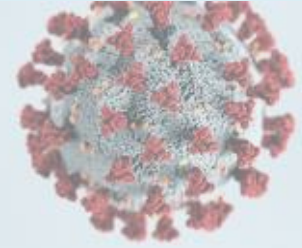


Symposium on Long COVID

Examining the Working Definition



Agenda

Day 1: Thursday, June 22, 2023, 1:00 p.m.-6:00 p.m. ET

Day 2: Friday, June 23, 2023, 8:30 a.m.-1:00 p.m. ET

In-Person Attendance	Virtual Attendance
<p>National Academy of Sciences Auditorium 2101 Constitution Ave. NW Washington, DC 20418</p>	<p>Livestream Link: https://www.nationalacademies.org/event/06-22-2023/examining-the-working-definition-for-long-covid-workshop</p>

Background:

Since the beginning of COVID-19 pandemic, infected individuals exhibited different patterns of recovery with a proportion reporting ongoing health issues. Different definitions of this emerging condition, known as Long COVID, have been proposed. At the request of the Office of the Assistant Secretary for Health (OASH) and the Administration for Strategic Preparedness and Response (ASPR), the National Academies of Sciences, Engineering, and Medicine convened a committee to undertake a [series of activities](#) to examine the U.S. Government current working definition for Long COVID and related technical terms.

Interim Working Definition: Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.

Objectives:

1. Discuss the approaches employed by the committee to solicit broad feedback about the U.S. Government working definition for Long COVID.
2. Examine the evidence supporting different elements of a Long COVID definition.
3. Based on the evidence and stakeholder input, discuss the necessary elements of a definition for Long COVID.
4. Explore emerging evidence, gaps, and key considerations for updating and modifying the definition in the future.
5. Understand industry and payer perspectives on the definition for Long COVID and consider how the definition might need to be adapted for different purposes, including but not limited to clinical research, epidemiologic and surveillance, policy, and advocacy and education.

DAY 1: THURSDAY, JUNE 22, 2023

SESSION I OPENING SESSION

1:00 p.m. **Welcome and Project Reel: A Multi-Phase and Collaborative Approach**

Harvey Fineberg, *Committee Chair*
President
Gordon and Betty Moore Foundation

1:10 p.m. **Opening Remarks**

Victor Dzau *virtual*
President
National Academy of Medicine

1:20 p.m. **Keynote Presentation – Long COVID: From Policy to Action**

Sarah Boateng *virtual*
Principal Deputy Assistant Secretary for Health
Department of Health and Human Services

SESSION II PLENARY SESSION: LESSONS LEARNED FROM INFECTION-ASSOCIATED CHRONIC CONDITIONS

1:35 p.m. **Lessons Learned from Lyme Disease**

Abigail Dumes, *Committee Member, virtual*
Assistant Professor
Department of Women's and Gender Studies
University of Michigan

1:45 p.m. **Fireside Chat with Patient Organization Leaders**

Karyn Bishof in conversation with key patient organization leaders about challenges faced by people living with Long COVID and associated conditions and implications for defining Long COVID.

Moderator: Karyn Bishof, *Committee Member*

Oved Amitay
President and CEO
Solve ME

Lauren Stiles
President
Dysautonomia International
Research Assistant Professor of Neurology
Stony Brook University Renaissance School of Medicine

Lisa McCorkell
Co-Founder
Patient-Led Research Collaborative

SESSION III IMPACTS OF LONG COVID ON OVERALL WELL-BEING

2:15 p.m.

