

Summary of Third Roundtable Meeting on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

October 12 and 14, 2021*

*Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a serious, long-term illness that affects many body systems. People with ME/CFS are often unable to conduct their usual activities. At times, ME/CFS may confine them to bed. People with ME/CFS have severe fatigue and sleep problems. ME/CFS may get worse after any activity, whether it's physical or mental. This symptom is called post-exertional malaise. Other symptoms can include problems with thinking and concentrating, dizziness, and pain. According to a 2015 Institute of Medicine (IOM) report, an estimated 836,000 to 2.5 million Americans suffer from ME/CFS. However, most of them have not been diagnosed.¹

This report summarizes the third ME/CFS Roundtable Meeting held virtually on two afternoons, October 12 and 14, 2021. The 2021 Roundtable meeting built on two prior in-person Roundtable meetings—the [first](#) in 2016 and the [second](#) in 2018. Like the earlier meetings, this one was hosted by the Centers for Disease Control and Prevention (CDC), National Center for Emerging and Zoonotic Infectious Diseases (NCEZID), Division of High-Consequence Pathogens and Pathology (DHCPP), Chronic Viral Diseases Branch (CVDB).

This meeting summary is organized in the order that topics appeared on the Roundtable meeting agenda and provides highlights from each Roundtable session. It is not a transcript or notation of every comment or suggestion made during the meeting, and it does not imply that CDC endorses or supports comments included in this report.

Meeting Overview: Objectives and Participants

With a theme of “Working Better Together,” the 2021 meeting had a different purpose than the first two Roundtable meetings: to enlist the support of **new and existing partners** and identify specific partnership opportunities that could lead to **improved outcomes for people with ME/CFS**. Partnership opportunities identified during the Roundtable meeting also will inform the CDC’s strategic planning objectives related to partnerships to address ME/CFS. CDC contracted with McKing Consulting Corporation (McKing) to do this work.

The meeting was informed by feedback shared from individual and group discussions that McKing conducted earlier in 2021. Specifically, McKing conducted 28 discussions with 41 stakeholders representing 23 organizations that included patient advocacy groups, research institutions, healthcare practices and systems, professional associations, and other federal agencies. Information generated in discussions was then prioritized for the meeting agenda. The

¹ IOM (Institute of Medicine). 2015. *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness*. Washington, DC: The National Academies Press.

agenda included presentations about how CDC works, a panel discussion highlighting successful partnership strategies from other CDC programs, an informal virtual networking session, and small group discussions to generate more specific ideas for advancing partnership goals and working better together. The meeting [agenda](#) is provided in Appendix 1.

The meeting was conducted using the Zoom virtual platform with the assistance of Ross Strategic (Ross), a subcontractor to McKing. Ross staff handled the invitation process as well as the virtual hosting and breakout sessions. The breakout sessions were offered so that smaller groups could discuss potential partnership activities that were grouped into three high-level categories that emerged from the prior stakeholder discussions: Healthcare Workforce Education (4 groups), Surveillance and Expanding the Science (4 groups), and Awareness and Stigma (2 groups). Participants were able to indicate their choice of breakout groups as part of the registration process and the groups were then organized based on those responses. Breakout sessions were repeated so that participants could join discussions on two of the three topics. Each group included between 8 and 10 participants, a CDC representative, a designated facilitator, and at least one notetaker.

The meeting and breakout sessions were not recorded, but McKing, Ross, and CDC staff took detailed notes during the main sessions and the breakout discussions, and also captured comments and questions submitted via Zoom's chat function.

In total, Ross Strategic sent formal invitations to 93 stakeholders: 41 to individuals who had participated in the engagement discussions; 43 to individuals who had not yet participated in stakeholder activities this program year; and 9 to CDC staff. Of these, 77 people joined the meeting on day one and 65 joined the meeting on day two (including meeting staff). A [full list](#) of call participants and meeting attendees can be found in Appendix 2.

Discussion Topics

Key Findings from ME/CFS Stakeholder Discussions

The McKing Consulting Corporation team presented highlights from the [individual and group discussions](#) with both long-term and newer partners that took place in March and April 2021, Appendix 3. One key takeaway from these discussions was a continuing interest in educating healthcare providers about ME/CFS. Participants also identified specific communication and outreach opportunities with the potential to address stigma and raise awareness with the provider community and the public. The discussions took place roughly one year into the COVID-19 pandemic.

Many participants noted that the public and scientific interest in post-COVID conditions (often referred to as Long COVID) has included recognition of the similarities to ME/CFS. This is expected to raise awareness and understanding of ME/CFS and treatments developed for post-COVID conditions could benefit patients with ME/CFS. Participants shared appreciation for their past collaboration with CDC, including materials developed through prior Roundtable meetings, as well as frustration with the slow pace of change and inconsistent communication flows (e.g., not being informed when new materials posted on CDC's website).

