

The left side of the slide features a dark teal background with several white geometric patterns. These include concentric circles, radiating lines, and a grid of small squares, all arranged in a way that suggests movement and connectivity.

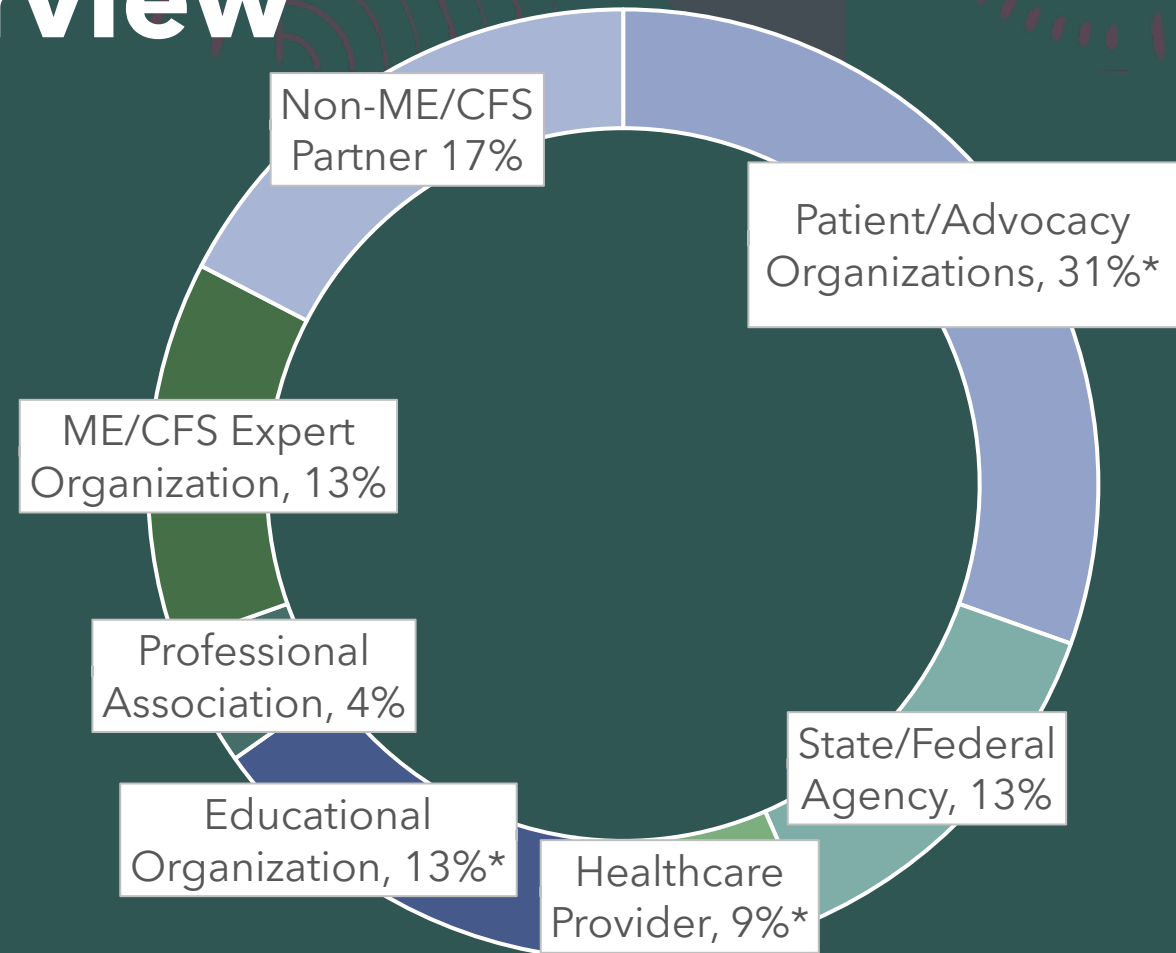
Highlights from Spring 2021 Stakeholder Discussions

McKing Consulting Corporation

Discussions Overview

- 26 conversations
- 39 individuals
- 23 organizations

** 3 individuals also identified as **healthcare providers** (in addition to educational organization and/or patient/advocacy organization representatives)*



Key partnerships;
purpose(s)

How partnerships are
identified and sustained

Partnership
challenges

Advice for
others

Working with
federal agencies (CDC
& others)

Interactions with
CDC's ME/CFS
program

Partnership
opportunities

Questions about
CDC's role in
ME/CFS

Stakeholder meeting interest
and suggestions

Discussion Topics

What did we learn?

