

Standing Committee on Emerging Infectious Diseases and 21st Century Health Threats: *Scoping Meeting 2 on Examining the Working Definition for Long COVID*

Agenda

Wednesday, February 8, 10:00 AM – 1:00 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:

- Examine lessons learned from other processes and experiences on stakeholder engagement efforts on disease definitions and research priorities;
- Identify similar efforts to define Long COVID that have been conducted or are currently underway;
- Identify elements of the process and work plan to refine the working definition of Long COVID; and,
- Introduce Standing Committee to and solicit feedback on the first section of the Stakeholder Engagement Strategy.

SESSION I

Efforts Currently Underway to Define Long COVID

10:00 AM

Welcome and Meeting 1 Recap

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

10:15 AM

Federal Efforts to Define Long COVID

Priti Patel

Senior Advisor for Post-Covid Conditions
Centers for Disease Control and Prevention

SESSION II

Information Gathering on Stakeholder Engagement to Define Diseases

10:30 AM

Stakeholder Engagement Efforts on Disease Definitions and Research Priorities

Russell Gruen

Author, [Effective stakeholder participation in setting research priorities using a Global Evidence Mapping approach](#)
Dean of the College of Health and Medicine
Australian National University

Olivia Magwood

Research Associate
Bruyère Research Institute

10:45 AM

Stakeholder Perspective on Meaningful Engagement

Lauren Stiles

President and co-founder,
Dysautonomia International
Research Assistant Professor of Neurology,
Stony Brook University School of Medicine

Lisa McCorkell

Author, [Patient-led research collaborative: Embedding patients in the Long COVID narrative](#)
Team Lead and Researcher
Patient-Led Research Collaborative

11:00 AM

Discussion with Panelists

Harvey Fineberg, *Standing Committee Chair*

President
Gordon and Betty Moore Foundation

Discussion Questions:

- How did you determine the number & balance of stakeholders to ensure that you had sufficient representation?
- What can you share about getting buy-in and support from hard to reach stakeholders?
- What particular information, data, and/or questions did you seek from stakeholders in order to inform the creation and refinement of your definition?
- Any other advice you have for us?

Meeting of the Standing Committee on Emerging Infectious Diseases and 21st Century Health Threats

11:30 AM

15-minute Break

SESSION III

Feedback on Draft Stakeholder Engagement Plan

11:45 AM

Discussion on Draft Stakeholder Engagement Plan Elements (Purpose, Objectives, Stakeholders)

Todd Erickson

Stakeholder Engagement Design Lead
EnSpark Consulting

SESSION IV

Wrap-Up and Next Steps

12:45 PM

Committee Reflection and 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

1:00 PM

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