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Supplementary appendix 1

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Core Outcome Set for Research and Clinical Practice in Post COVID-19 Condition (Long COVID): An International Delphi Consensus Study ‘PC-COS’

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Table S1: PC-COS Project Steering Committee

Name	Middle name	Surname	Institution	Country	Expertise	Lived experience of Long COVID?
EUROPEAN REGION						
Daniel		Munblit	Sechenov University/Imperial College London	Russia/UK	Allergy, Pediatrics	
Alla		Guekht	Research and Clinical Centre for Neuropsychiatry	Russia	Neurology	
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Paula		Williamson	University of Liverpool	UK	Methodology, COS development	
Jochen		Schmitt	University of Dresden	Germany	Methodology, COS development	
Christian		Apfelbacher	University of Magdeburg	Germany	Epidemiology, COS development	
Piero		Olliaro	University of Oxford	UK	Public Health, Infectious diseases	
Malcolm “Calum”	G.	Semple	University of Liverpool; Alder Hey Children’s Hospital Liverpool	UK	Respiratory and Infectious Diseases	No
John	O.	Warner	Imperial College London	UK	Allergy, Respiratory Medicine, Pediatrics	
Louise		Sigfrid	University of Oxford	UK	Public Health, Infectious diseases	No
Janet	T.	Scott	MRC-University of Glasgow Centre for Virus Research	UK	Infectious Diseases	
Audrey		DunnGalvin	University of Cork	Ireland	Medical Psychology	
Jon		Genuneit	Pediatric Epidemiology, Department of Pediatrics, Medical Faculty, Leipzig University	Germany	Epidemiology	
Frances		Simpson	Coventry University	UK	Psychology	

Danilo		Buonsenso	Department of Woman and Child Health and Public Health, Fondazione Policlinico Universitario A. Gemelli IRCCS, Rome, Italy	Italy	Pediatrics, Infectious Diseases	No
Manoj		Sivan	University of Leeds	UK	Rehabilitation Medicine	
Bob		Siegerink	Leiden University Medical Center	The Netherlands	Epidemiology	No
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Sergey		Avdeev	Sechenov University	Russia	Respiratory	
Charitini		Stavropoulou	City, University of London	UK	Health Services Research	No
Melina		Michelen	University of Oxford	UK	Public Health, Infectious diseases	
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Melanie		Calvert	University of Birmingham	UK	Outcomes Methodology	
Sarah	E.	Hughes	University of Birmingham	UK	Outcomes Methodology	
Shamil		Haroon	University of Birmingham	UK	Public Health, Primary Care, Respiratory Medicine	No
Sarah		Gorst	University of Liverpool	UK	Epidemiology	
Nicola		Harman	University of Liverpool	UK	Epidemiology	
Laura		Fregonese	European Medicines Agency	NL	Respiratory, Immunology, Regulatory Science	
Gail		Carson	University of Oxford	UK		
Athena		Akrami	UCL	UK	Neuroscience	Yes
Samuel		Knauss	Charité – Universitätsmedizin Berlin	Germany	Neurology with Experimental Neurology	
Margaret		O'Hara	Long Covid Support	UK	Patient and Public Involvement in Research	Yes
Nina		Seylanova	Sechenov University	Russia	ECR	No
Alisa		Kokorina	Pirogov Medical University	Russia	ECR	
Jessica		Chen	Imperial College London	UK	ECR	
Callum		Parr	Imperial College London	UK	ECR	
REGION OF THE AMERICAS						
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SOUTH-EAST ASIAN REGION						
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WHO						
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Wouter		De Groote	WHO	Switzerland	Global Health, Rehabilitation Medicine	No

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Tarun		Dua	WHO			
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Juan		Soriano Ortiz	WHO			

Table S2. The list of the Delphi dissemination recipients.

Groups contacted by study group	
Long COVID ACTS (Autonomous Communities Together Spain)	Patient advocacy group
Covid-19 Longhailer Advocacy Project	Patient advocacy group
Long COVID Alliance	Patient advocacy group
Stroke Association Supportnetwork-Ghana	Patient advocacy group
Long Covid Italia	Patient advocacy group
Untypical Coronavirus (post-covid) Public Group, <i>Russian Patients Group</i>	Patient advocacy group
Long Covid Support	Patient advocacy group
Long Covid Physio	Patient advocacy group
PatientLed research	Patient advocacy group
Clinician-patient UK Facebook group	Patient advocacy group
NHS England	Healthcare networks
UK clinics in South East London	Healthcare networks
US Clinics (details of clinicians running Long COVID clinics were collected from a wide range of collaborators and networks)	Healthcare networks
Australian networks (Provided by Dr Allison Tong)	Healthcare networks
NIH CONNECTS (at Vanderbilt University)	Healthcare networks
NIH RECOVER (at NYU Langone)	Healthcare networks
NICE (The National Institute for Health and Care Excellence)	Healthcare networks
Zhongnan Hospital of Wuhan University	Healthcare networks
ISARIC (International Severe Acute Respiratory and emerging Infection Consortium) Leads	Healthcare and research networks
Global Burden of Disease	Healthcare and research networks

NIHR Long COVID Working Group	Healthcare networks
COMET	Core Outcome Measures in Effectiveness Trials Initiative
COVID-END Community	Researchers community
Cochrane Collaboration	Researchers community
Lead authors of studies identified in systematic review work, including trial registry entries	
Recipients of WHO Post COVID COS distribution	
Recipients of WHO Neuro distribution	

Details of the Modified Delphi Consensus Process

Relevant stakeholders were identified via published studies, international organisations (e.g. WHO, ISARIC) and patient organisations and were invited to take part in the Delphi process either by direct email, including a direct link to join the consensus process, from the study team or from relevant patient or professional organisations. Patients from “Long COVID clinical services” were also sent email invitations. Calls for participation were also disseminated via international and local patient organisations and large private “Long COVID” social media groups (see appendix p 25). Relevant stakeholder group descriptions and a contact email were also provided on a study website (<https://www.pc-cos.org>). These additional stakeholders received Delphi registration links after eligibility confirmation by study team members (NSe, AK) and, if needed, discussion with the ‘core group’.

Reminder emails were sent to registered participants, who had not yet completed the survey, at 1 week and 2 weeks after survey launch. In the first Delphi round participants were given information describing the objective of a COS and this project, and then provided with the list of outcomes (accompanied with text providing a simple description for each outcome (see appendix p 27)) and were asked to rate their importance for inclusion in the COS. Participants were also asked to suggest any additional important outcomes. Any additional outcomes submitted were reviewed by the ‘core group’ to ensure no redundancy with original outcomes before inclusion in the second round.

In the second round of the Delphi process, participants were shown their prior rating from the first round, together with ratings of each of the three stakeholder groups (presented as the distribution of 1-9 ratings for each outcome) and asked to consider this information and again rate the outcome using the 1-9 scale. Only participants rating 50% or more of the outcomes in the first round were invited to the second survey. All outcomes from the first round were carried through to the second round. Reminder emails, highlighting the importance of completing the second round, were sent at regular intervals to participants who had not submitted their responses.

Details of Consensus meeting

Participants completing both rounds of the Delphi survey were eligible to participate and were asked to express their interest during the online Delphi process. These expressions of interest were considered to help assure distribution of attendees across the stakeholder groups and international representation. There were 27 voting participants who agreed to take part. There were only five health care professionals or researchers with post COVID-19 condition who agreed to take part; this was not sufficiently large for consensus-related voting as a separate stakeholder group so they were asked to select which of the other two groups they would be most appropriate to join; one joined the health care professionals or researchers group, and four joined the patient group. These final two stakeholder groups had the following composition: 12 Patients (7 UK, 1 Ireland, 1 Greece, 1 Belgian, 1 Spain, 1 USA), 15 health care professionals/researchers (2 USA, 2 India, 1 UK, 1 Russia, 1 Chile, 1 Switzerland, 1 Belgium, 1 Brazil, 1 Norway, 1 Canada, 1 Sweden, 1 Nigeria, 1 Ghana). Prior to attending the meeting, participants received background information and a copy of their own ratings from the Delphi survey and a summary of outcomes that would be discussed at the meeting. People with lived experience and their carers were also invited to attend a pre-meeting, led by the COMET Patient and Public Coordinator, where they were provided with further information about the purpose of COS, what to expect at the consensus meeting and had the opportunity to ask questions.