- Key Take-aways from Partner Discussions
 - Interest in **provider education** focus
 - Specific **communication** and **outreach** opportunities
 - **Post COVID** implications / opportunities
 - **Stakeholder meeting** ideas and input

Features of Successful Partnerships

- Trust
- Honesty and Candor
- Mutual Respect
- Communication
- Shared Purpose / Benefit
- Focus on Specific Tasks
- Clear Roles



ME/CFS Partnership Challenges

Persistent **stigma**,
misunderstanding,
dismissal of condition

Challenges for
patients and experts
to devote **time and
energy** to
participation

Lack of **recognition,
acceptance** within
provider community

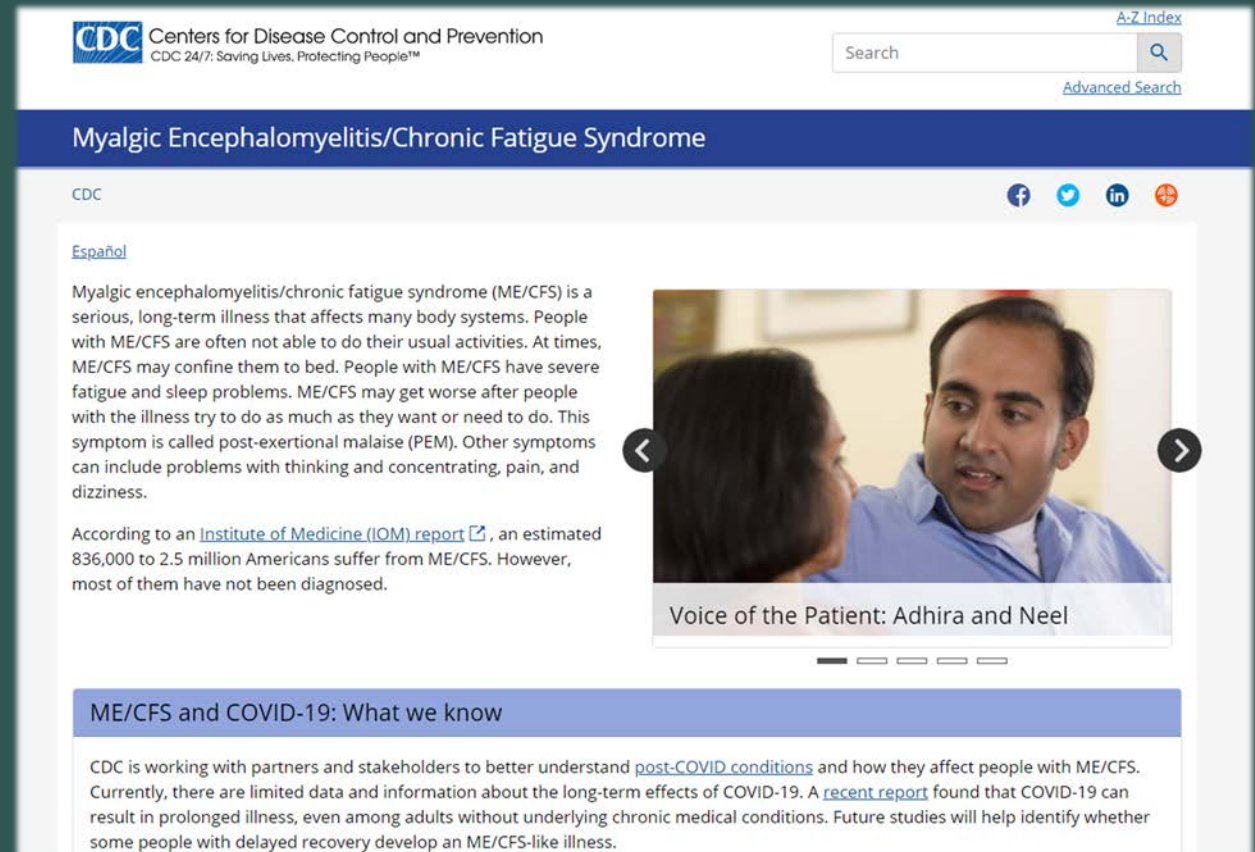
Lack of **surveillance,
prevalence data** to
rally support and
funding

