

# Summary of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Roundtable Meeting on September 26, 2016

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*\*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

On September 26, 2016, McKing Consulting Corporation staff, under contract to the Centers for Disease Control and Prevention (CDC), convened a Roundtable Meeting to obtain feedback about CDC's myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) website and other educational materials. The goal of this face-to-face meeting was to provide an opportunity for stakeholders to share their individual thoughts about how recent recommendations of the Institute of Medicine (IOM), published in *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness* (<http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>), could best be communicated through materials and content on the CDC website.

This report summarizes the themes and individual comments shared during the day's conversations at the Roundtable Meeting, organized in the order of topics discussed. This report 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 website revisions. This report was circulated in draft form to meeting participants and was modified to allow for incorporating received comments.

Prior to the meeting, McKing staff had gathered feedback from several online questions and a series of facilitated small group conference calls. One set of group calls included U.S. Department of Health and Human Services (HHS) staff from relevant operating divisions, including CDC, National Institutes of Health (NIH), and Agency for Healthcare Research and Quality (AHRQ). The other set of group calls included stakeholders composed of ME/CFS patients, advocates, clinicians with ME/CFS expertise, healthcare professional organizations, medical educators, and researchers/foundations. All call participants were given electronic copies of ME/CFS documents as background information. These documents included the IOM Report – Beyond ME-CFS, IOM Report Guide for Clinicians, Federal Drug Administration (FDA) ME/CFS The Voice of the Patient, NIH Pathways to Prevention Workshop, August 2015 Recommendations from HHS CFS Advisory Committee on the IOM report, and the link to the CDC CFS website.

Information from these calls was used as the basis for designing the meeting agenda and process. All call participants were invited to attend the face-to-face meeting. Those that were able to attend comprised the Roundtable Meeting participants.

## Meeting Overview: Objectives and Participants

The meeting was designed to accomplish three primary objectives:

- Share priority topics, key messages, and specific content for CDC to consider when revising its website on ME/CFS, based on the IOM report
- Share ideas for priority educational materials for specific target audiences
- Ensure a common understanding of next steps and timeline.

It is important to note that CDC received feedback from stakeholders on these objectives in advance of the meeting. Many stakeholders expressed concern about focusing on the IOM report and diagnosis without addressing treatment of ME/CFS. Comments on the draft report also addressed concerns about ME/CFS treatment on CDC's current website. CDC recognizes the importance of ME/CFS treatment and will carefully consider comments received relating to graded exercise therapy and cognitive behavioral therapy. However, a detailed consideration of treatment and management options for ME/CFS was beyond this meeting's scope and will need to be addressed in the future.

A total of 55 individuals participated in the meeting (see Appendix I for a complete list). 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, professional organizations, patient advocates, patients, and federal agencies. Several senior leaders from CDC's Division of High-Consequence Pathogens and Pathology (DHCPP) also attended the meeting and rotated among tables to hear participants' perspectives. Individuals discussed topics at their tables in breakout sessions, and then participants from each table shared their opinions to the larger group.

Dr. Elizabeth Unger, Chronic Viral Diseases Branch Chief, opened the meeting by welcoming everyone to the roundtable discussion. She reiterated the meeting's focus on the IOM report's recommendations related to clinical diagnosis of ME/CFS. She noted that CDC will soon begin using the term "myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)" for its web pages. Recognizing stakeholder dissatisfaction with options for names for this condition, the lack of consensus for a new name, and in order to move forward with dissemination of educational materials, CDC will follow the most recent recommendation of the HHS Chronic Fatigue Syndrome Advisory Committee (CFSAC) 2010 and match terminology used by other HHS agencies.

McKing staff facilitators reviewed the agenda (see Appendix 2) and shared housekeeping details and ground rules. Two brief presentations set the stage and provided context for the day's discussions. The first presentation from McKing staff summarized feedback to date from the facilitated phone call discussions. The second presentation, from Christine Pearson, the Division's Associate Director for Communication, addressed the CDC website — its parameters, opportunities and constraints (see PowerPoint slides in Appendix 3).

Participants engaged in a series of sequential discussions with their table members on three topics:

- IOM diagnostic criteria, post-exertional malaise (PEM) and algorithm
- How to present website content
- Portals and information for different target audiences.

A large group discussion went beyond the website topic to discuss additional educational materials important for specific target audiences. All of these discussions were designed to build on prior feedback, allow for further exchange, and let participants and CDC staff hear multiple perspectives.

Each participant was given a set of handouts, including relevant pages of the IOM report, CFSAC comments on the IOM report and suggested discussion questions (see Appendix 4). The attendees also were provided with examples of stock photos that could be used on the revised website and were asked for their individual opinion of whether these would be appropriate for use. Suggestions of any ideas or images that might be missing were also requested.

Each small table had a designated *Table Assistant* (McKing and CDC staff members) to capture key discussion points and themes. At the end of each discussion topic, McKing staff facilitators then moderated a large group discussion to encourage individuals to share comments from their small table conversations with the group at large.

## Discussion Topics

There were four discussion topics at the Roundtable meeting and comments and discussion points for each will be presented by section topic.

1. IOM Diagnostic Criteria, Post-Exertional Malaise (PEM), and Algorithm
2. How to Present Website Content
3. Portals/Information for Different Audiences

#### 4. Educational Materials

### Discussion Topic I: IOM Diagnostic Criteria, Post-Exertional Malaise (PEM), and Algorithm

#### *IOM Diagnostic Criteria and PEM*

Meeting participants had reviewed the IOM Report before the meeting but were given handouts (see Appendix 4) to help facilitate the discussion. One of the handouts was the diagnostic criteria from the IOM report, and these are presented in the box below:

Diagnosis requires that the patient have the following three symptoms:

1. A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities, that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest, and
2. Post-exertional malaise,\* and
3. Unrefreshing sleep\*

At least one of the two following manifestations is also required:

1. Cognitive impairment\* or
2. Orthostatic intolerance

\* Frequency and severity of symptoms should be assessed. The diagnosis of ME/CFS (SEID) should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity.

*Note: SEID is the acronym for Systemic Exertion Intolerance Disease*

As shown in the handouts in Appendix 4, for Discussion Topic I, meeting participants were asked to consider the following questions about the IOM report's diagnostic criteria and PEM, and then share their thoughts with other members at their tables:

1. *What key points should be on the CDC website to explain the IOM diagnostic criteria and what further detail is needed?*
2. *How can the website best describe post-exertional malaise (PEM)?*
3. *How should the different case definitions be discussed?*

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic I, diagnostic criteria and PEM. While the comments do not reflect everyone's thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- The IOM report provides a starting point, but “shouldn’t be worshipped.” As a review of the evidence base with recommendations for making a clinical diagnosis, the IOM report is designed to undergo review and revisions within five years.
- The CDC website should emphasize the diagnostic criteria — not only that all must be present for diagnosis, but also that they must be frequent as well as moderate to severe.
- The criteria could be organized and presented in a clearer way, to help the clinician achieve the goal of separating this illness from other possible causes of the symptoms (and therefore highlighting aspects of ME/CFS unique to the illness up front).
- The IOM prose description of ME/CFS on the website should be preceded by a CDC overview statement emphasizing that ME/CFS is a chronic, multi-system disease with multiple, underlying biological abnormalities. The disease can be variable in presentation both across different individual patients and within an individual patient, from day to day or week to week. For a substantial number of patients (but not all), the illness also has a sudden onset. Because sudden or acute onset is hard to define, CDC should consider the term “post-infectious onset” (reported by up to 80% of patients).
- The discussion of PEM on the CDC website should compare how ME/CFS patients respond to physical or mental exertion, in comparison to either healthy people or those with other medical conditions.
- Patients may not be ill enough — especially when they first seek help — to experience “unrefreshing sleep” or PEM.
- The website should include a checklist and/or other resources for patients to help them prepare for a visit with a physician who may not be as familiar with ME/CFS and its symptoms as they are with other diseases. The site should highlight not only symptoms, but also their severity, with descriptive language

(e.g., “I’m so fatigued I can’t work,” or “I’m tired and never wake up feeling refreshed”).

- The language about a 6-month interval (of symptom duration) should be placed later in the criteria and adjusted for adolescents (who need to be reassessed much sooner).

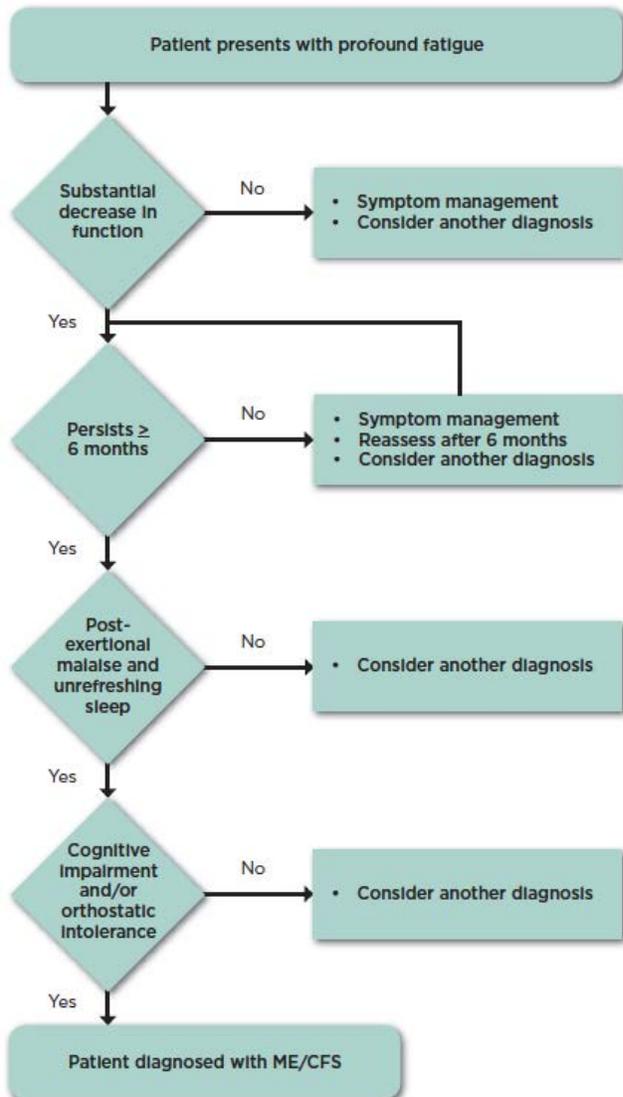
### Diagnostic Algorithm

The IOM report’s diagnostic algorithm is depicted in the accompanying diagram and meeting participants were asked to think about the following questions related to the diagnostic algorithm:

1. How should the algorithm be included on the website?
2. What context should be provided to best understand/use it?
3. How should diagnostic criteria be used?

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic I, the Diagnostic Algorithm. While the comments do not reflect everyone’s thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- The algorithm’s purpose and audience should be kept in mind: for mid-level providers, nurse practitioners, physicians’ assistants, or family practice physicians with little time available to work through steps that help them sort through multiple, nonspecific symptoms. They should still do a work-up, even if the answers to the algorithm decision points are all “yes.”



- Placing “profound fatigue” at the top of the algorithm might confuse some readers, because other symptoms may be more debilitating for some patients.
- The IOM’s requirements for research studies and a robust evidence base has meant that symptoms besides fatigue (such as a sore throat) are unacknowledged. The CDC website should consider listing other symptoms and noting that there are different degrees of evidence, supported by either existing research or patients’ reports of their experiences.
- Related to the evidence base, since many clinicians continue to question whether ME/CFS is a real disease, it might be helpful to add (in addition to the IOM criteria) a statement along the lines of “Others with clinical and personal experience note these symptoms ...”
- The algorithm should include explanatory notes or drop-down menus with more detailed information.

## Discussion Topic 2: How to Present Website Content

### Key Content for CDC’s Website

Participants received a handout listing key facts about ME/CFS and a draft prototype of the CDC ME/CFS website (both provided in Appendix 4). Questions related to these handouts included:

1. *Should all of the content of the Key Facts be presented on the website?*
2. *Is there other information that should also be presented (for example, any additional epidemiologic data)?*
3. *What are the likely points of confusion or misunderstanding that should be addressed?*
4. *What special nuances or “tone” considerations should be taken into account?*

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic 2, Key Content for the Website and Suggested Additional Information. While the comments do not reflect everyone’s thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- Add details about the nuances of symptoms indicating onset (such as headaches of new severity or type, tender or swollen lymph nodes, muscle pain, or sensitivity to food or medications), and noting that symptoms may wax and wane.

- Add information about pain as a symptom (e.g., widespread myalgia that hurts like the flu, localized or fibro pain, skin pain).
- Emphasize PEM more prominently and note that ME/CFS is characterized by significant relapse after physical, cognitive or emotional exertion.
- Add autonomic dysfunction to the list of symptoms.
- Note co-morbidities that may occur, perhaps as a list of common co-morbidities.
- Add neurological symptoms.
- Use links to provide additional details and information, if these cannot be provided directly on the CDC website (e.g., to the IOM report’s Clinicians’ Guide).
- Include guidelines for physicians to prepare patients for a disability evaluation.
- Add information relevant to special populations (e.g., pregnant women).

### Points of Confusion or Misunderstanding to Address

The following comments about points of confusion or misunderstanding on CDC’s ME/CFS website are from individual meeting participants. While the comments do not reflect everyone’s thoughts at the meeting, they convey the discussion of this topic.

- If the website will refer to this disorder as ME/CFS, it should provide a brief history of different names (to provide context for providers).
- The prevalence section should not suggest that more women than men are affected; instead, it should note that ME/CFS affects all genders, ethnicities, and age groups.
- The variability of symptoms and onset (from person to person, and across affected individuals) is likely to cause confusion and should be addressed.
- A disclaimer could address weaknesses in the evidence currently available (which limits the potential conclusions that can be drawn at this time).
- Consideration should be given to referring to symptoms as “core diagnostic features” instead, separating them from the effects of the disease.

- A large number of patients have been told they have CFS, but do not have systemic or orthostatic exertion intolerance. The website should be clear that patients with unidentified chronic fatigue but who do not meet the other case-defining criteria do not have ME/CFS; otherwise, CFS will continue to be a confusing “wastebasket” diagnosis.

### Special Nuance or Tone Considerations

The following general comment about nuance or tone considerations on CDC’s ME/CFS website is from several individual meeting participants.

- The tone of the website should be positive and should give hope to patients, by noting that research to find causes and treatments is ongoing and that helpful therapies for symptom management are available (even if the efficacy of various therapies may be unknown).

### Use of Photos

As part of the discussion on Key Content for the Website, participants received a handout with examples of stock photos. The following comments about photos on CDC’s ME/CFS website are from individual meeting participants, and while the comments do not reflect everyone’s thoughts at the meeting, they convey the discussion of this topic.

- Participants were split on their opinions of the stock photos shared during the meeting with some in favor and some opposed to certain photos.
- Individuals commented that photos should show more diversity and more children.
- Participants remarked that photos with pills or medications are not useful because there is no cure for ME/CFS
- Participants would prefer that the website use real patients rather than stock photos.
- One individual commented that photos need to show “sick” people, not just “tired” people. Another idea was to pair “good day” and “bad day” photos to show the contrasts.
- Some participants felt that, while photos do not convey important information, they make the website more personal and “warmer” to the audience. Flat text is off putting; pictures of people convey empathy and the human element of the disease.

### Discussion Topic 3: Portals and Information for Different Audiences

Participants were given a two-page excerpt from the IOM Report titled Operationalizing the Diagnosis, and asked to discuss the following question:

- 1) *What additional content or information would be most useful for each of these audiences?*
  - a) *Healthcare professionals*
  - b) *Patients, parents and advocates*
  - c) *Education professionals*

### Portals and Content for Healthcare Professionals

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic 3, Portals and Information for Different Audiences. While the comments do not reflect everyone's thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- Healthcare professionals can be reached in a variety of ways, such as “lunch-and-learn” awareness days, updating or refreshing CMEs, and creating videos that show how an ME/CFS clinician and patient interact and discuss symptoms and progression (including raising the topic of disability and workplace accommodations, and reviewing medications).
- Information on operationalizing the diagnosis should be prepared for nurses, who may have more time with patients.
- Although no pharmaceutical treatment approved by the Food and Drug Administration (FDA) for ME/CFS is available, seasoned physicians do have anecdotal experience using non-FDA-approved treatments. CDC should consider convening a committee of physicians (perhaps cosponsored by NIH) to collect these ideas, review them, and post them on the website.
- CDC's website could help promote the idea that clinicians should serve their ME/CFS patients similarly to other chronic illness patients — validating their experiences, offering checklists for patients to discuss their symptoms and how these affect day-to-day functioning, and addressing symptom relief.
- CDC should reach out to healthcare professionals who serve minority populations.

## **Portals and Content for Patients, Parents and Advocates**

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic 3, Portals and Information for Different Audiences. While the comments do not reflect everyone's thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- Patients should be prompted and encouraged to keep a diary (to be reviewed at initial and future visits).
- Patients need checklists and guides for how to discuss their symptoms with clinicians.
- Patient/parent materials and portals could be separated from those for advocates, who are a distinct audience (and one that CDC could make better use of by promoting information through their networks).
- Within the patient population overall, pediatric and adolescent patients have unique needs.
- The CDC pediatric ME/CFS website cross-links to the Department of Education and provides downloadable fact sheets; it could serve as a model.

## **Portals and Content for Medical Education Professionals**

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic 3, Portals and Information for Different Audiences. While the comments do not reflect everyone's thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- Technology can be used to engage adult learners and provide more details, possibly in interactive ways, through case stories. An academic partner may be able to assist with this.
- School nurses and other healthcare professionals in the educational field should be recipients of information on ME/CFS (in general, and in their training).
- Historically Black Colleges and Universities and medical schools should be contacted with specific outreach to minority physicians and those serving predominantly minority populations.

## Additional Suggestions

The following comments about portals and content on CDC's ME/CFS website are from individual meeting participants. While the comments do not reflect everyone's thoughts at the meeting, they convey the discussion of this topic.

- All website materials should be available for printing (for those without Internet access).
- An overall dissemination strategy (beyond the website and educational materials) is needed to address other challenges such as International Classification of Diseases (ICD) codes and insurance issues, ideally involving other federal agencies (e.g., Social Security Administration).

## Discussion Topic 4: Additional Educational Materials

In the final meeting session, participants were asked to suggest additional educational materials and strategies beyond the CDC website to best serve the needs of healthcare professionals, parents and schools, medical education professionals, and patients. This discussion was conducted as a large group session, facilitated by McKing, using the following questions:

- 1) In addition to the CDC website, what types of additional educational materials are needed and why?*
- 2) What incentives (e.g., continuing education credits, certificates or other credentials) should be offered to encourage use of the educational materials?*

## Materials for Healthcare Professionals

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic 4, Additional Educational Materials. While the comments do not reflect everyone's thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- One suggestion was to follow a model from a National Academy Press monograph in August 2016 about how to destigmatize mental health and substance abuse, which would be relevant to ME/CFS. For example, the monograph suggests creating a long communication campaign (at least 10 years), orchestrated at the national level with grassroots components, and with messages tailored to specific audiences and delivered by members of that audience, such as physician-to-physician communication.