Impacts of Long COVID on Health and Socio-Economic Well-Being and Implications for Defining Long COVID

Moderator: Monica Verduzco Gutierrez, Committee Member

Patient Perspective on Long COVID and Health-Related Quality of Life

Kelly Sealey
Long COVID Patient Advocate

Research and Perspectives from Patients on Employment, Disability, Socioeconomic Status, Educational, and Developmental Outcomes

Netia McCray
Executive Director
Mbadika
Long COVID Patient Advocate

Racial and Ethnic Disparities

Yongkang Zhang
Assistant Professor
Department of Population Health Sciences
Weill Cornell Medical College

Association of Post COVID-19 Condition Symptoms and Employment

Roy Perlis
Ronald I. Dozoretz, MD Endowed Chair
Associate Chief for Research
Department of Psychiatry
Director of the Center for Quantitative Health
Massachusetts General Hospital

Long COVID and Impairments

Tae Chung
Director
Johns Hopkins Postural Orthostatic Tachycardia Syndrome (POTS) Program
Assistant Professor of Physical Medicine and Rehabilitation and Neurology
Johns Hopkins Medicine

CDC INSPIRE

Michael Gottlieb *virtual*
Associate Professor and Vice Chair
Department of Emergency Medicine
Rush University Medical Center

Q&A

3:30 p.m.

30-MINUTE BREAK

SESSION IV

RESEARCH ON THE CLINICAL MANIFESTATIONS, EPIDEMIOLOGIC CHARACTERISTICS, AND UNDERLYING MECHANISMS OF LONG COVID

4:00 p.m.

Clinical Manifestations and Epidemiologic Characteristics of Long COVID – Signs and Symptom, Onset and Duration, Attribution to Infection

Moderator: Jerry Krishnan, *Committee Member*

Development of a Definition of PASC Infection

Co-Presenter: Tanayott Thaweethai

Associate Director, Biostatistics Research and Engagement
Massachusetts General Hospital
Instructor in Medicine,
Harvard Medical School

Co-Presenter: Leora Horwitz

Professor
NYU Langone

Identification of SARS-CoV-2 Sub-Phenotypes

Mark Weiner

Professor of Clinical Population Health Sciences and Medicine
Weill Cornell Medical College

Recovery and Symptom Trajectories up to Two Years After SARS-CoV-2 Infection

Milo Puhan *virtual*

Professor
Epidemiology, Biostatistics and Prevention Institute
University of Zurich

Epidemiology, Immunology, and Clinical Characteristics of COVID-19 (EPIC3)

Jennifer Ross *virtual*

Assistant Professor of Medicine
University of Washington
Attending physician in Infectious Diseases
VA Puget Sound Health Care System
Co-Principal Investigator/Study Chair
Epidemiology, Immunology, and Clinical Characteristics of COVID-19 (EPIC3)
Department of Veterans Affairs

Epidemiologic Characteristics of Long COVID

Sharon Saydah

Post-COVID Conditions and Long Term Sequelae Team Lead
Epidemiology Branch
Coronavirus and Other Respiratory Viruses Division
National Center for Immunizations and Respiratory Diseases
Centers for Disease Control and Prevention

Q&A

Symposium on Long COVID: Examining the Working Definition

5:00 p.m. **Biomarkers and Underlying Mechanisms of Long COVID**

Moderator: Andrea Troxel, *Committee Member*

Immune Mechanisms Underlying COVID-19 Pathology and PASC

Sindhu Mohandas

Assistant Professor of Clinical Pediatrics
Division of Infectious Diseases
Children's Hospital Los Angeles
Keck School of Medicine
University of Southern California, Los Angeles

Multiple Early Factors Anticipate PASC

James Heath *virtual*

President and Professor
Institute for Systems Biology in Seattle

The Neurobiology of Long COVID

Michelle Monje *virtual*

Professor of Neurology
Howard Hughes Medical Institute Investigator
Stanford University

Biomarkers and Underlying Mechanisms of Infection-Associated Chronic Illnesses

Tim Coetzee *virtual*

Chief Advocacy, Services and Science Officer
National MS Society
Co-Chair, Toward a Common Research Agenda in Infection - Associated Chronic Illnesses: A Workshop to Examine Common, Overlapping Clinical and Biological Factors