Participants also shared their ideas about features of successful partnerships, as well as aspects of ME/CFS that make partnerships more challenging, such as constraints on how much time and energy people most directly affected by ME/CFS (as patients or caregivers) can devote to advocacy and other efforts.

In addition, CDC partners had questions about how CDC operates, its role in addressing ME/CFS, and specific ways CDC could contribute its public health expertise and/or use its influence. In response to questions posed about CDC, the 2021 Roundtable featured remarks from CDC ME/CFS and other program staff, who offered more details about CDC and clarified the context in which CDC and the ME/CFS program operate.

Several potential areas were identified in stakeholder engagement discussions for working together (i.e., CDC working with partners, and partners working with each other) that could strengthen impact over and above what might be achieved working individually. These topics were discussed in greater detail during the smaller breakout sessions (summarized later in this report). They include:

- **Healthcare Workforce Education:** Increasing patients' access to healthcare providers who can identify and treat patients, and helping administrative professionals lower the administrative burdens on patients.
- **Surveillance and Expanding the Science:** Better characterizing and understanding who is affected by ME/CFS, ensuring diverse groups and stakeholders are included in scientific efforts.
- **Awareness and Stigma:** Promoting public understanding of ME/CFS, increasing general awareness to diminish stigma, and disseminating resources to directly assist people living with ME/CFS and their families.

Setting the Stage for Partnerships

To help Roundtable meeting participants understand the CDC ME/CFS program, Dr. Elizabeth Unger shared CDC's organizational chart, which showed all the CDC centers and offices organized around different areas of public health. The National Center for Emerging and

Zoonotic Infectious Diseases (NCEZID), the ME/CFS program’s organizational home, is one of three centers focused on infectious diseases. Within NCEZID, the Chronic Viral Diseases Branch, which Dr. Unger leads, is part of the Division of High-Consequence Pathogens and Pathology—one of seven divisions in the center.

Dr. Unger described how CDC takes a public health approach to its programmatic activities. Public health recognizes that partnerships are central to success, as by definition the public is impacted by the work. Planning, implementation, and evaluation are part of this public health approach, and some programmatic activities contribute information in more than one way. Planning involves surveillance and epidemiology to determine the problem, risk factors and who is affected, and an assessment of needs. Knowledge from these activities contributes to research and interventions. Evaluation includes how well the interventions are working as well as sustainability and relevance of the initiatives.

Dr. Unger pointed to several successful partnership examples that mirror the “Working Better Together” theme, such as #MEAction’s Call to Action to urge state health departments to track ME/CFS, which led to the inclusion of an optional ME/CFS module in the Behavioral Risk Factor Surveillance System (BRFSS). Dr. Unger also noted that several joint manuscripts generated by the Multi-Site Clinical Assessment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (MCAM) collaborators (i.e., clinicians and expert ME/CFS researchers). Studies are currently in preparation, covering topics including exercise challenge, cognition, orthostatic intolerance, heterogeneity not explained by site differences, and findings from a natural killer (NK) cell function study.

In closing, Dr. Unger said that post-COVID conditions can help shine a light on ME/CFS; she is already seeing signs of changing attitudes towards ME/CFS. Post-COVID conditions are a significant part of CDC’s COVID response, and branch staff are part of these efforts through deployment to the COVID Epidemiology and Surveillance Task Force and will continue to manage post-COVID conditions projects. The full [presentation](#) can be found in Appendix 4.

A Brief Overview of Federal Partnerships

Next, policy specialist Mr. Timothy McLeod reiterated the mutual benefits of strong partnerships among federal agencies, community-based organizations, and other partners and reviewed different types of federal engagement mechanisms, [Appendix 5](#). Federal agency collaborations with outside groups can range from technical assistance to public and professional education, as well as applied research or evaluation.

Two common mechanisms that outline each group’s roles and responsibilities are Memoranda of Understanding (MOUs) and Data Use Agreements (DUAs). A key difference between the two, Mr. McLeod explained, is that MOUs formalize the mutual understandings, goals, and plans

between parties, but are not legally binding. Indeed, the value of MOUs often lies in the process of creating them when mutual understanding is built. DUAs, on the other hand, are legally binding documents that govern various aspects of how organizations share data (e.g., confidentiality requirements).

Federal agencies also collaborate with partners and transfer funds through grants, cooperative agreements, and contracts. Mr. McLeod noted the CDC Foundation's role in matching potential donors and/or collaborating partners to CDC initiatives, describing a rigorous ethics review process and examples of conditions where gifts cannot be accepted (e.g., from the tobacco industry).

