Overview of CDC Website

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ME/CFS Roundtable
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Federal/HHS websites

Requirements for Federal, HHS and CDC websites

- Federal websites must follow laws, regulations, and policies
  - Quality – plain language, objectivity, integrity
  - Section 508c law (accessibility for people with disabilities)
- HHS/CDC websites
  - Standardized design (i.e., design templates)
  - Use a WCMS (web content management system)
    to deploy content swiftly in other channels –web, mobile, social media, apps.
  - Clearance

www.cdc.gov

What is the purpose of the website?

CDC.gov is CDC's primary online communication channel. Annually, there are close to 500 million page views to the site, averaging 41 million page views per month. CDC.gov provides users with credible, reliable health information on:

- Diseases and Conditions
- Emergencies and Disasters
- Environmental Health
- Healthy Living
- Injury, Violence and Safety
- Travelers' Health
- Workplace Safety and Health
- And more…

Who is the website designed for?

- Anyone interested in health issues
- Students and educators
- Public health professionals
- Healthcare providers
- Researchers and scientists
- Partner organizations
- Policy makers
- Media
- Businesses

Health Literacy

Health Literacy:

- A person's capacity to read and **understand** basic health information to make decisions about their health

- More than just whether people can read and write.

- Includes understanding of numbers

- Depends on: education level, age, language, socioeconomic status

In general, it's low...

- Only 12% proficient in health literacy
- ~1/3 had basic or below basic health literacy
- All racial groups/ethnicities
- Over 75 percent adults with <HS were at basic level or below.
- People over 65 more likely lower literacy

Figure 1. Adults' Health Literacy Level: 2003

- 12%
- 14%
- 53%
- 21%

Below Basic | Basic | Intermediate | Proficient
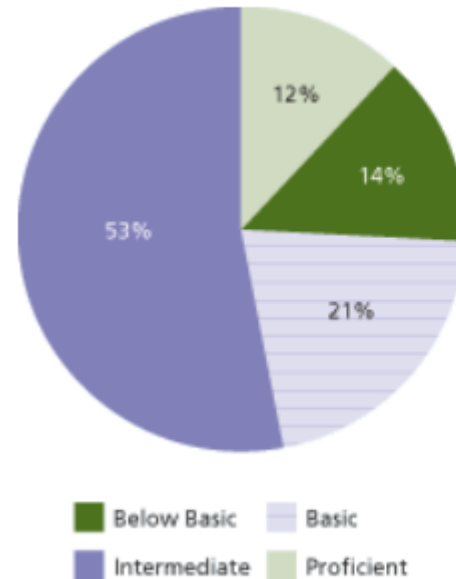
Many complicating factors…

- They aren't familiar with medical terms or how their bodies work.
- They have to interpret statistics and evaluate risks and benefits that affect their health and safety.
- They are diagnosed with a serious illness and are scared and confused.
- They have health conditions that require complicated self-care.

Plain Language

PLAIN LANGUAGE

Plain language improves communication. Decide who you are trying to communicate with and decide on your key message. Be clear.

– *Dr. Thomas Frieden, CDC Director, 2012*

When we provide health information, we must:

- Help people find information they need

- Understand how to provide useful information

- Decide which information and services work best for different situations and people so they can act

Misconceptions of Plain Language

- Not "dumbing down" the science or "talking down" to the reader
- Key elements of plain language include:
  - organizing information so that the most important points come first.
  - breaking complex information into small, easy to understand chunks.
  - using simple language and defining technical terms.
  - Design for clarity – white space, bullets, visually easy to follow.

Translating to plain language

- Same content, different audiences = different ways of expressing the same information

  - Example sentence for clinician: The prevalence of hypertension in this population has increased twofold within the past two years.

  - Example sentence for student: Twice as many of these people have high blood pressure now than they did two years ago.

All words are not equal...

Scientific term	Plain language
Transmission	Spread
Incidence	Rate
Perform hand hygiene	Wash your hands
Morbidity	Illness
Hemorrhage	Bleeding

Audience-centered communications

VACCINES. MEDICINES. ADVICE.

Do you have questions about Zika virus or travel to the Olympics?

For Travelers

Where are you going?

-- Select One --

For Clinicians

Traveler destination

-- Select One --

How we arrange our websites

- Topline info by topic
- Plain language

Melioidosis

Melioidosis, also called Whitmore's disease, is an infectious disease that can infect humans or animals. The disease is caused by the bacterium *Burkholderia pseudomallei.*

It is predominately a disease of tropical climates, especially in Southeast Asia and northern Australia where it is widespread. The bacteria causing melioidosis are found in contaminated water and soil. It is spread to humans and animals through direct contact with the contaminated source.

How we arrange our websites (cont.)