Table S3. References used for the development of the long list of outcomes.

i. References suggested by the Steering Committee members

	Document type	
1	Draft	ISARIC’s Characterising long term Covid-19: a living systematic review, M. Michelen et al.
2	Draft	Therapies for Long COVID in non-hospitalised individuals, (TLC) Study Group
3	Article	Al-Aly, Z., Xie, Y. & Bowe, B. High-dimensional characterization of post-acute sequelae of COVID-19. <i>Nature</i> 594, 259–264 (2021). https://doi.org/10.1038/s41586-021-03553-9
4	Article	Nalbandian, A., Sehgal, K., Gupta, A. et al. Post-acute COVID-19 syndrome. <i>Nat Med</i> 27, 601–615 (2021). https://doi.org/10.1038/s41591-021-01283-z
5	Draft	Long COVID outcome measures (shared by T, Nicholson)
6	CRF	Global COVID-19 Clinical Platform Case Report Form (CRF) for Post COVID condition (Post COVID-19 CRF), WHO
7	Article	Taquet M, Geddes JR, Husain M, Luciano S, Harrison PJ. 6-month neurological and psychiatric outcomes in 236 379 survivors of COVID-19: a retrospective cohort study using electronic health records. <i>Lancet Psychiatry</i> . 2021;8(5):416-427. doi:10.1016/S2215-0366(21)00084-5
8	Article	Ayoubkhani D, Khunti K, Nafilyan V, et al. Post-covid syndrome in individuals admitted to hospital with covid-19: retrospective cohort study. <i>BMJ</i> . 2021;372:n693. Published 2021 Mar 31. doi:10.1136/bmj.n693
9	National Guidance	National guidance for post-COVID syndrome assessment clinics (UK)
10	Draft	Proposed Epidemiologic Phenotypes for Post-COVID Conditions: Classification of Illness Beyond Four Weeks of Acute Infection
11	Viewpoint	Olliaro PL. An integrated understanding of long-term sequelae after acute COVID-19. <i>Lancet Respir Med</i> . 2021;9(7):679-680. doi:10.1016/S2213-2600(21)00206-X
12	Article	Wu X, Liu X, Zhou Y, et al. 3-month, 6-month, 9-month, and 12-month respiratory outcomes in patients following COVID-19-related hospitalisation: a prospective study. <i>Lancet Respir Med</i> . 2021;9(7):747-754. doi:10.1016/S2213-2600(21)00174-0
13	Preprint	J. Rogers et al. The neurology and neuropsychiatry of COVID-19: a systematic review and meta-analysis of the early literature reveals frequent CNS manifestations and key emerging narratives, https://www.medrxiv.org/content/10.1101/2021.02.24.21252335v1
14	Article	Machado FVC, Meys R, Delbressine JM, et al. Construct validity of the Post-COVID-19 Functional Status Scale in adult subjects with COVID-19. <i>Health Qual Life Outcomes</i> . 2021;19(1):40. Published 2021 Feb 3. doi:10.1186/s12955-021-01691-2
15	Preprint	H. Davis et al. Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact. https://www.medrxiv.org/content/10.1101/2020.12.24.20248802v2
16	Preprint	S. Lopez-Leon et al. More than 50 Long-term effects of COVID-19: a systematic review and meta-analysis. https://www.medrxiv.org/content/10.1101/2021.01.27.21250617v2
		ii. References from ISARIC Living Systematic Review (1)
1	Article	Greenhalgh T, Knight M, A’Court C, et al. Management of post-acute covid-19 in primary care. <i>BMJ</i> 2020;370. doi:10.1136/bmj.m3026
2	Article	Sudre CH, Murray B, Varsavsky T, et al. Attributes and predictors of long COVID. <i>Nat Med</i> 2021;27:626–31. doi:10.1038/s41591-021-01292-y
3	Article	Zhang J, Xu J, Zhou S, et al. The characteristics of 527 discharged COVID-19 patients undergoing long-term follow-up in China. <i>Int J Infect Dis IJID Off Publ Int Soc Infect Dis</i> 2021;104:685–92. doi:10.1016/j.ijid.2021.01.064
4	Article	Petersen MS, Kristiansen MF, Hanusson KD, et al. Long COVID in the Faroe Islands: A Longitudinal Study Among Nonhospitalized Patients. <i>Clin Infect Dis</i> Published Online First: 30 November 2020. doi:10.1093/cid/ciaa1792
5	Article	Nguyen NN, Hoang VT, Lagier J-C, et al. Long-term persistence of olfactory and gustatory disorders in COVID-19 patients. <i>Clin Microbiol Infect Off Publ Eur Soc Clin Microbiol Infect Dis</i> Published Online First: 5 January 2021. doi:10.1016/j.cmi.2020.12.021
6	Article	Qu G, Zhen Q, Wang W, et al. Health-related quality of life of COVID-19 patients after discharge: A multicenter follow-up study. <i>J Clin Nurs</i> ;n/a. doi: https://doi.org/10.1111/jocn.15733

7	Article	Logue JK, Franko NM, McCulloch DJ, et al. Sequelae in Adults at 6 Months After COVID-19 Infection. <i>JAMA Netw Open</i> 2021;4:e210830. doi:10.1001/jamanetworkopen.2021.0830
8	Article	Nugent J, Aklilu A, Yamamoto Y, et al. Assessment of Acute Kidney Injury and Longitudinal Kidney Function After Hospital Discharge Among Patients With and Without COVID-19. <i>JAMA Netw Open</i> 2021;4:e211095. doi:10.1001/jamanetworkopen.2021.1095
9	Article	Arnold DT, Hamilton FW, Milne A, et al. Patient outcomes after hospitalisation with COVID-19 and implications for follow-up: results from a prospective UK cohort. <i>Thorax</i> 2021;76:399–401. doi:10.1136/thoraxjnl-2020-216086
10	Article	Blanco J-R, Cobos-Ceballos M-J, Navarro F, et al. Pulmonary long-term consequences of COVID19 infections after hospital discharge. <i>Clin Microbiol Infect</i> 2021;0. doi:10.1016/j.cmi.2021.02.019
11	Article	Sykes DL, Holdsworth L, Jawad N, et al. Post-COVID-19 Symptom Burden: What is Long-COVID and How Should We Manage It? <i>Lung</i> 2021;199:113–9. doi:10.1007/s00408-021-00423-z
12	Article	Jacobson KB, Rao M, Bonilla H, et al. Patients with uncomplicated COVID-19 have long-term persistent symptoms and functional impairment similar to patients with severe COVID-19: a cautionary tale during a global pandemic. <i>Clin Infect Dis Off Publ Infect Dis Soc Am</i> Published Online First: 7 February 2021. doi:10.1093/cid/ciab103
13	Article	Anastasio F, Barbuto S, Scarnecchia E, et al. Medium-term impact of COVID-19 on pulmonary function, functional capacity and quality of life. <i>Eur Respir J</i> Published Online First: 11 February 2021. doi:10.1183/13993003.04015-2020
14	Article	Bellan M, Soddu D, Balbo PE, et al. Respiratory and Psychophysical Sequelae Among Patients With COVID-19 Four Months After Hospital Discharge. <i>JAMA Netw Open</i> 2021;4:e2036142. doi:10.1001/jamanetworkopen.2020.36142
15	Article	Xu J, Zhou M, Luo P, et al. Plasma metabolomic profiling of patients recovered from COVID-19 with pulmonary sequelae 3 months after discharge. <i>Clin Infect Dis Off Publ Infect Dis Soc Am</i> Published Online First: 17 February 2021. doi:10.1093/cid/ciab147
16	Article	Xiong Q, Xu M, Li J, et al. Clinical sequelae of COVID-19 survivors in Wuhan, China: a singlecentre longitudinal study. <i>Clin Microbiol Infect Off Publ Eur Soc Clin Microbiol Infect Dis</i> 2021;27:89–95. doi:10.1016/j.cmi.2020.09.023
17	Article	Weng J, Li Y, Li J, et al. Gastrointestinal sequelae 90 days after discharge for COVID-19. <i>Lancet Gastroenterol Hepatol</i> 2021;6:344–6. doi:10.1016/S2468-1253(21)00076-5
18	Article	Han X, Fan Y, Alwalid O, et al. Six-month Follow-up Chest CT Findings after Severe COVID-19 Pneumonia. <i>Radiology</i> 2021;299:E177–86. doi:10.1148/radiol.2021203153
19	Article	Klein H, Asseo K, Kami N, et al. Onset, duration and unresolved symptoms, including smell and taste changes, in mild COVID-19 infection: a cohort study in Israeli patients. <i>Clin Microbiol Infect</i> 2021;27:769–74. doi:10.1016/j.cmi.2021.02.008
20	Article	Sonnweber T, Sahanic S, Pizzini A, et al. Cardiopulmonary recovery after COVID-19 – an observational prospective multi-center trial. <i>Eur Respir J</i> Published Online First: 1 January 2020. doi:10.1183/13993003.03481-2020
21	Article	Méndez R, Latorre A, González-Jiménez P, et al. Reduced Diffusion Capacity in COVID-19 Survivors. <i>Ann Am Thorac Soc</i> Published Online First: 20 January 2021. doi:10.1513/AnnalsATS.202011-1452RL
22	Article	Rass V, Beer R, Josef Schieffcker A, et al. Neurological outcome and quality of life three months after COVID-19: a prospective observational cohort study. <i>Eur J Neurol</i> Published Online First: 7 March 2021. doi:10.1111/ene.14803
23	Article	Sibila O, Albacar N, Perea L, et al. Lung Function sequelae in COVID-19 Patients 3 Months After Hospital Discharge. <i>Arch Bronconeumol</i> 2021;57:59–61. doi:10.1016/j.arbres.2021.01.036
24	Article	Zhang D, Zhang C, Li X, et al. Thin-section computed tomography findings and longitudinal variations of the residual pulmonary sequelae after discharge in patients with COVID-19: a shortterm follow-up study. <i>Eur Radiol</i> Published Online First: 11 March 2021. doi:10.1007/s00330-021-07799-9
25	Article	Qin W, Chen S, Zhang Y, et al. Diffusion Capacity Abnormalities for Carbon Monoxide in Patients with COVID-19 At Three-Month Follow-up. <i>Eur Respir J</i> Published Online First: 11 February 2021. doi:10.1183/13993003.03677-2020
26	Article	Alharthy A, Abuhamdah M, Balhamar A, et al. Residual Lung Injury in Patients Recovering From COVID-19 Critical Illness: A Prospective Longitudinal Point-of-Care Lung Ultrasound Study. <i>J Ultrasound Med;n/a</i> . doi:https://doi.org/10.1002/jum.15563
27	Article	Parente-Arias P, Barreira-Fernandez P, Quintana-Sanjuas A, et al. Recovery rate and factors associated with smell and taste disruption in patients with coronavirus disease 2019. <i>Am J Otolaryngol</i> 2021;42:102648. doi:10.1016/j.amjoto.2020.102648
28	Article	L Huang TZ P Zhao, D Tang. Cardiac involvement in patients recovered from COVID-2019 identified using magnetic resonance imaging. <i>JACC ...</i> Published Online First: 2020.https://imaging.onlinejacc.org/content/early/2020/07/30/j.cimg.2020.05.004?versioned=t rue
29	Article	Gherlone EF, Polizzi E, Tetè G, et al. Frequent and Persistent Salivary Gland Ectasia and Oral Disease After COVID-19. <i>J Dent Res</i> 2021;100:464–71. doi:10.1177/0022034521997112