Differing opinions
and agendas within
ME/CFS community

“Branding” of
ME/CFS as disease of
wealthy white
women; disparities
remain hidden

CDC Partnerships: Strengths

- **Updated website** and materials
- Role in helping to **legitimize ME/CFS; credibility** in provider community
- Internal advocacy with **other federal agencies** (NIH)
- Bringing **new partners** to the table (e.g., NASN)
- **Dedicated team**



The screenshot shows the CDC website page for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. The page features the CDC logo and tagline at the top, a search bar, and a navigation menu. The main content area includes a section titled "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome" with a sub-section for "Español". The text describes the illness as a serious, long-term condition affecting many body systems, often leading to fatigue and sleep problems. It mentions that people with ME/CFS may get worse after exertion, a symptom called post-exertional malaise (PEM). A video player is embedded on the page, showing a man and a woman in a conversation, with the caption "Voice of the Patient: Adhira and Neel". Below the video, there is a section titled "ME/CFS and COVID-19: What we know" which discusses the current limited data on the long-term effects of COVID-19 on people with ME/CFS.

CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives. Protecting People™

Search

[Advanced Search](#)

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

CDC [Facebook](#) [Twitter](#) [LinkedIn](#) [YouTube](#)

[Español](#)

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a serious, long-term illness that affects many body systems. People with ME/CFS are often not able to do 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 people with the illness try to do as much as they want or need to do. This symptom is called post-exertional malaise (PEM). Other symptoms can include problems with thinking and concentrating, pain, and dizziness.

According to an [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.

Voice of the Patient: Adhira and Neel

ME/CFS and COVID-19: What we know

CDC is working with partners and stakeholders to better understand [post-COVID conditions](#) and how they affect people with ME/CFS. Currently, there are limited data and information about the long-term effects of COVID-19. A [recent report](#) found that COVID-19 can result in prolonged illness, even among adults without underlying chronic medical conditions. Future studies will help identify whether some people with delayed recovery develop an ME/CFS-like illness.

CDC Partnerships: Challenges

- Need for more frequent, transparent communication
 - Results of multi-site study
 - Internal coordination re post COVID
 - Results of prior Roundtable meetings
- Lack of understanding about CDC, its role, and constraints (e.g. funding limits and bureaucracy)
- Unmet expectations about surveillance and provider education
- Comparisons with NIH
- Lingering mistrust, history

How to Strengthen Partnerships: Strategies & Advice from Partners

Group

Group together **multisystemic "sister" diseases** with fatigue/pain in common

Focus

Pick **one or more areas of focus**

Communicate

Communicate more **frequently** with partners

Plan

Create a **shared plan with action steps and outcomes**

Seize

Seize **post COVID opportunity**



Patients are seeking out and finding ME/CFS patients and learning from them

The ME/CFS community has a lot to offer providers and scientists who are treating and researching post-COVID conditions

Population of patients potentially large, with implications for all providers and health systems

Both ME/CFS and post-COVID conditions have implications for telemedicine, e-consults, reimbursements for longer visits

Could encourage more inter-agency coordination at federal and state levels

**Partner
Reflections
on COVID-19
& ME/CFS
(from
Stakeholder
Discussions)**

**ME/CFS
Opportunities
Identified by
Stakeholders
During
Spring 2021
Discussions**

WORKFORCE EDUCATION

BUILDING THE KNOWLEDGE
BASE

IMPROVING SURVEILLANCE

AWARENESS & STIGMA

Workforce Education Opportunities



Areas of Interest

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

Research Opportunities to Build the Knowledge Base



Areas of Interest

- Find commonalities across post-viral syndromes
- Standardize tools and scales to prepare for treatment trials
- Develop clinical models of care
- Address research gaps

Surveillance Opportunities



Areas of Interest

- Promote accurate documentation of ME/CFS in the medical record
- Expand ME/CFS prevalence estimation
- Expand school-based surveillance

Opportunities to Increase Awareness and Reduce Stigma



Areas of Interest

- Promote the need for social and economic support
- 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