- Boxes by topic
- Fairly standard categories
- Breakouts for health care workers/other key audiences

TRANSMISSION
How do people get melioidosis?

RISK OF EXPOSURE
Who is at risk?

SIGNS AND SYMPTOMS
What are the signs and symptoms?

TREATMENT
How is it treated?

PREVENTION
How can it be prevented?

HEALTH CARE WORKERS
Diagnosis, Infection Classifications

How we arrange our websites (cont.)

Health Care Workers

Diagnosis

Melioidosis is diagnosed by isolating *Burkholderia pseudomallei* from blood, urine, sputum, skin lesions, or abscesses; or by detecting an antibody response to the bacteria.

Infection Classifications

Melioidosis can be categorized as an acute or localized infection, acute pulmonary infection, acute bloodstream infection, or disseminated infection. Sub-clinical infections are also possible. The incubation period (time between exposure and appearance of clinical symptoms) is not clearly defined, but may range from one day to many years; generally symptoms appear two to four weeks after exposure. Although healthy people may get melioidosis, the major risk factors are diabetes, liver disease, renal disease, thalassemia, cancer or another immune-suppressing condition not related to HIV.

What CDC is doing with plain language

- More than just how we write

- Use the [Clear Communication Index](#) to assess and improve our public communication materials.

- Our websites follow the best practices in web design and navigation.

Translating to plain language

- **CDC Original Sentence**

Health care-associated influenza infections can occur in any **health care setting** and are most common when influenza is also circulating in the community.

- **Plain Language Sentence**

You can get the flu in the **doctor's office, hospital, or clinic**, especially when the flu is spreading in the community.

Linking to/from cdc.gov

- CDC.gov is a public domain web site, which means anyone may link to our website at no cost and without specific permission.
- External linking only after careful consideration
  - Case-by-case basis
  - Scientifically valid
  - Serves the public's health
  - No explicit or implied endorsement
  - Disclaimers

Content on CDC website

- All content on CDC website goes through agency clearance
  - Multiple levels
- During the clearance process, content often revised

Questions?

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348   www.cdc.gov

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.

Agenda Review and Summary of Feedback to Date

MYALGIC ENCEPHALOMYELITIS (ME)/ CHRONIC FATIGUE SYNDROME (CFS) ROUNDTABLE MEETING

ATLANTA, GA

SUSAN BAKER AND NICOLE LEZIN

McKing Consulting Corporation

AGENDA REVIEW

HOUSEKEEPING

- Folder contents
- Restroom locations
- Coffee/water on back table

BASIC GROUND RULES

- Cell phones on silent/vibrate
- Be respectful of others
- Avoid side conversations
- Use microphone
- Share "air time"
- All assume responsibility for staying on schedule

MEETING OBJECTIVES

- Builds on input from calls and emails over past six months

- Allows for further discussion/back-and-forth and sharing ideas from different perspectives on:
  - Priority topics, key messages and specific content for CDC to consider when revising its website on ME/CFS, based on IOM Report
  - Priority educational materials for specific target audiences

- Confirms next steps

MEETING AGENDA

- Start with 2 brief presentations to set the stage and provide context
  - Feedback to date from SC and TDW
  - CDC website
- Short break
- First of 3 small table discussions (with break for lunch)
  - IOM diagnostic criteria, PEM, and algorithm (10:45)
  - How to present website content (1:00)
  - Portals/information for different target audiences (2:15)

MEETING AGENDA (CONTINUED)

- Small table discussions will follow a specific process, to be described after break at 10:45
- Final discussion in large group on additional educational materials needed for specific audiences
- Next steps and closing remarks

FEEDBACK TO DATE

FEEDBACK TO DATE

Presentation will cover:

- Sources of feedback
- Topics covered
- Results

SOURCES OF FEEDBACK

- Online feedback from Steering Committee (SC) and Technical Development Workgroup (TDW) to identify conference call topics (March 2016)
  - 29 respondents
- SC/TDW conference call discussions (April 2016)
  - 4 calls; 32 participants
- Input from individual SC/TDW members (Ongoing)

TOPICS OF ONLINE FEEDBACK

- Most important topics to cover
- What patients, clinicians, and the general public most need to know
- Most important information about ME/CFS to convey on CDC's website
- Name preferences
- Familiarity with IOM Report

TOPICS OF CONFERENCE CALLS

- Reactions to IOM diagnostic criteria and algorithm
- Sources of confusion/misunderstanding about diagnostic criteria
- Additional information for clinicians
- Increasing clinicians' acceptance of ME/CFS
- CDC website
  - Key content
  - What not to include

Summary of Online Feedback

TOPICS TO COVER

- Management/treatment
- Diagnostic criteria
- How to apply criteria; diagnostic work-up
- Name change
- "All of the above"

WHAT DO CLINICIANS NEED TO KNOW?