30	Article	Hopkins C, Surda P, Vaira LA, et al. Six month follow-up of self-reported loss of smell during the COVID-19 pandemic. <i>Rhinology</i> 2021;59:26–31. doi:10.4193/Rhin20.544
31	Article	Simani L, Ramezani M, Darazam IA, et al. Prevalence and correlates of chronic fatigue syndrome and post-traumatic stress disorder after the outbreak of the COVID-19. <i>J Neurovirol</i> 2021;27:154–9. doi:10.1007/s13365-021-00949-1
32	Article	Venturelli S, Benatti SV, Casati M, et al. Surviving COVID-19 in Bergamo province: a post-acute outpatient re-evaluation. <i>Epidemiol Infect</i> 2021;149:e32. doi:10.1017/S0950268821000145
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iii. Clinical trials protocols

Trial ID	Study title
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1	NCT04768257	Physical Activity Post Coronavirus (COVID-19). A Longitudinal Study
2	DRKS00024434	Immune-mediated pathogenesis and development of autoimmunity in neurological manifestations of COVID-19 - IPEA
3	NCT04736732	The IRCM POST-COVID-19 (IPCO) Clinic: A Multidisciplinary Approach to Evaluate Short and Long-term Complications of COVID-19
4	ISRCTN15615697	Endocrinopathies post COVID-19
5	CTRI/2021/01/030816	Post COVID-19 ENT manifestations-An institutional based prospective study.
6	NCT04728906	Targeted-cell Therapy Using Epithelial Stem Cells and Patients' Cardiomyocytes Loaded in Amnion Bilayer to Regenerate Myocardial Infarction Post COVID-19 Complication
7	CTRI/2021/01/030734	Assessment of Pulmonary Complications in Post Covid Patients - NA
8	CTRI/2021/01/030573	Post Hospital Discharge follow-up of Health-Related Quality of Life (HRQOL) of COVID-19 infected patients. (COVID QOL India) - MIER/COVID/QOL/India/001
9	NCT04716465	Dysautonomia in Patients Post COVID-19 Infection (DYSCO)
10	NCT04718506	Rehabilitation for Post-COVID-19 Syndrome Through a Multicomponent, Educational and Supervised Exercise Intervention [RECOVE]
11	NCT04701892	Central Sensitisation in Post Covid-19 Infection Patients: a Prospective Cohort Study (SILENT 2)
12	NCT04703452	Central Sensitisation in Post Covid-19 Infection Patients: a Cross-sectional Study (SILENT 1)
13	NCT04705831	A Randomized, Double Blind, Placebo Controlled, Cross-Over, Proof-of-Concept Study to Evaluate the Benefit of RUCONEST (C1 Esterase Inhibitor [Recombinant]) in Improving Neurological Symptoms in Post-SARS-CoV-2 Infection
14	CTRI/2021/01/030235	Lung Function Indices Measured by Forced Oscillation Test in Post Covid patients: An Observational Study.
15	CTRI/2020/12/029985	An Open-labeled study to investigate efficacy of add-on personalized Ayurveda intervention in Covid-19 Patients with moderate diseases severity with type 2 diabetes followed by 60 day follow-up of post-viral syndrome post Covid-19 in comparison to standalone treatment based on ICMR guidelines - AAIC
16	NCT04678700	Implementation of a Respiratory Physiotherapy Program in Post COVID-19 Patients Through Tele-assistance
17	CTRI/2020/12/029755	Assessment and characterisation of symptoms and quality of life in post covid patients
18	CTRI/2020/12/029733	To Assess CT Chest finding of Post-covid Pneumonia Patient
19	NCT04657484	Comparison of the Efficacy and Safety of Two Corticosteroid Regimens in the Treatment of Diffuse Lung Disease After Coronavirus Disease 2019 (COVID-19) Pneumonia
20	NCT04649957	Profiling the Determinants of Recovery to Establish Novel Rehabilitation Guidelines to Improve Clinically Relevant and Patient-reported Outcomes in the Post-COVID-19 Period
21	NCT04647656	Hyperbaric Oxygen Therapy for Post-COVID-19 Syndrome: a Prospective, Randomized, Double Blind Study.
22	CTRI/2020/11/029437	A retrospective study to evaluate clinical and radiological course in COVID 19 interstitial pneumonia.
23	CTRI/2020/11/029305	Clarithromycin in post Covid parenchymal organizing pneumonia - an open labelled randomized control trial - PCOVID
24	NCT04634318	Organization of Pulmonary Rehabilitation of Post-COVID-19 Patient With Sequelae. Assessment and Therapeutic Indication of Tele-rehabilitation Versus Conventional Rehabilitation
25	CTRI/2020/11/029188	Assessment of quality of life in patients who have recovered from SARS -COV 2 infection
26	CTRI/2020/11/029025	AN OPEN LABEL SINGLE CENTRE PROSPECTIVE OBSERVATIONAL STUDY TO EVALUATE THE RADIOLOGICAL PATTERNS:POST COVID 19 COMPLICATIONS AND CLINICAL OUTCOME RESOLUTIONS OF LUNGS AND BRAIN IN COVID 19 CONFIRMED PATIENTS TREATED WITH AN ANTIVIRAL DRUG ZingiVir-H.
27	DRKS00023334	SARS-CoViD-Endothelitis Study via Retinal Vascular Analysis (COVID-19) - VoViThel
28	ACTRN12620001114932	Morbidity Post COVID-19 - Investigation and call to action

