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)
Discussion Topics

- **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
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**
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

<table>
<thead>
<tr>
<th>Group</th>
<th>Focus</th>
<th>Communicate</th>
<th>Plan</th>
<th>Seize</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group together <strong>multisystemic “sister” diseases</strong> with fatigue/pain in common</td>
<td>Pick <strong>one or more areas of focus</strong></td>
<td>Communicate more <strong>frequently</strong> with partners</td>
<td>Create a <strong>shared plan with action steps and outcomes</strong></td>
<td>Seize <strong>post COVID opportunity</strong></td>
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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.
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