

Standing Committee on Emerging Infectious Diseases and 21st Century Health Threats: *Scoping Meeting 1 on Examining the Working Definition for Long COVID*

Agenda

Wednesday, January 25, 2:00 PM – 5:00 PM ET

Background: At the request of the Office of the Assistant Secretary for Health (OASH) and the Administration for Strategic Preparedness and Response (ASPR), the Standing Committee on Emerging Infectious Diseases and 21st Century Health Threats has been asked to refine the U.S. Government's current interim working definition of Long COVID and related technical terms for specific uses, including but not limited to, for clinical care, research, surveillance, and health communication. The goal of this undertaking is to help patients' access care and services for Long COVID-related conditions, aid clinicians in the diagnosis and treatment of Long COVID, and to begin to harmonize research and surveillance efforts, taking into consideration the international context.

Experts from the Standing Committee on Emerging Infectious Diseases and 21st Century Health Threats will scope and develop a work plan and stakeholder engagement process to examine and refine the current U.S. Government working definition of Long COVID and related technical terms. Additional external experts, including individuals with lived experience, will be engaged.

Objectives:

- Discuss scope of work and plan for the project;
- Identify similar efforts to define Long COVID that have been conducted or are currently underway and solicit ideas about the current definitions;
- Initiate information gathering on major Long COVID symptoms and manifestations;
- Understand major issues, including barriers, that would inform the effort;
- Examine lessons learned from other processes and experiences for developing disease definitions and diagnostic criteria;
- Identify areas of expertise and key stakeholder groups to engage in this effort; and
- Identify elements of the process and work plan to refine the working definition of Long COVID.

SESSION I Discussion of the Charge to the Standing Committee

2:00 PM Welcome and Introductions

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

2:15 PM

Presentation of Sponsor's Charge to the Committee and Discussion

D. Christian Hassell

Deputy Assistant Secretary

Senior Science Advisor

Administration for Strategic Preparedness and Response (ASPR)

Allison O'Donnell

Senior Long Covid Coordinator

Office of the Assistant Secretary for Health (OASH)

2:45 PM

Role of the Standing Committee in Developing Work Plan and Stakeholder Engagement Strategy

Lisa Brown

Senior Program Officer

Board on Health Sciences Policy

Health and Medicine Division

2:50 PM

BREAK

SESSION II

Information Gathering to Inform Effort to Define Long COVID

3:00 PM

Welcome and Introduce Panelists

Harvey Fineberg, *Standing Committee Chair*

President

Gordon and Betty Moore Foundation

3:05 PM

Efforts Currently Underway to Define Long COVID and Discussion of Key Issues and Barriers to Defining Long COVID

Federal Efforts

Clinton Wright

Associate Director

Director, Division of Clinical Research

National Institute of Neurological Disorders and Stroke (NINDS)

WHO Clinical Case Definition Working Group on Post-COVID-19 Condition

Janet Victoria Diaz

Author, [A Clinical Case Definition of Post-COVID-19 Condition by a Delphi Consensus](#)

Head of Clinical Management

World Health Organization

Srinivas Murthy

Author, [A Clinical Case Definition of Post-COVID-19 Condition by a Delphi Consensus](#)

Clinical Associate Professor

Department of Pediatrics

BC Children's Hospital Research Institute

Frontline Community Perspective

Aluko Hope

Medical Director, [OHSU Long COVID-19 Clinic](#)

Associate Professor of Medicine

Division of Pulmonary and Critical Care Medicine

Oregon Health & Science University (OHSU)

Lessons Learned from Other Processes and Experiences for Developing Disease Definitions

Jenny Doust

Author, [Guidance for Modifying the Definition of Diseases: A Checklist](#)

Clinical Professorial Research Fellow

Australian Women and Girls' Health Research Centre

School of Public Health

The University of Queensland

Discussion Questions:

- Current and Past Efforts for Developing a Definition for Long COVID
 - What efforts are currently underway or have been conducted previously to define Long COVID?
 - Which entities and agencies and organizations are generally leading these efforts? (Primarily at the U.S. national level)
 - What have been the processes used to establish definitions for Long COVID?
 - What have been the principal objectives for establishing definitions in these efforts?
- Issues and Barriers
 - What have been the issues and barriers that have been faced by entities defining Long COVID?
 - Have there been efforts to address these barriers? If yes, have these efforts been successful? Any recommendations for the way forward?
- Information on Symptoms and Manifestations Important to Defining Long COVID
 - What are the symptoms and manifestations of Long COVID evidenced so far? How do these findings affect a definition(s)?
 - What is the estimated percentage of COVID-19 patients are experiencing Long COVID? (Nationally compared with international information)
 - What approaches and tools have healthcare providers used for diagnosing Long COVID?
- Past Efforts for Developing Disease Definitions
 - What have been major considerations in past efforts to establish disease definitions more broadly?
 - Which entities and stakeholders have taken primary role in the process?
 - How can past efforts be improved to help established a more patient-centered case definition for diseases?

3:40 PM

Discussion with all Panelists

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

SESSION III

Initial Stakeholder Mapping

4:15 PM

Initial Discussion on Key Areas of Expertise and Stakeholders to Engage

Laura Gramling, *Stakeholder Engagement Consultant*
President
EnSpark Consulting

SESSION IV

Wrap-Up and Next Steps

4:35 PM

Committee Reflection and Discussion on Charge

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

4:50 PM

Discussion of Work Plan, Information-Gathering Strategies, and Next Steps

- Discuss options for conducting work
- Identify information-gathering needs based on task:
 - Experts to invite to speak with the committee
 - Information requests for the sponsors
 - Other information needed
- Review next steps

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

Lisa Brown
Senior Program Officer
Board on Health Sciences Policy
Health and Medicine Division

5:00 PM

ADJOURN MEETING