- To encourage additional research, another suggestion was to convey to practitioners that with so little research and so little understood about how to alleviate the pain and suffering that characterize ME/CFS, any advances have the potential to be groundbreaking.
- CDC’s Train-the-Trainer model was suggested as an appropriate mechanism, especially because it includes allied health professionals (e.g., physical therapists and nurses). Certificates for attending such courses provide incentives, and technology (e.g., inexpensive YouTube videos) could help extend the reach to both professionals and the public.
- Major medical associations (e.g., American Medical Association, American Academy of Pediatrics) and specialties could be reached with ME/CFS information in their programs and sub-specialty meetings; CDC could prepare slides to accompany talks that could be delivered in these venues (for which CMEs could be earned).
- Another educational model and materials effective with clinicians is the Faces of Social Security and Faces of Disability campaigns. A new Social Security Initiative (SSI) is focused on CME with SSI doctors, which CDC could join.

### Materials for Parents and Schools

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic 4, Additional Educational Materials. While the comments do not reflect everyone’s thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- One participant recalled an effective Public Service Announcement (PSA) in movie theaters sponsored by the American Chronic Pain Association; audience recall of the PSA’s message was at 80%.
- Parenting magazines and the well-connected, active networks of “mom bloggers” were other suggestions for reaching parents. Parent-teacher organizations might be another effective channel for reaching parents and schools, as would association gatherings or training venues for school personnel (e.g., school nurses, guidance counselors, social workers, and administrators). The ME/CFS Association in Massachusetts developed a program to educate school nurses, which was well received and could serve as a model for other states.

Community social service agencies, mental health agencies, health departments, youth/family service agencies, and juvenile courts (which get involved in truancy cases) are other important audiences.

- For all these audiences, a hotline or other mechanism connecting them to others with more experience would be helpful.

### **Materials for Medical Education Professionals**

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic 4, Additional Educational Materials. While the comments do not reflect everyone's thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- Reaching clinicians during their training, while they are still open to new ideas and less susceptible to the stigma surrounding a particular topic or disorder, offers the greatest potential (compared to late-career education). Still, most health professionals need some sort of certification and continuing education throughout their careers, so finding ways to include ME/CFE in those processes would be helpful.
- In addition to CME courses (particularly online versions), independent content providers (Epic Content Systems, HealthWise, Up to Date) should have the most recent, accurate materials. Likewise, outreach to content providers for websites such as WebMD should be explored.
- Assessing a clinical practice's readiness to change is an important element in adoption of the IOM and CFSAC recommendations; CDC could play a role in influencing medical societies and others with active outreach. Likewise, reaching out to medical school deans (who typically set the curriculum) could be worthwhile, even though incorporating new topics into the curriculum takes time.
- Centers of Excellence should offer fellowship programs in ME/CFS. Programs that train physicians to serve in rural or underserved areas (e.g., the Echo program) are another potential channel to reach clinicians during their education.

- Some clinical specialties are moving away from recertification exams at standard intervals to more problem- and scenario-based learning modules, which could represent significant opportunities to include ME/CFS-specific scenarios.
- New Jersey’s ME/CFS Association sponsors an annual medical scholarship program that requires applicants to submit a 10-12 page report on ME/CFS — which in itself helps expand awareness and knowledge among medical students.

## Materials for Patients

The following bulleted items are comments from individual meeting participants and pertain to Discussion Topic 4, Additional Educational Materials. While the comments do not reflect everyone’s thoughts at the meeting or any final outcomes of the meeting, they convey the discussion of this topic.

- Outreach to ethnic media would be helpful, particularly because there are relatively few studies on ethnic patients and their prevalence may be higher, due to under-reporting.
- CDC could seek help from Hollywood, possibly through existing CDC partnerships that develop public health-themed pitches to show writers.
- Another way to reach patients directly is through the reputable patient-centered materials of organizations that already do this well, such as Kaiser Permanente or the Veterans Administration.

## 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 will be compiled into a summary report to be posted on the CDC website. Detailed notes and feedback will then be reviewed carefully to revise the website and begin laying the groundwork for additional educational materials on ME/CFS.

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**Appendix 1: Participant List**

**Appendix 2: Meeting Agenda**

**Appendix 3: PowerPoint Slides**

**Appendix 4: Handouts and Discussion Questions**