Q&A

SESSION V DAY 1 CLOSING REMARKS

5:45 p.m. **Chair's Reflection**

Harvey Fineberg, *Committee Chair*

President
Gordon and Betty Moore Foundation

6:00 p.m. **End Day 1**

DAY 2: FRIDAY, JUNE 23, 2023

SESSION VI WELCOME TO DAY 2

8:30 a.m. Welcome and Recap of Day 1

Harvey Fineberg, *Committee Chair*
President
Gordon and Betty Moore Foundation

8:35 a.m. Keynote Presentation – The Therapeutic Validation of Long COVID

Jeremy Faust
Physician
Division of Health Policy and Public Health
Brigham and Women's Hospital
Harvard Medical School
Editor-in-Chief
Medpage Today

8:50 a.m.

Fireside Chat – Untangling the Concept and Terminology of a “Definition”

Dr. Harvey Fineberg in conversation with Dr. Jim Curran about concepts related to defining a disease or syndrome, implications for defining Long COVID, and lessons learned from HIV/AIDS.

Harvey Fineberg, *Committee Chair*
President
Gordon and Betty Moore Foundation

James Curran
Dean Emeritus
Rollins School of Public Health
Emory University

SESSION VII LESS STUDIED LONG COVID SYMPTOMS AND EVIDENCE GAPS

9:15 a.m. Less Studied Long COVID Symptoms and Gaps in Evidence

Moderator: Linda Sprague Martinez, *Committee Member*

Perspective on Considerations for Definitions from the ME/CFS Program at CDC

Jeanne Bertolli *virtual*
Deputy Chief
Chronic Viral Diseases Branch
Division of High Consequence Pathogens and Pathology
National Center for Zoonotic and Emerging Infectious Diseases
Centers for Disease Control and Prevention

Prevalence of ME/CFS-like Illness Following COVID-19 in a Large Integrated Health System

Jacek Skarbinski *virtual*

Physician

Assistant Program Director

Kaiser Permanente Northern California HIV Fellowship

Research Scientist

Kaiser Permanent Northern California

Gastrointestinal System and Long COVID

Saurabh Mehandru

Physician Scientist

Professor and Vice Chair of Research

Icahn School of Medicine at Mount Sinai

Reproductive Health Conditions, Connective Tissue Disorders, and Spinal Pathologies in Long COVID and Associated Illnesses

Beth Pollack *virtual*

Research Scientist

Department of Biological Engineering

Massachusetts Institute of Technology

Post-Exertional Malaise, Sleep Disturbances, Cognitive Issues, and Dysautonomia and Long COVID

Tae Chung

Director

Johns Hopkins Postural Orthostatic Tachycardia Syndrome (POTS) Program

Assistant Professor of Physical Medicine and Rehabilitation

Johns Hopkins Medicine

Autonomic Symptoms, Mechanisms, and Pathology in Long COVID

Lauren Stiles

President

Dysautonomia International

Research Assistant Professor of Neurology

Stony Brook University Renaissance School of Medicine

Pediatric Long COVID

Laura Malone

Co-Director, Pediatric Post-COVID19 Rehabilitation Clinic

Kennedy Krieger Institute

Assistant Professor of Neurology and Physical Medicine and Rehabilitation

Johns Hopkins University School of Medicine

Q&A

10:30 a.m.

30-MINUTE BREAK

SESSION VIII MULTI-SECTORAL PERSPECTIVE ON THE DEFINITION FOR LONG COVID

11:00 a.m. Drug Developers, Payer, and Health Plan Perspectives on Long COVID Definition

Moderator: Peter Palese, Committee Member

Drug Developers

Phyllis Arthur

Vice President

Infectious Diseases and Diagnostics

BIO

Health Insurance Plans

Winnie Chi

Director of Population Research

Elevance Health

Q&A

11:30 a.m. Updating and Disseminating a Definition – Policy, Communications, and Training and Education Considerations for a Long COVID Definition