29	NCT04607928	Phase-II Randomized Clinical Trial to Evaluate the Effect of Pirfenidone Compared to Placebo in Post-COVID19 Pulmonary Fibrosis
30	NCT04604704	Pilot Study Into Low Dose Naltrexone (LDN) and Nicotinamide Adenine Dinucleotide (NAD+) for Treatment of Patients With Post-COVID-19 Syndrome (Long-COVID19)
31	NCT04604080	Post-COVID-19 Epidemic Depression Assessment in Adults in South Punjab Pakistan
32	NCT04592354	Anhydrous Enol-Oxaloacetate (AEO) on Improving Fatigue in Post-COVID-19 Survivors
33	NCT04595240	Semen Analysis Changes in Covid-19 Positive Patients
34	NCT04584450	Investigation of Validity and Reliability of Post-COVID-19 Functional Status Scale
35	NL8947	ReCOVer: A Randomised Controlled Trial testing the efficacy of Cognitive Behavioural Therapy for preventing chronic post-infectious fatigue among patients diagnosed with COVID-19.
36	CTRI/2020/10/028179	Impact of Post COVID Physiotherapy and Rehabilitation in Bangladesh
37	NCT04574050	A Self - Guided, Internet - Based Intervention for Patients With Chronic Breathlessness (SELF-BREATHE): Feasibility Randomised Controlled Trial
38	NCT04561141	Post Covid Syndrome: Clinical Pattern and Functional Assessment
39	NCT04551781	Short Term Low Dose Corticosteroids for Management of Post Covid-19 Pulmonary Fibrosis
40	NCT04544605	Special Chinese Medicine Out-patient Programme for Discharged COVID-19 Patients: An Observational Study
41	NCT04534478	Randomized, Open, Parallel, Single-center, Non-inferiority Clinical Trial, With an Active Control Group, Comparing Two Oral Prednisone Regimens With the Aim of Optimizing the Therapeutic Strategy in Patients With Organizing Pneumonia Post-COVID-19 Infection
42	NCT04601415	Diagnosis of Heart Failure in the Post-COVID-19 Clinic, Primary Care and Hospital Setting Using a Digital Stethoscope With Artificial Intelligence (AI) Electrocardiogram (ECG)
43	NCT04525911	Assessment of Long-term Impact Post COVID-19 for Patients and Health Care Professionals of the European Hospital
44	NCT04514705	Clinical Respiratory Investigation in Post Covid-19 Patients
45	ACTRN12620000778987	Persistent lung and arterial inflammation following COVID-19 pneumonia
46	CTRI/2020/07/026821	Study of dermatological changes post COVID-19 illness within 3 months of recovery.
47	NCT04487691	Autologous Nebulized Platelet Lysate for Post COVID-19 Syndrome
48	NCT04479293	Assessment of Functional Recovery From COVID-19 Using the Proposed Post- COVID-19 Functional Status Score
49	RBR-4wnx2q	Evaluation, pulmonary rehabilitation and follow-up of individuals affected by Covid-19 after hospital high - treatment and clinical follow-up
50	NCT04414904	Determining the Reproductive Health of Men Post-COVID-19 Infection
51	NCT04388436	Cardiopulmonary and Immunological Impacts of Covid-19 in a Cohort of Survivors
52	NCT04374474	Olfactory Retraining Therapy and Budesonide Nasal Rinse for Anosmia Treatment in Patients Post-CoVID 19. A Randomized Controlled Trial
53	DRKS00024434	Immune-mediated pathogenesis and development of autoimmunity in neurological manifestations of COVID-19
54	ACTRN12621000031864	Home-based virtual rehabilitation for people with persistent symptoms after COVID-19 disease (Long COVID-19)
55	NCT04695704	Montelukast Clinical Trial in Mild-moderate Respiratory Symptoms in Patients With Long-COVID (ESPERANZA COVID)
56	NCT04659889	Clinical and Haematological Phenotypes in Long COVID
57	NCT04876417	tDCS for Post COVID-19 Fatigue

58	NCT04798066	Intermediate Size Expanded Access Protocol Evaluating HB-adMSC's for the Treatment of Post-COVID-19 Syndrome (LongHaulers)
59	NCT04694768	Implementation of Rehabilitation Program for Post COVID-19
60	NCT04718506	Rehabilitation for Post-COVID-19 Syndrome Through a Supervised Exercise Intervention (RECOVE)
61	NCT04881305	Characterizing Long-term Cognitive and Emotional Impairment in Post-COVID-19 Sequelae
62	NCT04849598	Automatic Oxygen Titration in Patients After SARS-CoV-2 Infection
63	NCT04885504	Post COVID-19 Biorepository
64	NCT04836351	Rehabilitation for Patients With Persistent Symptoms Post COVID-19
65	NCT04811859	The Effect of Inspiratory Muscle Training in Post COVID-19 Patients
66	NCT04813718	Post COVID-19 Syndrome and the Gut-lung Axis
67	NCT04716465	Dysautonomia in Patients Post COVID-19 Infection (DYSCO)
68	NCT04794985	Post-COVID-Health Study: Multidimensional Health Status of COVID-19 Survivors One Year After a SARS-CoV-2 Infection
69	NCT04818489	Colchicine and Post-COVID-19 Pulmonary Fibrosis
70	NCT04860869	Endocrine, Metabolic and Microbiome Influence on the Post COVID-19 Syndrome
71	NCT04794036	Efficacy of an Asynchronous Telerehabilitation Programme in Post-COVID-19 Patient
72	NCT04841759	The Effects of a Multi-factorial Rehabilitation Program for Healthcare Workers Suffering From Post-COVID-19 Fatigue Syndrome
73	NCT04806880	Study Evaluating the Olfactory Recovery of Anosmia Post COVID-19 by Olfactory Rehabilitation Assisted by Web-application (COVIDANOSMIA)
74	NCT04796064	Low Versus High-Intensity Aerobic Training in Community-dwelling Older Men With Post-COVID 19 (SARS-CoV-2) Sarcopenia
75	NCT04705831	Study to Evaluate the Benefit of RUCONEST in Improving Neurological Symptoms in Post COVID-19 Infection
76	NCT04799444	LATE-COVID/LATE-COVID-Kids - Observational Study in Children and Adults (LATE-COVID)
77	NCT04860206	Post COVID19 Functional and Cognitive Assessments (PostCovidZRS)
78	NCT04889313	Post-COVID Neurologic Symptoms : a Somatic Spectrum Disorder ? (SOMATiC)
79	NCT04789395	Evaluation of Post-covid 19 Patients Who Receive Ozonotherapy With Thorax CT
80	NCT04859894	Physiological Studies in Post-COVID-19 Syndrome, and the Association With DNA Methylation
81	NCT04799977	COVID-19: Post-covid Olfactory Disorders Assessment
82	NCT04830943	Cerebrolycin for Treatment of Covid-related Anosmia and Ageusia
83	NCT04793269	Characteristics of Long COVID-19 Syndrome
84	NCT04586413	Post Acute COVID-19 Quality of Life (PAC-19QoL) Tool Development and Patient Registry (PAC-19QoLReg)
85	NCT04573062	Natural History of Post-Coronavirus Disease 19 Convalescence at the National Institutes of Health
86	NCT04794374	Effects of Telerehabilitation After Discharge in COVID-19 Survivors
87	NCT04886414	Home-based Care and Hand Hygiene Interventions in Honduras
88	NCT04810065	SingStrong: Strong Lungs Through Song - Long COVID-19 Study

89	NCT04871815	Effects of Sodium Pyruvate Nasal Spray in COVID-19 Long Haulers.
90	NCT04795557	Efficacy of Adaptogens in Patients With Long COVID-19
91	NCT04809974	Clinical Trial of Niagen to Examine Recovery in People With Persistent Cognitive and Physical Symptoms After COVID-19 Illness (Long-COVID)
92	NCT04842448	Safety and Efficacy of Hyperbaric Oxygen Therapy for Long COVID Syndrome
93	NCT04786353	Long COVID Kids DK - Investigating Long-term Covid-19
94	NCT04806620	Comparison of ME/CFS and Long COVID-19 Patients
95	NCT04883190	Fatigue a Long COVID-19 Symptom Substudy of FSC19-KN Trial
96	NCT04880161	A Study to Evaluate Ampion in Patients With Prolonged Respiratory Symptoms Due to COVID-19 (Long COVID)
97	NCT04851561	Post-coronavirus Disease-2019 Fatigue
98	NCT04872309	MUlti-nuclear MR Imaging Investigation of Respiratory Disease-associated CHanges in Lung Physiology
99	NCT04652518	LYT-100 in Post-acute COVID-19 Respiratory Disease
100	NCT04854772	Mind Body Intervention for COVID-19 Long Haul Syndrome
101	NCT04508712	Long-term Outcomes in Patients With COVID-19
102	NCT04715919	Long Term Outcomes of Coronavirus Disease-19 (COVID-19)
103	NCT04362150	Long-term Impact of Infection With Novel Coronavirus (COVID-19)
104	NCT04686734	Long-term Effects of COVID-19 in Adolescents
105	NCT04599998	Long-term Follow-up Findings of Inpatients for COVID-19 Pneumonia
106	NCT04685629	Covid-19 Long-term Revalidation Follow-up (Colonel)
107	NCT04581135	Study to Investigate Long-term Pulmonary and Extrapulmonary Effects of COVID-19
108	NCT04828135	Dual MRI for Cardiopulmonary COVID-19 Long Haulers
109	NCT04871789	Optimization of Patients Long-term Management After the Coronavirus Infection COVID-19 (OPTIMIST)
110	NCT04644341	Tele-monitoring of COVID-19 Survivors for Long-Term Impacts
111	NCT04814914	An Observational Clinical Study to Evaluate COVID-19 Symptoms in "Long Hauler" Patients Who Participated in K031-120 or K032-120
112	NCT04376840	Prevalence of Long-term Respiratory Complications of Severe SARS-CoV-2 Pneumonia - COVID-19
113	NCT04382755	Zilucoplan® in Improving Oxygenation and Short- and Long-term Outcome of COVID-19 Patients With Acute Hypoxic Respiratory Failure (ZILU-COV)
114	NCT04605757	Long-term Evolution of Pulmonary Involvement of Novel SARS-COV-2 Infection (COVID-19): Follow the Covid Study
115	NCT04893070	Impact of SARS-CoV-2 (COVID-19) Infection, Treated in Ambulatory Care, on Long-term Quality of Life in a Parisian Military Population (COVIDAMBUCMA1)
116	NCT04401163	Long-term Pulmonary Outcomes After Infection With Sars-CoV-2
117	NCT04360538	Long Term Outcomes of Patients With COVID-19 (COVID19 LTFU)
118	NCT04830852	Pediatric SARS-CoV-2 and MIS-C Long-term Follow-up
119	NCT04376658	Quality of Life and Long-term Outcomes After Hospitalization for COVID-19

120	NCT04359927	Long-term Effects of Coronavirus Disease 2019 on the Cardiovascular System: CV COVID-19 Registry (CV-COVID-19)
121	NCT04385901	Long Term Functional Outcomes of COVID-19 Patients Treated by Rehabilitation Services via Telehealth
122	NCT04519320	Medium and Long Term Follow-up of COVID-19 Infected Patients: Research and Characterization of Pulmonary Sequelae (COV-RECUP)
123	NCT04756193	Evaluate Long Term Cardiovascular and Pulmonary Complications After COVID-19 With Point of Care Ultrasound
124	NCT04813575	COVID-19 Pathophysiology of Long Term Implications
125	NCT04893668	Depression and Anxiety in Long Term Coronavirus Disease (COVID) 19 (DALT-COV)
126	NCT04477902	Long-Term Experience and Health Effects of COVID-19
127	NCT04356378	Long Term Physical Functional Limitations in Daily Living in SARS-CoV2 Infected Patients Hospitalized in the Acute Phase Then Requiring Rehabilitation (CAPACoV19)
128	NCT04605965	WEAICOR: Wearables to Investigate the Long Term Cardiovascular and Behavioral Impacts of COVID-19 (WEAICOR)
129	NCT04881266	Long-Term Functional, Quality-of-Life, Neuropsychological and Cognitive Outcomes in COVID-19 Critical Illness Survivors (LUNGTERMcov)
130	NCT04678830	COVID-19 Long-Haulers Study
131	NCT04559100	Long-term Characterization of Patients With Severe/Critical Infection by COVID-19 Virus
132	NCT04673279	Long-term COVID-19 Immune Response in a Vulnerable Neighbourhood in Argentina
133	NCT04444661	Effects of COVID-19 Induced Deconditioning After Long-term High Intensity Resistance Exercise
134	NCT04347850	A Cohort of Patients With Possible or Confirmed SARS-CoV-2 (COVID-19) (COVIDothèque)
135	NCT04410107	Lung Function, Exercise Capacity and Health-Related Quality of Life After Severe COVID-19
136	NCT04836767	Evaluation of Physical and Functional Status in Patients With COVID-19 in Long Term
137	NCT04326920	Sargramostim in Patients With Acute Hypoxic Respiratory Failure Due to COVID-19 (SARPAC)
138	NCT04330638	Treatment of COVID-19 Patients With Anti-interleukin Drugs (COV-AID)
139	NCT04401449	Cardiopulmonary Inflammation and Multi-System Imaging During the Clinical Course of COVID-19 Infection in Asymptomatic and Symptomatic Persons
140	NCT04384029	The Geneva Covid-19 CVD Study
141	NCT04397172	Intensive Care Associated Complications and Outcome of Acute Respiratory Distress Syndrome Due to COVID-19
142	NCT04368845	Telerehabilitation in Patients With COVID-19 After Hospitalization. The ATHLOS Study (ATHLOS)
143	NCT04416464	Quality of Life and Patient-centered Outcomes After ICU Admission for COVID-19
144	NCT04661462	Health After Covid-19 in Tyrol
145	NCT04593069	The COGCOV Study in ICU Patients

Table S4. The long list of outcomes used in post-COVID-19 condition studies.

Outcome area	Outcome domain (per COMET taxonomy)	Outcome
Death	1. Mortality/survival (n = 1)	All-cause mortality
Physiological/ clinical	2. Blood and lymphatic system outcomes (n = 9)	Sustained prothrombotic changes
		Anaemia
		Thrombocytopenia
		Neutrophil to lymphocyte ratio changes
		Changes in inflammatory markers
		Changes in serum creatine kinase (CK)
		Changes in lactate dehydrogenase (LDH)
		Changes in glutamic-pyruvic transaminase (GPT)
		Electrolytes changes
	3. Cardiac outcomes (n = 12)	Angina pectoris
		Acute coronary disease
		Heart rhythm issues
		Heart failure
		Palpitations
		Chest tightness
		Newly diagnosed hypertension
		Myocardial fibrosis
		Myo- or pericarditis
		Changes in cardiovascular fitness
		Signal variations in the Electrocardiogram (ECG)
	4. Endocrine outcomes (n = 7)	High blood pressure
		Diabetes mellitus
		Worsening control of existing diabetes (T1/T2)
		Diabetic ketoacidosis

		Hyperlipidaemia
		Subacute thyroiditis
		Hyperthyroidism
		Hypothalamic–pituitary–adrenal axis suppression
	5. Ear and labyrinth outcomes (n = 2)	Tinnitus
		Hearing problems
	6. Eye outcomes (n = 5)	Visual disturbance
		Red eyes/eye irritation
		Conjunctivitis
		Dry eye disease
		Sicca syndrome
	7. Gastrointestinal outcomes (n = 10)	Nausea or vomiting
		Diarrhoea
		Gastritis
		Dyspepsia
		GORD
		Dysphagia
		Bloody stool
		Enrichment of opportunistic organisms and depletion of beneficial commensals
		Post-infectious irritable bowel syndrome
		Constipation
	8. General outcomes (n = 20)	Fatigue
		Fever
		Malaise
		Weakness
		New daytime sweating
		New nighttime sweating
		Flushing

		Loss of appetite
		Hair loss
		Unspecified pain
		Sleep disorder
		Chest pain
		Breathlessness
		Sleep apnea
		Voice change
		Abdominal pain
		Faints
		Limb edema
		Dry mouth
		Dental issues
	9. Hepatobiliary outcomes (n = 2)	Chronic liver disease
		Liver function test changes
	10. Immune system outcomes (n = 2)	Hyperinflammatory state induced SARS-CoV-2
		Post-MIS-C: coronary artery aneurysm, neurologic (headache, encephalopathy, stroke and seizure) complications
	11. Infection and infestation outcomes (n = 2)	Prolonged viral fecal shedding
		Tuberculosis
	12. Metabolism and nutrition outcomes (n = 4)	Unintentional weight loss
		Unintentional weight gain
		New onset bone demineralisation
		Unintentional change in Body Constitution
	13. Musculoskeletal and connective tissue outcomes (n = 6)	Myalgia
		Arthralgia
		Limb pain - upper or lower
		Muscle atrophy
		Changes in neuromuscular performance during resistance exercise

		Dorsal/low back pain
	14. Outcomes relating to neoplasms: benign, malignant and unspecified (including cysts and polyps) (n = 1)	Worsening of pre-existing cancer/neoplasm
	15. Nervous system outcomes (n = 23)	Dizziness
		Headache
		Stroke
		Autonomic dysfunction
		Tremors
		Seizures
		Taste disturbance
		Smell disturbance
		Bradykinesia
		Dysmetria
		Speech difficulty / dysarthria
		Numbness
		Guillain-Barré syndrome
		Abnormal reflex status
		Trigeminal neuralgia
		Neuralgia/neuropathy
		Frontal release signs
		Parkinsonism
		Problems with balance
		Encephalitis
	Brain physiology changes	
	Restless legs	
	Abnormal muscle tone	
	16. Renal and urinary outcomes (n = 8)	New onset bladder incontinence
		Acute kidney injury

		Chronic kidney disease
		Urinary tract infections
		Problems passing urine
		Microhaematuria
		Renal function tests change
		COVID-19-associated nephropathy (COVAN)
	17. Reproductive system and breast outcomes (n = 4)	Dysmenorrhea
		Erectile dysfunction
		Semen/Sperm changes
		Infertility
	18. Psychiatric outcomes (n = 14)	Depression
		Anxiety
		Post-traumatic stress disorder (PTSD)
		Acute stress disorder
		Mood change
		OCD
		Behaviour change
		Thoughts of self-harm/suicide
		Risk to self and/or others
		Psychosis
		Traumatic bereavement
		Substance abuse
		Smoking habit
		Hallucinations
	19. Respiratory, thoracic and mediastinal outcomes (n = 18)	Sore throat
		Sneezing
		New onset COPD
		Excessive sputum expectoration

		Nasal congestion
		Catarrh
		Wheezing
		Cough
		Lung fibrosis
		Pleurisy
		Pleural effusion
		Pain on breathing
		Pulmonary function abnormalities
		Hypoxaemia
		Respiratory failure
		Respiratory disease
		Bronchiectasis
		Asthma
	20. Skin and subcutaneous tissue outcomes (n = 2)	Ulcers
		Skin rash
	21. Vascular outcomes (n = 3)	Thromboembolism
		Venous thrombosis
		Pulmonary and systemic vascular disease
	22. Congenital, familial and genetic outcomes (n = 0)	
	23. Pregnancy, puerperium and perinatal outcomes, including breastfeeding and weaning (n = 0)	
Life impact	24. Physical functioning (n = 4)	Post-exertional malaise
		Impaired mobility
		Walking / gait abnormality
		Problems with usual activities

	25. Social functioning (n = 1)	COVID related relationship issues
	26. Role functioning (n = 2)	Functioning
		Work/occupational function changes
	27. Emotional functioning/wellbeing (n = 9)	Demoralization symptoms
		Coping issues
		Low mood
		Burnout
		Perceived stigma/ discrimination
		Worry about infecting others
		Worry about invasion of privacy
		Need for accurate information from the government
		Fear of no full recovery
	28. Cognitive functioning (n = 3)	Confusion
		Concentration impairment
		Memory impairment
	29. Global quality of life (n = 2)	Reduced quality of life
		Reduction in health-related quality of life scores
	30. Perceived health status (n = 1)	Illness perceptions
	31. Delivery of care (n = 5)	Lack of information/ uncertain prognosis
		Difficulty accessing and navigating services
		Difficulty being taken seriously/achieving a diagnosis
		Variation in standards (e.g. inconsistent criteria for seeing, investigating and referring patients)
		Variable quality of the therapeutic relationship
	32. Personal circumstances (n = 3)	Self-care ability
		COVID related life issues such as debt, unemployment, family relationships
		Personal finances difficulties
Resource use	33. Economic (n = 1)	Health economic

	34. Hospital (n = 1)	Post-Intensive Care Syndrome
	35. Need for further intervention (n = 7)	Hospital readmission
		Further healthcare contact
		Lung transplantation
		Oxygen dependence
		RRT requirement
		Need for regular medical check-ups after discharge
		Need for psychiatric service
	36. Societal/carer burden (n = 2)	Care dependency
		Carer burden
Adverse events	37. Adverse events/effects (n =2)	Vaccination adverse effects
		Adverse effects of prednisolone

Table S5. The list of outcomes presented to the Delphi participants.

		OUTCOMES	LAY DEFINITIONS
1	Mortality/survival	Survival	How long does someone live
2	Physiological/clinical	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)
3	Physiological/clinical	Endocrine and metabolic functioning, symptoms, and conditions	New onset or worsening of problems related to the glands that make hormones, hormonal balance (e.g., diabetes, thyroid problems, adrenal gland or steroid problems, changes in body weight, bone mineral problems)
4	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)
5	Physiological/clinical	Gastrointestinal functioning, symptoms, and conditions	New onset or worsening of problems with stomach aches, nausea (feeling sick)/vomiting, diarrhea, malabsorption, constipation, gas, or indigestion (heartburn)
6	Physiological/clinical	Fatigue or Exhaustion	New onset or worsening in severity or duration of feeling exhausted, having too little energy, or needing more rest
7	Physiological/clinical	Pain	New onset or worsening of problems related to uncomfortable feelings in the body that can include sharp or burning pain, dull ache, or stinging or throbbing feeling, pain that comes and goes
8	Physiological/clinical	Sleep-related functioning, symptoms, and conditions	New onset or worsening of problems with falling or staying asleep, need for sleeping medications/aids, excessive sleepiness, or lack of refreshing sleep/poor sleep quality
9	Physiological/clinical	Nervous system functioning, symptoms, and conditions	New onset or worsening of dizziness, fainting, headache, tremors/shaking, seizures/fits, tingling feelings, muscle twitching, decreased sensation, stroke, inability to move part of the body, lack of coordination, or speech difficulty
10	Physiological/clinical	Cognitive functioning, symptoms, and conditions	New onset or worsening problems with memory, communication, concentration, or understanding instructions
11	Physiological/clinical	Mental functioning, symptoms, and conditions	New onset or worsening problems with emotions and mood, including anxiety/worrying, panic attacks, depression, suicidal thoughts, or post-traumatic stress disorder
12	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)
13	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
14	Physiological/clinical	Reproductive and sexual functioning, symptoms, and conditions	New onset or worsening problems with menstrual periods, infertility (i.e., ability to make a baby), desire for sex, ability to have sex, or discomfort during sex

15	Physiological/clinical	Respiratory functioning, symptoms, and conditions	New onset or worsening problems with lungs or breathing (e.g., shortness of breath, chest tightness, or coughing)
16	Physiological/clinical	Skin, hair and/or nail-related functioning, symptoms, and conditions	New onset or worsening problems with ulcers, skin rash, itch, red spots or lumps on toes (COVID toes), hair thinning/loss, changes in nails
17	Life impact	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.
18	Life impact	Social role-functioning and relationships problems	New onset or worsening problems with connecting with others, maintaining friendships and romantic relationship
19	Life impact	Work/occupational changes and study	New onset or worsening problems with being able to resume work, study or activities/hobbies
20	Life impact	Stigma	Fear or experiences of being discriminated against, including by employer, medical professionals, family/friends/neighbours, or others
21	Life impact	Satisfaction with life, or personal enjoyment	Satisfaction with life, or personal enjoyment, loss of being the person who you were
22	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)
23	Resource use	Family/carer burden	Being a burden on caregiver/family or friends/colleagues; impact of sickness on other people in your life
24	Physiological/clinical	Post-exertion symptoms*	Worsening of symptoms following physical or mental exertion that can last for a prolonged duration
25	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
26	Physiological/clinical	Eye symptoms and conditions **	New onset or worsening of eye-related problems, such as visual changes (e.g. blurring, double vision, floaters), itching, dryness or excessive tearing or increased sensitivity to light.

* - an outcome added after people with lived experience representatives review

** - outcomes suggested by Round 1 participants, and rated during Round 2

Table S6. Full details of Delphi participants.

	Round 1 <i>n</i> = 1535	Round 2 <i>n</i> = 1148
Stakeholder group, <i>n</i>		
Person with post COVID-19 condition	774	553
Family member/caregiver	36	26
Health professional with post COVID-19 condition	148	110
Researchers with post COVID-19 condition	21	16
Health professional	448	350
Researcher	108	93
Gender, <i>n</i>		
Male	392	301
Female	1135	841
Non-binary, other or no answer	6	4
Other	1	1
Prefer not to answer	1	1
Age group, <i>n</i>		

18-29	89	57
30-39	404	299
40-49	565	423
50-59	343	262
60-69	119	94
70-79	15	13
Countries, <i>n</i>		
Afghanistan	1	0
Argentina	13	10
Australia	25	22
Austria	1	1
Belarus	1	0
Belgium	12	11
Brazil	30	22
Burkina Faso	1	1
Canada	72	58
Chile	20	12

China	16	12
Colombia	8	5
Costa Rica	1	1
Croatia	1	1
Czech Republic	1	0
Democratic republic of Congo	1	0
Denmark	8	7
Ecuador	1	0
Egypt	2	1
Ethiopia	1	1
Finland	5	3
France	21	19
Gambia	1	1
Germany	45	39
Ghana	5	3
Greece	4	2
India	36	19
Indonesia	5	3

Ireland	7	5
Israel	2	1
Italy	20	13
Ivory Coast	1	1
Japan	2	2
Kazakhstan	5	3
Latvia	1	1
Malawi	2	2
Malaysia	4	4
Mali	1	1
Mauritius	1	0
Mexico	6	4
Myanmar	1	0
Nepal	9	5
Netherlands	12	10
New Zealand	4	2
Nigeria	1	1
Norway	6	6

Pakistan	1	1
Panama	1	0
Peru	4	3
Philippines	2	2
Portugal	4	2
Republic of Korea	3	3
Republic of Moldova	2	1
Russia	33	15
Saudi Arabia	2	1
Singapore	1	0
South Africa	8	5
Spain	525	374
Sri Lanka	1	1
Sweden	5	5
Switzerland	6	4
Tanzania	3	2
Thailand	1	1
Turkey	2	1

Ukraine	9	1
United Arab Emirates	3	2
United Kingdom	284	242
United States of America	207	163
Venezuela (Bolivarian Republic of)	1	1
Zambia	2	1
Zimbabwe	1	1
Not specified	1	1
Ethnicity, <i>n</i>		
White	975	753
South Asian	68	47
Hispanic/Latino/Spanish	350	246
East Asian/Pacific Islander	43	33
Indigenous peoples	4	4
Black	25	16
Middle Eastern/North African	12	10
Other	58	39

Table S7. Results following two rounds of Delphi and selection of outcomes for the consensus meeting.

					Patients and Family members/Caregivers (n=579)				HPs and Researchers with Long COVID (n=126)			HPs and Researchers without Long COVID (n=443)				
					Not that important	Important but not critical	Critically Important		Not that important	Important but not critical	Critically Important		Not that important	Important but not critical	Critically Important	
	Outcome	Help Text	R1 result	Overall result	%1-2	%4-6	%7-9	Patient/Carer Result P	%1-3	%4-6	%7-9	HP/Res COVID Result	%1-3	%4-6	%7-9	HP/Res Result
MORTALITY/SURVIVAL	Survival	<i>How long does someone live</i>		Discuss	6.9	14.0	79.0	Medium	1.6	12.2	86.2	In	1.1	8.9	89.9	In

PHYSIOLOGICAL/ CLINICAL	Cardiovascular functioning, symptoms and conditions	<i>New onset or worsening of problems affecting the heart (e.g. pounding or racing heart) and the blood vessels (e.g., veins or arteries), lightheadedness/fainting (including on standing).</i>		In	3.5	16.5	80.0	In	2.4	3.2	94.4	In	0.9	10.9	88.2	In
	Endocrine and metabolic functioning, symptoms and conditions	<i>New onset or worsening of problems related to the glands that make hormones, hormonal balance (e.g., diabetes, thyroid problems, adrenal gland or steroid problems, changes in body weight, bone mineral problems)</i>		Query discuss at end	6.3	20.5	73.2	Medium	1.6	20.2	78.2	Medium	3.9	47.0	49.1	Out
	Hearing-related functioning, symptoms and conditions	<i>New onset or worsening of problems with hearing (e.g., hearing loss, ringing or buzzing in the ears ('tinnitus'), increased sensitivity to sounds)</i>		Out	15.6	45.3	39.1	Out	10.4	46.4	43.2	Out	16.1	67.3	16.6	Out
	Gastrointestinal functioning, symptoms and conditions	<i>New onset or worsening of problems with stomach aches, nausea (feeling sick)/vomiting, diarrhea, malabsorption, constipation, gas, or indigestion (heartburn), appetite or weight change</i>		Query discuss at end	5.4	24.3	70.3	Medium	0.8	24.0	75.2	Medium	4.8	58.5	36.6	Out

Fatigue or Exhaustion	<i>New onset or worsening in severity or duration of feeling exhausted, having too little energy, or needing more rest</i>	In	In	0.9	5.5	93.7	In	0.0	0.8	99.2	In	0.0	4.8	95.2	In
Pain	<i>New onset or worsening of problems related to uncomfortable feelings in the body that can include sharp or burning pain, dull ache, or stinging or throbbing feeling, pain that comes and goes</i>		In	3.2	14.0	82.8	In	0.0	8.0	92.0	In	1.1	17.7	81.2	In
Sleep-related functioning, symptoms and conditions	<i>New onset or worsening of problems with falling or staying asleep, need for sleeping medications/aids, excessive sleepiness, or lack of refreshing sleep/poor sleep quality</i>		Discuss	2.1	18.0	79.9	Medium	0.8	12.0	87.2	In	1.1	23.5	75.3	Medium
Nervous system functioning, symptoms and conditions	<i>New onset or worsening of dizziness, fainting, headache, tremors/shaking, seizures/fits, tingling feelings, decreased sensation, stroke, inability to move part of the body, lack of coordination/balance or speech difficulty.</i>		In	1.2	9.5	89.3	In	0.8	4.8	94.4	In	0.5	12.7	86.9	In
Cognitive functioning, symptoms and conditions	<i>New onset or worsening problems with memory, communication, concentration, or understanding instructions</i>	In	In	1.7	11.9	86.4	In	0.0	3.2	96.8	In	0.7	4.5	94.8	In

Mental functioning, symptoms and conditions	<i>New onset or worsening problems with emotions and mood, including anxiety/worrying, avoidance, catastrophizing, panic attacks, depression, suicidal thoughts, or post-traumatic stress disorder</i>	In	In	3.8	11.9	84.3	In	0.8	7.2	92.0	In	0.0	5.6	94.4	In
Taste- and/or smell-related functioning, symptoms and conditions	<i>New onset or worsening problems with altered or reduced/loss of taste or smell (e.g., familiar things smell or taste bad or different)</i>		Out	19.7	43.2	37.1	Out	5.6	52.4	42.1	Out	5.9	61.9	32.2	Out
Kidney and urinary-related functioning, symptoms and conditions	<i>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>		Query discuss at end	16.0	33.3	50.7	Medium	8.7	33.3	57.9	Medium	7.5	56.9	35.7	Out
Reproductive and sexual functioning, symptoms and conditions	<i>New onset or worsening problems with menstrual periods, infertility (i.e., ability to make a baby), desire for sex, ability to have sex, or discomfort during sex</i>	Out	Out	17.5	41.3	41.3	Out	9.5	50.0	40.5	Out	9.7	66.0	24.4	Out
Respiratory functioning; symptoms; and conditions	<i>New onset or worsening problems with lungs or breathing (e.g., shortness of breath, chest tightness or coughing)</i>	In	In	3.8	11.6	84.5	In	0.8	4.8	94.4	In	0.0	3.4	96.6	In

	Skin; hair and/or nail-related functioning, symptoms and conditions	<i>New onset or worsening problems with ulcers, skin rash, itch, red spots or lumps on toes (COVID toes), hair thinning/loss, changes in nails</i>	Out	Out	12.2	44.7	43.1	Out	6.4	52.0	41.6	Out	19.6	65.6	14.8	Out
LIFE IMPACT	Physical functioning; symptoms; and conditions	<i>New onset or worsening problems with physical abilities, such as walking, dressing, or eating</i>		In	0.5	8.7	90.8	In	0.0	3.2	96.8	In	0.0	2.0	98.0	In
	Social role-functioning and relationships problems	<i>New onset or worsening problems with connecting with others, maintaining friendships and romantic relationship</i>	In	Query discuss at end	4.9	29.8	65.3	Medium	2.4	19.2	78.4	Medium	1.1	22.9	76.0	Medium
	Work/occupational changes and study	<i>New onset or worsening problems with being able to resume work, study or activities/hobbies</i>		In	2.1	10.5	87.4	In	0.0	7.2	92.8	In	0.7	11.2	88.2	In
	Stigma	<i>Fear or experiences of being discriminated against, including by employer, medical professionals, family/friends/neighbours, or others</i>		Out	11.3	39.3	49.4	Out	5.6	46.4	48.0	Out	12.6	63.0	24.4	Out

	Satisfaction with life; or personal enjoyment	<i>Satisfaction with life, or personal enjoyment, loss of being the person who you were</i>	Out	Discuss	2.1	18.2	79.7	Medium	0.0	16.1	83.9	In	0.7	23.6	75.7	Medium
RESOURCE USE	Healthcare resource utilisation	<i>Seeing more healthcare professionals (e.g., doctor, physiotherapist, psychologist); taking new medications; returning to the hospital or emergency care; including complimentary/alternative medicine (e.g., acupuncturists, naturopaths)</i>		Discuss	2.5	20.2	77.3	Medium	0.8	18.7	80.5	In	0.7	24.7	74.7	Medium
	Family/carer burden	<i>Being a burden on caregiver/family or friends/colleagues; impact of sickness on other people in your life</i>		Query discuss at end	5.9	27.5	66.6	Medium	4.0	19.2	76.8	Medium	1.1	30.4	68.5	Medium
PHYSIOLOGICAL/ CLINICAL	Post-exertion symptoms	<i>Worsening of symptoms following physical or mental exertion that can last for a prolonged duration</i>		In	0.7	6.9	92.4	In	0.0	4.8	95.2	In	0.5	12.6	86.9	In
	Eye symptoms and conditions	<i>New onset or worsening of eye-related problems, such as visual changes (e.g. blurring, double vision, floaters), itching, dryness or excessive tearing or increased sensitivity to light</i>		Query discuss at end	10.1	30.0	59.9	Medium	4.0	48.8	47.2	Out	15.3	62.8	21.8	Out

	Muscle and joint symptoms and conditions	<i>New onset or worsening of joint or muscle problems, such as muscle weakness or joint stiffness or swelling</i>		Discuss	3.5	15.3	81.1	In	0.0	15.2	84.8	In	2.1	37.6	60.3	Medium
Total																
In			5	10												
Out			3	5												
Discuss				5												
Query discuss at end				6												

Table S8. Attrition between Rounds one and two.

Stakeholder	Number registered (% of total registrations)	Completed R1 n (% of registrations)	Number of participants invited to R2*	Completed R2 n (% of completed R1 and invited to R2)
People with long COVID/post COVID condition and their and Carers	912 (54)	810 (89)	807	579 (72)
Health professional and Researchers with Long COVID/Post-COVID condition	191 (11)	169 (88)	169	126 (75)
Health professional and Researchers (without COVID)	589 (35)	556 (94)	554	443 (80)
Total	1692	1535 (91)	1530*	1148

*This figure takes into account participants who could not be reached because of mail delivery failures (n=5)

Table S9. Consensus meeting participants.

	N (%)
Healthcare professionals/Researchers	15 (100)
Delphi stakeholder group	
Health professional (including those who also do research) ¹	10 (67)
Researcher (without any clinical patient care duties) ²	4 (26)
Health professional with Long COVID/Post-COVID condition ¹	1 (7)
Country of residence	
Belgium	1 (7)
Brazil	1 (7)
Canada	1 (7)
Chile	1 (7)
Ghana	1 (7)
India	2 (13)
Nigeria	1 (7)
Norway	1 (7)
Russia	1 (7)
Sweden	1 (7)
Switzerland	1 (7)
UK	1 (7)
USA	2 (13)
People with long COVID and their carers	12 (100)
Delphi stakeholder Group	
Person with Long COVID/Post-COVID Condition	7 (58)
Family member/caregiver of person with Long COVID/Post-COVID Condition	1 (8)
Health professional with Long COVID/Post-COVID condition ³	4 (33)
Country of residence	
Belgium	1 (8)
Greece	1 (8)
Ireland	1 (8)
Spain	1 (8)
UK	7 (58)
USA	1 (8)
¹ Health professionals who care for people with long COVID ² Researchers who undertake research in long COVID ³ Health professionals who do not provide care for people with long COVID	

Table S10. Delphi process and Consensus meeting results.

Domain	Outcome	Outcome description	% people with long COVID rating 7-9 in the online Delphi	%HCPs/ researchers with long COVID voting 7-9 in the online Delphi	% HCPs /researchers voting 7-9 in the online Delphi	% people with long COVID voting 7-9 in consensus meeting	% HCPs voting 7-9 in consensus meeting	Result
Mortality outcomes	Survival	How long does someone live	79	86	90	83	92	Included in the COS
	Physiological/clinical outcomes	Sleep-related functioning, symptoms and conditions	New onset or worsening of problems with falling or staying asleep, need for sleeping medications/aids, excessive sleepiness, or lack of refreshing sleep/poor sleep quality	80	87	75	75	64
Muscle and joint symptoms and conditions		New onset or worsening of joint or muscle problems, such as muscle weakness or joint stiffness or swelling	81	85	60	92	25	Not included in the COS
Life impact outcomes	Satisfaction with life or personal enjoyment	Satisfaction with life, or personal enjoyment, loss of being the person who you were	80	84	76	42	27	Not included in the COS
	Social role functioning and relationships problems	New onset or worsening problems with connecting with others, maintaining friendships and romantic relationship	65	78	76	25	18	Not included in the COS
Resource use outcomes	Family/carer burden	Being a burden on caregiver/family or friends/colleagues; impact of sickness on other people in your life	67	77	69	33	36	Not included in the COS
	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)	77	81	75	92	73	in the COS

Table S11. Participants wishing to be acknowledged.

Adriana
Africa Martínez Amezcua
Aitana
Alba
Alejandra Sánchez Alonso
Alicia
Alicia Claver Lacruz
Ana
Ana Isabel Arroba Rocha
Ana Isabel Casas Novellón
Ana Isabel Rodríguez
Ana Lacalle Henche
Ana María
Ana María Blasco Catalán
Angela Castaño Ruiz
Angela Morales Elbaz
Antonio Martín Castillejo
Aránzazu Angel
Ascension
Beatriz
Beatriz
Begoña Puges Comas
Begoña Ruiz
Carlos
Carlos a. Alvarez-Moreno
Carlos Sierra Sahun
Carne Navarrete
Carmen Fernandez

Carmen Gimeno Zamora
Carmen Molina
Carmen Tejero Cano
Carolina
Carolina Daneyko Marinas
Carolina Foster
Castro Horacio Matías
Cesareo Moreno Pérez
Charo
Concepcion Martín Cortijo
Cristina Arnáiz Domínguez
Cristina Garcia
Cristina Gomez Cativiela
Cristina Hernandez Puente
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Fatima
Federico Carini
Felipe Araya Casanova
Fernando Elosúa
Francisca Madrid Botello
Francisco Sánchez Ruiz
Francy Cantor-Cruz
Gabriela Delsignore
Gema Marián González González
Gemma Sáez Ons
GiovaniI Assuncao De Azevedo Alves
Giuliana María Pesaresi
Gonzalo Queipo
Inma Pérez del Toro
Inmaculada Samaniego Galan
Isabel
Isabel Herreros
Isabelle Delez
Itziar
Ivan
Javier
Javier Pacho Sánchez
Joan
Jordi Rello
Jorge
José

Jose Andres Calvache
José Antonio Martín Quero
Jose F. Parodi
José Ignacio Ruiz Serrano
José Jacinto
Jose Zuccoli
Josep Oriol Mesa Rey
Josep Ortega
Juan
Juan José Lòpez Cantero
Judit Vidal Marimon
Julia García Morán
Julieta
Kristina Jausoro Alzola
Ladislao Diaz Ballve
Laura rapela
Leidy Depestre Benitez
Lidia
Loretta
Luis Antonio Gorordo-Delsol
Luis D Capacete Novo
Luis González Argomániz
M Jose
M Victoria Perez
M. Pietat Espin
M ^a Dolores Garcia Llamas
Maira Cuello
Maite
Manuel Prieto
Manuela

Mar Ariza
Mar Lefort
Mar Sendra
Marcela
Marga Flores
Maria
Maria
Maria Aida Alzola Medina
María Almagro Del Rosal
María Angeles Rodríguez de Guzmán Moreno
Maria De Los Angeles Diaz Garrido
Maria Del Mar Racero
María Dolores
María Dolores Dominguez Cáceres
Maria Dolores Peleato Catalan
María Esther Franco Carranza
María Eugenia Díez Moreno
María Eugenia Prieto Calonge
Maria Gracia Sánchez Ruiz
María Jesús Bermúdez Rivero
Maria Luisa Costa Talavera
Maria Montoya Martínez
María Noël Zucco Solari
Maria Pilar Uruen Pelegrin
Marie-Claire
Marimar Sánchez Perez
Marína Ibañez
Mario
Mario Hurtado Donaire
Marisa Milla Ibañez

Marta
Marta Arranz Cárcamo
Marta Begueria Sopesens
Marta Castro García
Marta Fuentes
Marta Isabel Casas Santiago
Marta Sanguino López
Marta Villafañez
Mary
Mercedes
Mercedes Sánchez Sancho
Mertxe
Milagros Del Pino Nieto
Miriam
Miriam
Miriam Jesica Martin Duran
Monica
Monica Condominas Pich
Montse Alcolado
Montserrat Canal
Myrian Brun
Natalia Reina
Nicolasa Ramirez Torres
Nieves Camara
Nuria
Nuria
Nuria
Nuria Tabuenca Prat
Patricia
Patricia D.R.

Patricia Garcia Gomez
Pavel Contreras
Paz TI
Pilar
Pilar
Pilar del aguila
Pilar Suarez García
Pilar Yagüe Sebastian
Rafael
Raquel
Raquel Anton Boada
Raquel Valls
Raül
Rebeca
Ricardo Allegri
Rocío Biedma Romero
Roger Paredes
Rosa María Alvarez Bernal
Rosa María San Martin
Rosa Puerta Alonso
Rosana Prados Román
Rosario Arias
Ruben Garcia Sanchez
Ruth Lobo
Sabrina
Sagrario
Sandra
Sandra González Muñoz
Sandra Muñoz
Sandra RG

Sara
Sara Lancho
Seila Torrón Domínguez
Sheyla
Silvia
Silvia Sanz Arumí
Sofía
Susanne Kessler
Tatiana
Teresa Villani
Vanesa
Vanessa
Vanessa
Veronica Rojas Jara
Viginia Martínez Buelga
Yanine Perez
Yolanda