting results

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE in consensus meeting	Result

Cardiovascular functioning, symptoms and conditions	PedsQL Cardiac Module	16/28 (57)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Circulation scale)	7/27 (25)	Not included in the COMS
	Malmo POTS score (MAPS)	18/27 (64)	Not included in the COMS
Gastrointestinal functioning, symptoms, and conditions	PedsQL Gastrointestinal Symptoms Scales	23/26 (88)	Included in the COMS
	Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS)	2/26 (8)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Stomach and Digestion Scale)	6/26 (23)	Not included in the COMS
Fatigue or Exhaustion	Chalder fatigue questionnaire	3/26 (12)	Not included in the COMS
	PROMIS Paediatric Fatigue	3/26 (12)	Not included in the COMS
	PedsQL Multidimensional Fatigue Scale	26/26 (100)	Included in the COMS
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	3/26 (12)	Not included in the COMS
Post-exertion symptoms	CDC symptom inventory for CFS	5/26 (19)	Not included in the COMS
	PEM items from DePaul Symptom Questionnaire	10/26 (38)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	6/26 (23)	Not included in the COMS
	PROMIS Pediatric Cognitive Function - Short Form 7a	9/24 (36)	Not included in the COMS

Neuro-cognitive system functioning, symptoms, and conditions	PedsQL Cognitive Functioning Scale	21/25 (84)	Included in the COMS
	Symptom Burden Questionnaire for Long COVID (Memory, Thinking & Communication scale, movement scale, muscles and joints, pain scales)	4/24 (16)	Not included in the COMS
Physical functioning, symptoms, and conditions	EQ5DY instrument	24/25 (96)	Included in the COMS
	PROMIS Physical Activity	2/25 (8)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	3/25 (12)	Not included in the COMS
Work/occupational and study changes	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	5/22 (23)	Not included in the COMS
	WHO DAS 2 Children and Youth 36-Item Version	7/23 (30)	Not included in the COMS

Appendix 4

PC-COS Children 'How to measure' Consensus workshop report

Meeting date and time: 31st July 2023

Location: Online (Zoom)

THE POST-COVID CORE OUTCOME SET (PC-COS) FOR CHILDREN AND YOUNG PEOPLE

PC-COS CHILDREN

Contents

1. Summary

After conducting a two-round expert Delphi survey on outcome measures, an online consensus workshop took place on 31st July 2023. The purpose of this workshop was to deliberate on which outcome measures ought to be included or excluded from the core outcome set (COS). This report provides a summary of the discussions, voting results, and the finalised core outcome measurement instruments set for post-COVID-19 condition in children and young people.

2. Consensus workshop participants

Forty-six individuals attended the consensus workshop. This included six non-voting members from the study team, nine observers, one facilitator, and 30 voting participants. All voting participants had completed both rounds of the online Delphi survey. Of these, 22 were health professionals or researchers, and eight were individuals with Long COVID or their carers.

Some participants could not remain present for the entire workshop due to intermittent internet connection and/or other commitments. The final tally of voting participants for each outcome is detailed in this report.

Consensus workshop participants

	Total number (%)[3]	Voting participants (%)
Healthcare professionals/Researchers	**29 (100)**	**22 (100)**
Delphi stakeholder group:		
- Health professional (including those who also do research)[1]	16 (55)	11 (50)
- Researcher (without any clinical patient care duties)[2]	13 (45)	11 (50)
Country of residence		
Australia	2 (7)	1 (4·5)
Chile	2 (7)	1 (4·5)
Germany	1 (3·4)	1 (4·5)
Israel	1 (3·4)	1 (4·5)
Italy	1 (3·4)	1 (4·5)
Lithuania	1 (3·4)	0 (0)
Latvia	1 (3·4)	1 (4·5)
Malaysia	1 (3·4)	1 (4·5)
Netherlands	1 (3·4)	1 (4·5)
Poland	1 (3·4)	1 (4·5)
Romania	2 (7)	2 (9)
Switzerland	1 (3·4)	0 (0)
UK	9 (31)	7 (32)
USA	5 (17)	4 (18)
Children and young people (≤18 years old) with Long COVID and their family and carers	**9 (100)**	**8 (100)**
Delphi stakeholder Group:		
- Family/caregivers of CYP with Long COVID	9 (100)	8 (100)
Country of residence		
Ireland	1 (11)	1 (13)
Netherlands	1 (11)	1 (13)
UK	6 (66·6)	5 (63)
USA	1 (11)	1 (13)

[1] Health professionals who care for people with Long COVID/post COVID-19 condition
[2] Researchers who undertake research in Long COVID/post COVID-19 condition
[3] One observer did not provide information on their stakeholder group and country of residence

3. Voting and discussions

3.1 Cardiovascular functioning, symptoms and conditions outcome measures discussion

Researchers emphasised the challenges associated with using questionnaires, particularly when children are involved. They noted that children often face difficulties comprehending questionnaires, suggesting that simpler tests like the sit to stand or NASA lean test might be more effective. The efficacy and importance of simple testing was a recurring theme. It has been re-emphasised that PC-COS Children project is aiming to deliver COMS that will be applicable worldwide regardless of settings and it has been agreed a priori that tests and/or tools requiring physician's/researcher's assistance and/or access to clinical/research facilities will be excluded.

The discussion also delved into concerns about the applicability of certain instruments. Some researchers felt that specific questionnaires could sometimes cover too few domains or include questions that might not be relevant or valid for disabled patients. For instance, while PedsQL was seen as encompassing fewer domains than POTS, the latter has not yet been validated and lacks the longstanding track record that PedsQL possesses.

Another area of discussion revolved around the potential discrepancies in perceptions between children and their parents. This discrepancy became especially salient when considering scales that were designed primarily for adults and might not be entirely suitable for a paediatric audience. Despite this, some participants believed that these tools could still serve as screening instruments, even if they have not been validated for the target population.

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE in consensus meeting	Result
Cardiovascular functioning, symptoms and conditions	PedsQL Cardiac Module	16/28 (57)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Circulation scale)	7/27 (25)	Not included in the COMS
	Malmo POTS score (MAPS)	18/27 (64)	Not included in the COMS

3.2 Gastrointestinal functioning, symptoms and conditions outcome measures

The simplicity of the SBQ was widely acknowledged and appreciated by the participants. However, debates surfaced around other tools, with some considering them overly extensive and superfluous. A crucial point raised was the current lack of validation for SBQ in the paediatric population, concerning its universal applicability.

A divergence in perspectives was evident between health professionals/researchers and carers concerning the persistence and variability of gastrointestinal symptoms. While some health professionals and researchers deemed the PedsQL too intricate and exhaustive, carers leaned towards appreciating its thoroughness, provided the questions remained pertinent. This sentiment underscored a broader theme, where carers often desired comprehensive tools that might be perceived as cumbersome by researchers. Carers also pointed out the limitation in the '7 days' timeframe stipulated in some questionnaires. They felt it insufficient to encapsulate the ebb and flow of symptoms, a sentiment not universally echoed by the health professionals/researchers.

Notably, some caretakers highlighted gaps in the existing tools. They pointed out certain areas where the questionnaires fell short, such as emphasising vomiting but neglecting nausea. A glaring omission, as noted by the carers, was the absence of queries about alterations in taste, as well as eating and drinking habits – aspects that are especially relevant in the context of post-COVID-19 conditions. This brought to light the necessity for tools to be both exhaustive and specific to capture the unique challenges faced by the CYP cohort. An interesting point was made regarding the environment in which these questionnaires are administered. Carers mentioned that children might feel more at ease and authentic in answering questions in familiar settings, contrasting the sometimes intimidating clinical environment.

In conclusion, while there was an agreement on the importance of capturing gastrointestinal symptoms comprehensively, the tools and methods to achieve this effectively remained a subject of debate. All participants converged on the idea that including questions about taste and swallowing would be crucial to provide a holistic understanding of the children's experiences.

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE in consensus meeting	Result
Gastrointestinal functioning, symptoms, and conditions	PedsQL Gastrointestinal Symptoms Scales	23/26 (88)	Included in the COMS
	Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS)	2/26 (8)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Stomach and Digestion Scale)	6/26 (23)	Not included in the COMS

3.3 Fatigue or exhaustion outcome measures

The group highlighted the value of questionnaires which integrate self-reports, with the consensus being that children are quite adept at articulating their fatigue symptoms. An essential aspect identified was the inclusion of cognitive components in these measures. Some participants raised concerns about the lack of such components in certain questionnaires, such as PROMIS. Another area of contention, similarly to earlier discussions, was the timeframe with the general feeling that a '7-day' window was not sufficiently representative of the nature of Long COVID fatigue.

The Chalder Fatigue Scale gained some praise for its straightforwardness, but there were reservations regarding its validation. One of the health professionals/researchers expressed a preference for tests validated in multiple languages, emphasising the importance of accessibility to a wider audience.

An underlying theme was the desire to encompass basic functioning in the measures. Carers voiced their wish for questions that reflect everyday tasks like dressing and showering. Unfortunately, they noted that none of the current questionnaires delve into these nuances.

Concluding the discussions, there seemed to be a collective nod towards the PedsQL Multidimensional Fatigue Scale. Participants appreciated its extensive coverage, the inclusion of self-reports, and its timeframe, which captures a month, thus allowing for the consideration of symptom fluctuation. The overall sentiment was that the PedsQL offered a comprehensive insight into the fatigue experienced by children and young people with post-COVID-19 conditions.

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE in consensus meeting	Result
Fatigue or Exhaustion	Chalder fatigue questionnaire	3/26 (12)	Not included in the COMS
	PROMIS Paediatric Fatigue	3/26 (12)	Not included in the COMS
	PedsQL Multidimensional Fatigue Scale	26/26 (100)	Included in the COMS
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	3/26 (12)	Not included in the COMS

3.4 Post-exertion symptoms outcome measures

Researchers identified an overlap between post-exertion malaise (PEM) and fatigue, acknowledging the challenge in distinguishing the two due to the limited number of tools that specifically measure PEM. Health professionals expressed concerns about the wording in the CDC's set of questions, deeming it too intricate, which might lead to misinterpretations. Carers voiced their belief in the necessity to adapt and modernise specific questions in the DePaul questionnaire to better represent the current realities, such as the shift to remote learning brought about by the pandemic. They suggested revising the phrase 'attending school' to a broader term like 'Participating in any education.'

An interesting dynamic emerged wherein health professionals initially expressed a positive perspective on PEM items from DePaul Symptom Questionnaire as a measure. However, after hearing some carers articulate their reservations, their stance evolved, leading to a change in opinion.

A common thread of concern from the researchers was the belief that the available questions and their framing may not accurately encapsulate the unique manifestation of PEM in Long COVID and the exacerbation of symptoms that accompany it. In echoing this sentiment, carers resonated with the feeling that the existing instruments fall short of truly portraying their children's experiences and the impact of the condition.

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE in consensus meeting	Result
Post-exertion symptoms	CDC symptom inventory for CFS	5/26 (19)	Not included in the COMS
	PEM items from DePaul Symptom Questionnaire	10/26 (38)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	6/26 (23)	Not included in the COMS

3.5 Neuro-cognitive symptoms functioning, symptoms and conditions outcome measures

All participants acknowledged the merits of the PROMIS questionnaire, commending its straightforward nature and practicability. Yet, concerns arose regarding its narrow scope and how suitably it can be applied across varied age groups. The PedsQL tool seemed to garner more favour, especially from the researchers, as they highlighted its adaptability, given that it's available in multiple languages and is tailored for a range of age demographics. Another facet of PedsQL that stood out, especially to carers, was its dual reporting approach – allowing both parents and children to share their experiences. This was seen as particularly vital, given doubts over children's capacity to accurately convey their cognitive symptoms.

However, a unanimous call from carers was to refine the questions to make them more child-centric. They felt that certain scales, like the 'mild to severe' gradation in SBQ, might be challenging for children to grasp and provide accurate feedback on. More critically, they identified a gap in the current assessment tools: none seemed to encompass certain pivotal symptoms such as hindered learning capacities or speech difficulties, both of which are paramount in evaluating neuro-cognitive abilities.

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE in consensus meeting	Result
Neuro-cognitive system functioning, symptoms, and conditions	PROMIS Pediatric Cognitive Function - Short Form 7a	9/24 (36)	Not included in the COMS
	PedsQL Cognitive Functioning Scale	21/25 (84)	Included in the COMS
	Symptom Burden Questionnaire for Long COVID (Memory, Thinking & Communication scale, movement scale, muscles and joints, pain scales)	4/24 (16)	Not included in the COMS

3.6 Physical functioning, symptoms and conditions outcome measures

The EQ5DY, a measure designed to gauge health-related quality of life, was generally well-received by attendees. It was commended for its comprehensive reach, pragmatism, and succinctness. However, concerns were raised about its 'daily' time frame, given the inherent variability of Long COVID symptoms. Moreover, a notable omission from the EQ5DY was the aspect of sleep quality, which many believed was a crucial facet to assess.

On the other hand, questions derived from the PROMIS tool faced criticism, especially from carers. They took issue with its complexity and expressed doubts over its capability to procure precise answers. For instance, connections between perspiration and intense physical activities were deemed problematic. There was a prevailing sentiment among carers that the PROMIS framework might exclude those most severely affected by Long COVID, particularly those who grapple with routine daily tasks.

With regards to SBQ, several carers highlighted potential incompatibilities, particularly regarding its format and specific items such as housework, which might not be applicable to younger populations. Yet, the '7 days' time frame it employed found favour with the researcher contingent, as they believed it aptly captured the oscillating nature of Long COVID symptoms, in contrast to a 'daily' window.

In summary, while the EQ5DY was broadly appreciated for its holistic approach and almost unanimously voted for inclusion in COMS, the discussion underlined the necessity for more nuanced tools that capture the intricacies of Long COVID in young individuals, particularly given the shifting nature of its symptoms.

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE	Result

		in consensus meeting	
Physical functioning, symptoms, and conditions	EQ5DY instrument	24/25 (96)	Included in the COMS
	PROMIS Physical Activity	2/25 (8)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	3/25 (12)	Not included in the COMS

3.7 Work/occupational and study changes outcome measures

There was a shared ambivalence towards the tools under discussion, specifically the WHO DAS 2. While some researchers acknowledged potential of this instrument, pointing out its comprehensive nature, they also raised concerns about its exhaustive list of questions, fearing it might not be fitting for those already contending with fatigue. Similarly, while some carers recognised its thorough approach and how it encapsulates the multifaceted roles children and young people assume, others expressed reservations. These carers seemed to be sceptical about the questionnaire's relevance, feeling that it did not genuinely reflect the unique challenges of Long COVID.

A recurrent theme was the need for a more expansive approach. Health professionals/researchers suggested that the domain might have to widen its parameters, as the repercussions on daily life transcended mere shifts in work or study patterns. Carers, on the other hand, were critical of the manner in which questions were framed for children. They advocated for more empathetic phrasing, with an emphasis on being mindful of the potential impacts on children's mental well-being.

Nevertheless, despite these varied perspectives and the evident need for refining this domain, there was a consensus on its significance. Both experts and carers concurred that understanding the ramifications on education and social growth was indispensable, and this necessitated the development of suitable investigative methodologies. Some suggestions were made with regards to potential addition of a simple question or two, which, although not been validated, could serve as a triage questions allowing for detection of problems requiring more in-depth investigation.

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE in consensus meeting	Result
Work/occupational and study changes	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	5/22 (23)	Not included in the COMS
	WHO DAS 2 Children and Youth 36-Item Version	7/23 (30)	Not included in the COMS

4. Post voting discussion

One salient issue was the need for greater precision around the timeframes used in questions. Carers felt that the cyclical and fluctuating nature of Long COVID symptoms were not adequately represented in specific testing moments. Given that these symptoms can vary significantly, perhaps even daily, it was proposed that more frequent iterations of questionnaires, focused on shorter time frames such as the past week, might offer a more accurate reflection of the lived reality of Long COVID. There was also a clarion call to incorporate the perspectives of children more actively. Since questionnaires are often filled out on behalf of the children, it's crucial that their experiences and voices are not marginalised or overshadowed.

Some carers expressed feeling somewhat sidelined during usual discussions around Long COVID, perceiving a differential treatment compared to health professionals and researchers. They commended the PC-COS Children project for transparency and democratic approach, but highlighted the need in a better dialogue between all relevant stakeholders. This sentiment underscores the broader challenge of balancing diverse stakeholder viewpoints in the future processes.

In essence, the post-voting dialogue underscored the need for a more nuanced approach to capturing the complexities of long COVID in children and young people, while also emphasising the importance of inclusivity in discussions and decisions.

Table 1
Pre-defined definition of consensus applied in the consensus workshop *

Consensus classification	Description	Definition
Consensus in	Consensus that instrument should be included in the proposed measure set	70% or more of participants voting 'yes'
No consensus	Uncertainty about importance of outcome	Anything else

Table 2
Consensus workshop voting results

COS outcome	Outcome Measure	N (%) participants voting to INCLUDE in consensus meeting	Result
Cardiovascular functioning, symptoms and conditions	PedsQL Cardiac Module	16/28 (57)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Circulation scale)	7/27 (25)	Not included in the COMS
	Malmo POTS score (MAPS)	18/27 (64)	Not included in the COMS
Gastrointestinal functioning, symptoms, and conditions	PedsQL Gastrointestinal Symptoms Scales	23/26 (88)	Included in the COMS
	Questionnaire on Pediatric Gastrointestinal Symptoms (QPGS)	2/26 (8)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Stomach and Digestion Scale)	6/26 (23)	Not included in the COMS
Fatigue or Exhaustion	Chalder fatigue questionnaire	3/26 (12)	Not included in the COMS
	PROMIS Paediatric Fatigue	3/26 (12)	Not included in the COMS
	PedsQL Multidimensional Fatigue Scale	26/26 (100)	Included in the COMS
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	3/26 (12)	Not included in the COMS
Post-exertion symptoms	CDC symptom inventory for CFS	5/26 (19)	Not included in the COMS

	PEM items from DePaul Symptom Questionnaire	10/26 (38)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Fatigue scale)	6/26 (23)	Not included in the COMS
Neuro-cognitive system functioning, symptoms, and conditions	PROMIS Pediatric Cognitive Function - Short Form 7a	9/24 (36)	Not included in the COMS
	PedsQL Cognitive Functioning Scale	21/25 (84)	Included in the COMS
	Symptom Burden Questionnaire for Long COVID (Memory, Thinking & Communication scale, movement scale, muscles and joints, pain scales)	4/24 (16)	Not included in the COMS
Physical functioning, symptoms, and conditions	EQ5DY instrument	24/25 (96)	Included in the COMS
	PROMIS Physical Activity	2/25 (8)	Not included in the COMS
	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	3/25 (12)	Not included in the COMS
Work/occupational and study changes	Symptom Burden Questionnaire for Long COVID (Impact on Daily Life Scale)	5/22 (23)	Not included in the COMS
	WHO DAS 2 Children and Youth 36-Item Version	7/23 (30)	Not included in the COMS