Moderator: Wes Ely, Committee Member

Coding ICD-10: Characterizing a New Disease Through an ICD-10 Lens

Emily Pfaff

Assistant Professor

UNC Chapel Hill School of Medicine

PCP and Reimbursement Perspective

Julie Wood

Family Physician

Senior Vice President

Research, Science, and Health of the Public

American Academy of Family Physicians

CDC Long COVID and Fatiguing Illness Recovery Program

Christian Ramers *virtual*

Chief, Population Health

Family Health Centers of San Diego

Disability Perspective

Rebecca Vallas *virtual*

Senior Fellow, The Century Foundation

Senior Adviser, Disability Economic Justice Collaborative

Applied Governmental Public Health Perspective

Leisha Nolen *virtual*

State Epidemiologist

Utah Department of Health

Q&A

SESSION IX DAY 2 CLOSING REMARKS

12:30 p.m. Final Words from the Sponsors

Michael Iademarco

Rear Admiral and Assistant Surgeon General, U. S. Public Health Service Deputy Assistant Secretary for Science and Medicine
Office of the Assistant Secretary of Health

D. Christian Hassell

Deputy Assistant Secretary
Senior Science Advisor
Administration for Strategic Preparedness and Response (ASPR)

12:45 p.m. Symposium Closing Remarks

Harvey Fineberg, Committee Chair

President
Gordon and Betty Moore Foundation

1:00 p.m. Adjourn Symposium

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Health and Safety Considerations

For those attending in-person, this is an indoor event at the [National Academy of Sciences Building](#). *We acknowledge that many of you are working hard to protect yourself and others from COVID-19 and acknowledge that there may be those in attendance with infection-associated chronic illnesses, immunodeficiency, and other forms of chronic illness and disability and therefore, we are communicating the COVID-19 considerations below.* Please note that this building is open to the public and there will be other meetings in-progress.

Attendees should not feel obligated to travel to participate in the meeting. We encourage remote attendance to the meeting for anyone who is not comfortable traveling to or participating in the in-person meeting. We have developed a program that is attentive to our virtual attendees and will be interactive and engaging for all. Additionally, if you are unable to attend any parts of the meeting, the meeting recordings will be made available after the meeting.

Vaccination

As of March 20, 2023, proof of COVID-19 vaccination requirements at the National Academy of Sciences Building are no longer in effect. However, we encourage those eligible and for whom it is safe to do so [to be fully vaccinated](#).

Testing

We encourage you to take a test each day before entering the meeting space. If you test positive, please follow [CDC guidelines](#) and join the meeting remotely. Free self-administered nasal swab COVID-19 tests will be available at the meeting registration table.

Symptoms

If you are feeling symptoms of possible COVID-19, such as a fever, cough, shortness of breath, conjunctivitis, fatigue, muscle or body aches, headache, new loss of taste or smell, sore throat, congestion or runny nose, nausea, vomiting, or diarrhea or any other recent onset symptoms, whether you test positive or not, we ask that you not attend the meeting in person.

Masking

The National Academies facilities are mask friendly and follow the latest [CDC guidelines on masking](#). Attendees for this meeting are encouraged to wear masks (preferably KN95, N95, or equivalent) when indoors. Free masks will be available at the meeting registration table.

Room Ventilation

Meeting spaces will be equipped with air purifiers.

Outdoor Space

As weather allows, attendees for this meeting will have access to an optional outdoor seating area. We encourage attendees to enjoy this space during meal times or when connecting with other attendees socially if you would like to do so.

Energy Considerations and Quiet Room

This activity provides the opportunity to share input and participate in discussions about a definition for Long COVID. This activity requires computer use or travel, focus, listening to presentations, speaking or writing, and cognitive exertion. We encourage attendees to take breaks as frequently and as long as needed. A Quiet Room will be made available with low noise, low light, and air purifiers. There will be space for those attendees who wish to bring a yoga mat, blanket, picnic mat, etc. to rest.

Mobility Accessibility

This building and meeting space are accessible to accommodate wheelchairs and similar equipment. If needed, we can partner you with a volunteer to help you navigate the meeting. Please indicate your needs on the registration form, and we will make arrangements to accommodate.