- ME/CFS is a chronic, complex, multi-symptom disease – not a psychiatric illness
- Clinicians should not dismiss ME/CFS patients, in tone or diagnostic approach
- Post-exertional malaise (PEM) as hallmark
- Caution recommending CBT/GET

WHAT DO PATIENTS AND CAREGIVERS NEED TO KNOW?

- Same information as clinicians. (ME/CFS is real; you are not crazy.)
- Currently no cure or lab test for diagnosis, but self management/symptom management can help
- Every patient deserves an accurate diagnosis, but an accurate diagnosis takes time.
  - Awareness of symptoms is key (for diagnosis and self management)
- Content of IOM Report
- Importance of adaptation strategies (e.g., pacing, energy envelope); symptoms wax and wane

NEED TO KNOW – PATIENTS AND CAREGIVERS (CONTINUED)

- Prevalence of misinformation (among clinicians and public at large)
  - "Doctors don't know everything."
  - How to prepare for medical visits
- Resources
  - Eligibility for Social Security benefits
- Support for emotional consequences of diagnosis ("You are not alone.")

WHAT DOES THE PUBLIC
NEED TO KNOW?

- In addition to information similar to what clinicians and patients/caregivers need to know …
  - ME/CFS is real and physiological, but widely misunderstood
  - ME/CFS is extremely debilitating (and pain and disability are often invisible)
  - ME/CFS is not rare; it affects children as well as adults; all ethnicities and genders

NEED TO KNOW – PUBLIC (CONTINUED)

○ How individuals can help and how schools, workplaces, etc. can be more accommodating

○ Symptoms wax and wane (i.e., just because someone could do something last week, he or she may not necessarily be able to do so this week …)

○ Where to go for more accurate information

CDC WEBSITE FEEDBACK

- Update with more current information
- Remove or downplay CBT/GET language
- Use CDC website to provide clarity and consistency; reduce misinformation and confusion

Summary of Conference Call Feedback

REACTIONS TO IOM DIAGNOSTIC CRITERIA

- Varied reactions
  - Affirming … too simplistic … not detailed enough
- Intended audience = clinicians, not researchers
  - Too wide a net? (i.e., lack of exclusionary criteria could lead to overdiagnosis)
  - Reflects assumption that clinicians know how to perform a differential diagnosis for fatigue (therefore, does not list all possible causes)
- Concerns
  - Post-exertional malaise (PEM) – highlight how exercise affects patients differently
  - Lack of attention to possible neurological symptoms in patients with more complex cases

REACTIONS TO IOM DIAGNOSTIC CRITERIA (CONTINUED)

- Suggestions
  - Refute ME/CFS as manifestation of depression/anxiety
  - Acknowledge gray areas
- Additional resources for clinicians
  - CFSAC review of IOM criteria
  - International Association of CFS/ME primer

IOM ALGORITHM

- Emphasize necessity of a thorough work-up
- Diagnosis cannot be made hastily
  - Further evaluation is needed after diagnosis
  - "Re-assess after 6 months" may be too long an interval for pediatric patients
- Remind clinicians that patients present differently and may have different co-morbidities
- Opportunity for "skip logic" flow chart

ADDRESSING POSSIBLE SOURCES OF CONFUSION

- History/timeline of names and case definitions over time
- Acknowledge differences between 1994 International Research Case Definition (Fukuda) and IOM criteria
  - Two different groups of patients?
- Feature epidemiological data to counter misconceptions about who is affected

ADDITIONAL INFORMATION FOR CLINICIANS

- Health care providers need better skills/training to elicit information about PEM
  - "If you get exercise today, are you better tomorrow?"
  - Use IOM Report's "Operationalizing the Diagnosis" guidance
- Increase awareness of prevalence/manifestations in different populations
  - Pediatric – may assume school phobia; ask about after-school activities, too
  - Racial/ethnic minorities – prevalence and severity

ADDITIONAL INFORMATION FOR CLINICIANS (CONTINUED)

- Impact of orthostatic intolerance and cognitive problems
- Patients may not recognize PEM until it is explained to them
- Some patients may have extensive knowledge of disease, research, evidence base, gleaned over years of struggling with ME/CFS
- Define terms clearly (e.g., exercise in terms of frequency, extent, potential effects)
- Understand what ME/CFS is **_and is not_**
- Limits of 10-minute visit

INCREASING CLINICIANS' ACCEPTANCE

- EPIC-type diagnosis/treatment guide
  - EPIC = Electronic Medical Records/flow software
- Trust clinical skills and refer to a specialist (as with other conditions)
- Communicate the evidence base
- Align with IOM criteria

ADDITIONAL CDC WEBSITE FEEDBACK

- Make the website more mobile-friendly
- Align with IOM Report
- Attention to:
  - Pediatric community
  - Needs of caregivers and families
- