

Summary of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Second Roundtable Meeting, August 30, 2018*

*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 complex, chronic, debilitating disease that affect multiple systems. A variety of laboratory abnormalities have been documented, but none of the findings are specific or sensitive for diagnostic use. The disease affects between 836,000 and 2.6 million Americans of all ethnicities, races, and socioeconomic groups.

In 2015, the Centers for Disease Control and Prevention (CDC) began the groundwork to address changes to the diagnostic criteria for ME/CFS recommended by the Institute of Medicine (IOM) in its 2015 report, *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*. The changes recommended by the IOM committee were designed to make the disease easier for clinicians to recognize and diagnose.

To help implement the IOM recommended changes and develop a dissemination strategy to reach healthcare professionals, CDC awarded a contract to McKing Consulting Corporation (McKing) in 2015. The initial project's main outcome was a set of recommendations for updating the CDC ME/CFS website and developing additional educational materials for specific audiences. These recommendations were based on feedback and input from a face-to-face Roundtable Meeting of stakeholders (primary care providers, patients, advocates, researchers, and other partners). A summary of the meeting: [CDC Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Stakeholder Engagement and Communication \(ME/CFS-SEC\)](#).

As a follow-up to the first Roundtable Meeting (2016), CDC contracted with the same McKing team in September 2017 to assist in continued development of educational materials. McKing's charge for the second project was to build on the initial project and continue to engage stakeholders in developing materials primarily for use by patients and healthcare providers. Through a series of conference calls, individual interviews, and another full-day Roundtable Meeting, McKing gathered stakeholder feedback on the content and design of materials, building on the input, work plans, and progress of the initial project activities.

This report summarizes the themes and individual comments shared during the day's conversations at the second Roundtable Meeting in 2018. This report is organized in the order of topics discussed. 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. As an overview of the meeting, the report does not reflect CDC's final plans for ME/CFS educational materials.

Meeting Overview: Objectives and Participants

The specific objectives of the follow-up meeting were to:

- Organize meetings with stakeholders to identify gaps in ME/CFS educational materials and plans for developing new materials
- Ensure the new materials include the IOM report's recommended criteria for disease diagnosis
- Incorporate stakeholder feedback to meet the needs of the intended audiences
- Supplement the CDC ME/CFS website with new educational materials

The first step in planning for the meeting was to identify and invite a select group of stakeholders—composed of ME/CFS patients, advocates, clinicians with ME/CFS expertise, healthcare professional organizations, medical educators, and researchers/foundations—to participate on a group conference call. (See full list of stakeholders in Appendix I.) Call participants were grouped to represent a diversity of perspectives, as much as possible, so that different stakeholder viewpoints could be shared and discussed.

Stakeholders were asked to review draft educational materials for use by patients and healthcare providers. The materials focused on key facts for clinicians, resources for patients and caregivers (including pediatric info), and a visual guide to assist patients in preparing for an office visit. They then and provided feedback during a scheduled one-hour conference call. They could sign up for conference call times that were convenient for them during March and April 2018. Eight conference calls were conducted to accommodate stakeholder preferences and include the maximum number of participants possible. A few individual calls also were made to get feedback from stakeholders who were unable to participate in the scheduled conference calls. The emphasis remained on getting maximum participation from all invited stakeholders, via conference call, attendance at the roundtable meeting, or both.

To focus the conference calls, stakeholders were given drafts of the three types of materials in advance of the call: patient checklist, healthcare professional fact sheet, and infographic.

McKing staff facilitated the calls by addressing the following questions:

- What are your overall reactions to the drafts?
- Is anything confusing or unclear?
- What additional information might people need?
- What would increase acceptance and use of the information?

Stakeholder responses from the conference calls were compiled and analyzed by McKing, then used to prepare revised versions of the materials. The revised materials were reviewed by CDC and shared with a small set of ME/CFS experts for another round of input in late June and early July 2018.

Responses were again compiled by McKing and used to engage CDC in identifying further refinements and revisions. Based on responses to the draft materials, the decision was made to focus on the patient and healthcare professional audiences for the roundtable meeting. Six draft documents on different topics were prepared for the patient audience, and another four documents on topics for healthcare professionals. Graphic elements were added to improve readability, understanding, acceptance and potential for use.

Feedback gleaned through the conference calls and expert input was used as the basis for designing a roundtable meeting convened on August 30, 2018, in Atlanta, Georgia. The meeting agenda is in Appendix 2.

The meeting was designed to accomplish three primary objectives:

- Share draft educational materials and elicit feedback to that would make them useful for the intended audiences
- Discuss ideas for additional educational materials for healthcare professionals, patients and families/caregivers, and education professionals
- Identify channels for reaching healthcare professionals.

A total of 40 individuals participated in the meeting. (See participant list in Appendix 1.) To encourage sharing of ideas and perspectives, participants were assigned to one of six small tables, each accommodating mixed representation from the various stakeholder groups: clinicians, medical educators, healthcare professional organizations, patient advocates, patients, and federal agencies. Several senior leaders from CDC's Division of High-Consequence Pathogens and Pathology (DHCPP) (which houses CDC's ME/CFS program) also attended the meeting and rotated among tables to hear participants' perspectives.

Discussion Topics

CDC emphasized that this project would pick up with lessons learned from the previous roundtable meeting of the ME/CFS work completed by McKing in February 2016. CDC's main objective was to build on the revised ME/CFS web page content, which had been launched in the summer of 2017 by developing educational tools that would help healthcare providers and people with ME/CFS. CDC reiterated the importance of taking patient and healthcare provider viewpoints into account and making sure that the patient and professional communities felt engaged in development of any educational materials.

CDC also expressed a commitment to continuing the dialogue between stakeholder groups to increase providers' understanding of patients' needs and perspectives and to bring in the public health community as a stakeholder (e.g., state and local health departments). The types and content of the ME/CFS educational materials to be developed were informed by the feedback collected from the 2016 ME/CFS Roundtable Meeting.

An initial list of materials suggested at the 2016 meeting included:

- Handout of key ME/CFS facts for clinicians that patients could bring to appointments
- Checklist for patients and caregivers to help them manage healthcare provider visits (including pediatric information)
- Visual guide (infographic) to assist patients in:
 - Preparing for a physician visit
 - Share their symptoms with their clinician
 - Interacting with physicians to get the best possible outcome
- Tips for physicians to prepare patients for disability evaluation.

McKing organized and condensed the suggested materials list above into a draft work plan fitting the project objectives and timeline. CDC then identified priorities among them that would address specific gaps identified by participants during the first roundtable meeting. In response, three types of draft materials were prepared by McKing:

1. **Patient Checklist:** intended for use as a resource for individuals who suspect they may have ME/CFS and are preparing for a visit with their doctor, to be posted on CDC's website.
2. **Healthcare Professional Fact Sheet:** intended for use as a resource for primary care practitioners to improve their ability to recognize and manage patients who may have ME/CFS, to be posted on CDC's website and likely shared through other professional channels.
3. **Infographic:** intended for use as a quick visual resource for anyone visiting CDC's website to learn more about ME/CFS. The graphics were shown at the August 2018 meeting to receive stakeholder feedback.

Dr. Elizabeth Unger, Chronic Viral Diseases Branch Chief, opened the meeting by welcoming everyone to the roundtable meeting. Dr. Unger reiterated the meeting's objectives and encouraged open discussion and dialogue. McKing facilitators then briefly reviewed the agenda and shared housekeeping details and ground rules. Three brief panel presentations set the stage and provided context for the day's discussions. These presentations focused on what makes educational materials successful, the preferred communication channels for healthcare providers, and what patients with ME/CFS want clinicians to know about their illnesses. (See PowerPoint slides in Appendix 3.)

What Makes Successful Educational Materials: Insights from Behavioral and Social Sciences. The first presentation by Valerie Johnson, a CDC health communication specialist, outlined CDC's Clear Communication Strategy, which incorporates McGuire's Hierarchy of Communication Effects and the Stages of Change model. CDC's VERB campaign (a social marketing campaign for youth physical activity) was presented as a demonstrably successful initiative using these

tools. She also outlined the Health Belief model, which CDC used successfully in combating the rampant rabies problem in Haiti. Using this model, the title of outreach materials was changed from the less effective “protect yourself from rabies” to the more effective “protect yourself, your family, and your community.” Ms. Johnson also described the Clear Communication Index, as a tool that helps select the audience, state clear communication objectives, engage the audience, and design the program with the audience in mind.

Healthcare Professionals’ Preferred Communication Channels: Findings from a National Survey. The second presentation by Fred Fridinger, DrPH, senior health communication specialist, described the outcomes of CDC’s national survey of healthcare providers’ preferences for receiving communication. Conducted with Porter Novelli in the summer of 2018, this was a Web-based survey of 12,000 primary care providers.

“I Told You I was Sick”: **What Patients Want Clinicians to Understand about ME/CFS.** Lily Chu, MD, MSHS, who is both a person living with ME/CFS and a physician, gave the final presentation. She noted that more than 70 percent of physicians are reluctant to diagnose ME/CFS, but 90 percent of patients found diagnosis to be a positive turning point. From a provider and patient standpoint, she outlined seven recurrent themes she found for the disease:

- ME/CFS is real, and patients’ experiences should be believed.
- ME/CFS should not be confused with chronic fatigue.
- Post-exertional malaise (PEM) is not the same as post-exertional fatigue.
- Conditions and co-morbidities other than ME/CFS should be explored and treated.
- Getting a diagnosis is vital. It relieves the patient’s anxiety, helps validate their experience, and helps them to strategize for the future.
- Recognizing how severe ME/CFS can be, the physician should inquire, evaluate, treat, and monitor all symptoms with regularity.
- Even though ME/CFS doesn’t have a cure, there are many actions clinicians can take to help the patient.
- Patients can offer unique knowledge and perspectives. They want to be involved in their own healthcare and contribute to related policies.

Following a brief question and answer session, participants met at their tables to discuss the draft materials for patients and their families/caregivers and for healthcare professionals. McKing staff then reconvened the full group to enable participants from each table to share their opinions with the larger group.

McKing provided a staff member to take notes during the plenary and other large group discussions. In addition, each small table had a designated table assistant (McKing and CDC staff members) to capture key discussion points and themes. To help McKing capture all individual opinions, roundtable participants were asked to turn in their notes at the end of the day to ensure a full recording of comments. Electronic scans of all participant notes received, including notes from table assistants, were provided to CDC.

The meeting's final discussion focused on reaching new healthcare provider audiences. With McKing's facilitation, participants shared their views on several topics:

- What groups constitute the new healthcare provider audiences that should be reached? Primary care providers, specialists, etc.?
- Which audience needs to know this ME/CFS information most urgently, and what is the likelihood of getting the information to them?
- How to capture people's interest in the information?

Keys to successful educational materials include audience, dissemination and understanding the message. Meeting participants offered individual suggestions about whom they considered to be priority audiences:

- First-line primary care providers and family physicians
 - Pediatricians
 - Osteopaths and integrated medicine practitioners
 - Physical therapists, physiatrists, and pain management specialists
 - Allergists/immunologists, rheumatologists, and psychiatrists
 - Nurse practitioners, physician assistants, and the nursing associations
 - Emergency department physicians
 - Nurse midwives
 - Mental health providers who aren't physicians
 - Dentists
 - Pharmacists and staff
 - Staff at all 50 state health departments (working with the Association of State and Territorial Health Officials (ASTHO))
 - The Individualized Education Program (IEP) school process that includes occupational therapists and speech language pathologists, could serve as a *de facto* referral system for children experiencing symptoms consistent with ME/CFS
- Individual meeting participants also offered creative ways to reach audiences:
- Use social media, geotargeting to reach narrow, particular segments like physicians.
 - Use Twitter, #ME/CFS, to get the message out and refer the reader back to the website or other sources for information.
 - Target providers by using the method of identifying certain diagnostic and pharmacy codes in the healthcare industry. For example, one could look up a diagnostic code of sleep problems and target those providers.
 - Develop a speakers' bureau, using speakers within their own organizations.
 - Provide medical journals with ME/CFS content they could publish (e.g., a one-pager summarizing the roundtable meeting).
 - Consider targeting ME/CFS providers-to-be (for example, like New Jersey's scholarship program for state resident medical students and the Frank Netter School of Medicine at Connecticut's Quinnipiac University, the first to include ME/CFS in its curriculum).

- Request that medical societies issue a bulletin or put information on their websites.
- Target large healthcare systems, like the Veterans Administration and Kaiser Permanente, through their continuing medical education (CME) courses.
- Develop a CME video on diagnostic coding to get maximum reimbursement for a visit, particularly a high-complexity visit.
- Ask to insert information in the clinician website UpToDate.
- Emphasize or create a certification linkage.
- Following examples of the American Academy of Family Physicians (AAFP), accredit the relevant activities done.
- Work with patient organizations (e.g. #ME Action, Solve ME/CFS Initiative) to gain national reach through chapters and networks.
- Consider a wide variety of media outreach, like national TV ads, TV show placements, national event ads (e.g. Superbowl), public service announcements, and national TV news channels (e.g. CNN Breaking News).

Next Steps

Dr. Unger closed the meeting by thanking participants for a productive discussion, and for their honest and valuable feedback. She noted that the day's deliberations would be compiled into a summary report to be posted on the CDC website (this report). CDC ME/CFS staff collected participants' notes and feedback. These would be reviewed carefully as CDC works to revise the website and begin laying the groundwork for additional educational materials on ME/CFS.