Appendix 5

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'

Nina Seylanova MD*[1], Anastasia Chernyavskaya MD*[2,3], Natalia Degtyareva BSc[4], Aigun Mursalova MD[4], Ali Ajam BSc[4], Lin Xiao BSc[4], Khazhar Aktulaeva BSc[4], Philipp Roshchin BSc[4], Polina Bobkova MD[4], Olalekan Lee Aiyegbusi PhD[5], Anbarasu Theodore Anbu MD[6], Christian Apfelbacher PhD[7], Ali Akbar Asadi-Pooya MD[8,9], Liat Ashkenazi-Hoffnung MD[10], Caroline Brackel MD[11,12], Danilo Buonsenso MD, PhD[13,14], Wouter de Groote[15], Janet V. Diaz MD[15], Daniele Dona MD, PhD[16], Audrey Dunn Galvin PhD[17], Jon Genuneit[18], Helen Goss[19], Sarah E. Hughes PhD[20], Christina J Jones PhD[21], Krutika Kuppalli MD[15], Laura A. Malone MD, PhD[22,23], Sammie McFarland[19], Dale M. Needham, MD, PhD[24,25,26], Nikita Nekliudov MD, MSc[27], Timothy R Nicholson PhD[28], Carlos R. Oliveira MD, PhD[29,30,31], Nicoline Schiess[32], Terry Y Segal MD[33], Louise Sigfrid[34], Claire Thorne PhD[35], Susanne Vijverberg PhD[36], John O. Warner[37], Wilson Milton Were[15], Paula R. Williamson PhD[38], Daniel Munblit MD, PhD*[39,40,41], and the PC-COS Children Study Group**

1 Independent researcher, London, UK

2 Department of Paediatrics and Paediatric Rheumatology, Sechenov First Moscow State Medical University (Sechenov University), Moscow, Russia

3 National Medical Research Center for Children's Health, Moscow, Russia

4 Sechenov First Moscow State Medical University (Sechenov University), Moscow, Russia

5 University of Birmingham, Birmingham, UK

6 Alder Hey Children's NHS Foundation Trust, Liverpool, UK

7 University of Magdeburg, Magdeburg, Germany

8 Epilepsy Research Center, Shiraz University of Medical Sciences, Shiraz, Iran

9 Jefferson Comprehensive Epilepsy Center, Thomas Jefferson University, Philadelphia, USA

10 Schneider Children's Medical Center of Israel, Petah Tikva, Israel

11 Amsterdam University Medical Centers, Amsterdam, the Netherlands

12 Department of Pediatrics, Tergooi Hospital, Blaricum, the Netherlands

13 Università Cattolica del Sacro Cuore, Rome, Italy

14 Department of Woman and Child Health and Public Health, Fondazione Policlinico Universitario A. Gemelli IRCCS, Rome, Italy

15 World Health Organization, Switzerland

16 Department for Women's and Children's Health, University of Padua, Padua, Italy

17 University of Cork, Cork, Ireland

18 Pediatric Epidemiology, Department of Pediatrics, Medical Faculty, Leipzig University, Leipzig, Germany

19 Long Covid Kids Charity, UK

20 Institute of Applied Health Research, University of Birmingham, Birmingham, UK

21 University of Surrey, Guildford, UK

22 Kennedy Krieger Institute, Baltimore, USA

23 Johns Hopkins University, Baltimore, USA

24 Outcomes After Critical Illness and Surgery (OACIS) Research Group, Johns Hopkins University, Baltimore, USA

25 Pulmonary and Critical Care Medicine, Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, USA

26 Physical Medicine and Rehabilitation, Johns Hopkins University School of Medicine, Baltimore, USA

27 Institute for Health Metrics and Evaluation, University of Washington, Seattle, USA

28 King's College London, London, UK

29 Yale University School of Medicine, Department of Pediatrics, Section of Infectious Diseases, New Haven, USA

30 Yale University School of Public Health, Department of Biostatistics, Division of Health Informatics, New Haven, USA

31 Yale New Haven Children's Hospital, New Haven, USA

32 Brain Health Unit, Mental Health and Substance Use Department, World Health Organization, Switzerland

33 University College London Hospitals NHS Foundation Trust, London, UK

34 ISARIC Global Support Centre, Centre for Tropical Medicine and Global Health, University of Oxford, Oxford, UK

35 Population, Policy and Practice Research and Teaching Dept, University College London GOS Institute of Child Health, London, UK

36 Amsterdam University Medical Centers, Amsterdam, the Netherlands

37 Imperial College London, London, UK

38 Department of Health Data Science, University of Liverpool, Liverpool, UK

39 Division of Care in Long Term Conditions, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, UK

40 Department of Paediatrics and Paediatric Infectious Diseases, Institute of Child's Health, Sechenov First Moscow State Medical University (Sechenov University), Moscow, Russia

41 Research and Clinical Center for Neuropsychiatry, Moscow, Russia

*Authors contributed equally to the study: apart from the two joint first authors, who contributed equally, the primary study team members and the last author, authors are listed in alphabetical order.

** Listed at end of the manuscript

Corresponding author:

Daniel Munblit MD, PhD. Division of Care in Long Term Conditions, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United Kingdom

Email: daniel.munblit@kcl.ac.uk

Additional methodological details

1. First phase (COS development)

1.1. Study group and participants

The International Study Group, which represented the International Paediatric Post-COVID Condition in Children Collaboration (IP4C) and consisted of healthcare professionals, researchers, methodologists, WHO representatives, and affected CYP, played a crucial role in designing and executing the project. The "core group" consisting of DM, NS, AC, DB, CB and SV was responsible for the study's methodology and management. DM, TN, DMN, and PRW discussed methodology for design and conduct of the study following a similar process for an adult-based study [10,11].

In the Delphi process, potential participants were selected from authors of published research, global institutions (e.g. WHO, IP4C, ISARIC), and patient organisations (e.g. Long Covid Kids). They received invitations to participate in the online Delphi process through direct emails from the research team or relevant patient/professional organisations. Additionally, Long COVID social media groups (primarily via Facebook and Twitter) were approached for recruitment, with eligibility criteria and contact information provided on the PC-COS study website (https://www.pc-cos.org/). Prospective participants underwent eligibility screening before registration as Delphi participants.

Only those participants who evaluated 50% or more of the outcomes in the first Delphi consensus round were invited to participate in the second round. Upon completion of both Delphi rounds, participants became eligible for the online consensus meeting and expressed interest in meeting participation as part of the online Delphi process. This approach aimed to ensure global representation and balanced stakeholder group distribution among attendees.

1.2. Delphi process and definitions

The order of outcomes presented in the Delphi process was randomised by domain categories (“mortality/survival”, “physiological/clinical”, “life impact” and “resource use”). A free-text option was available to suggest additional outcomes, which were assessed for inclusion in the second Delphi round (outcomes that formed ≥1% of the total number of suggested outcomes were included). All outcomes from the first round were included in the second round, regardless of the results.

2. Second phase (Outcome measurement instruments consensus)

2.1. Literature review of outcome measurement instruments

Instruments were systematically mapped to the core outcomes defined in the first phase of the project. This process was also instrumental in identifying and removing any duplicates and ensuring accurate mapping to outcomes. Any instruments that did not map to any of the COS domains were excluded from consideration. Additional instruments not used in published research and clinical trial protocols were considered based on expert suggestions and experience of adult project 11. For instance, PROMIS instruments were screened for eligibility and added to the list.