Several laws and statutes shape federal partnerships, Mr. McLeod explained, including the Federal Advisory Committee Act (FACA), which regulates how committees and external groups advise the federal government; the Paperwork Reduction Act (PRA), which is designed to avoid undue burdens on the public from government requests for information (such as surveys); and anti-lobbying provisions that restrict the use of federally appropriated funds for lobbying. Mr. McLeod noted that FACA regulations in part guide the CDC on partnerships activities, particularly with respect to how partners and individuals provide information and guidance to CDC. While CDC, its staff, and its partners are permitted to inform and educate legislative groups at all levels, federal funds cannot support lobbying activities (i.e., any activity designed to influence action related to pending or proposed legislation).

Mr. McLeod shared a number of resources for those seeking more information about any of these topics:

Guidance on partnering with CDC, including a factsheet:

<https://www.cdc.gov/partners/partnering.html>

Guidance from the General Services Administration on FACA:

<https://www.gsa.gov/policy-regulations/policy/federal-advisory-committee-act-faca-management-overview>

Paperwork Reduction Act overview:

<https://pra.digital.gov/about/>

Lobbying Restrictions for CDC Grantees:

<https://www.cdc.gov/grants/additional-requirements/ar-12.html>

Learning from Successful CDC Partnerships

To learn from successful partnerships across CDC, the Roundtable organizers convened a panel of representatives who described three different types of partnerships.

Wendy Rubin, MS, the partnership coordinator for the National Center on Birth Defects and Developmental Disabilities (NCBDDD), described a group of partners who overcame many differences in priorities and approaches to form a “Friends of NCBDDD” group around their shared concern for the health of babies, children, people with disabilities, and people with blood disorders. Appendix 6 ([Making Friends: Collaborating and Cooperating](#)).

Michele Walsh, M.Ed., Associate Director for Policy, Partnerships, and Strategic Communication in the Division of Population Health at CDC, is involved in partnership engagement for a wide variety of chronic diseases and conditions, including Alzheimer’s disease, arthritis, and lupus, as well as behavioral health issues such as emotional well-being and prevention of excessive alcohol use. Ms. Walsh described two categories of partnerships: programmatic and policy partnerships, in her presentation. Appendix 7 ([Partnering for Success: Lessons from the Division of Population Health](#)).

Judy Griffith, RN, MS, is a health education specialist in CDC’s Division of HIV Prevention. Ms. Griffith shared examples from Let’s Stop HIV Together (www.cdc.gov/StopHIVTogether), a CDC campaign focused on stigma, patient-centered care, testing, and prevention related to HIV—themes familiar to the ME/CFS community. She described the campaign’s efforts to reach a variety of stakeholders, including clinicians and consumers. Appendix 8 ([Let’s Stop HIV Together: Reducing Stigma through Promotion of HIV Resources](#)).

Virtual Breakout Sessions

During the virtual breakout sessions, participants split into smaller groups to identify activities that align with topics and interests of multiple partners, including CDC, and discuss how to move forward on these activities, including how each partner could contribute. The groups focused on three areas identified by partners during discussions prior to the roundtable meeting, with two rounds of each session topic: Healthcare Workforce Education, Surveillance and Expanding the Science, and Awareness and Stigma. Summaries for each section are presented below:

Suggested **Healthcare Workforce Education** activities:

- Increase understanding of ME/CFS as a legitimate illness
- Develop and employ methods to improve care for people with ME/CFS
- Increase the number of providers who are knowledgeable about ME/CFS
- Increase access to quality care for people with ME/CFS in primary care settings

Suggested **Surveillance and Expanding the Science** activities:

- Find commonalities across post-viral syndromes
- Standardized tools and scales to prepare for treatment trials

- Develop clinical models of care
- Address research gaps
- Promote accurate documentation of ME/CFS in medical records
- Expand ME/CFS prevalence estimation
- Expand school-based surveillance

Suggested **Awareness and Stigma** activities:

- Promote the need for social and economic support for people with ME/CFS
- Disseminate messages based on lived experience through various media to multiple audiences
- Reflect diversity in patient images and stories
- Increase awareness of disability and rehabilitation resources

Next Steps

Dr. Unger thanked participants for joining and sharing their ideas for the virtual roundtable's main theme: *Working Better Together*. Some participants called for working groups that could follow up on the issues discussed at the meeting, with concrete outcomes and implementation plans. Dr. Unger acknowledged this request and said that CDC will explore what options for ongoing engagement may be feasible and will continue to coordinate partnership meetings and work with the policy and partnership team in CDC's Division of High-Consequence Pathogens and Pathology.

Dr. Unger said she appreciated the opportunity to connect with participants in the virtual meeting format. In response to the breakout session reports, Dr. Unger also noted that CDC is interested in the ICD-10-CM initiative, seeing this as a potential partnership opportunity for working together to add more ME/CFS related codes, starting with healthcare providers.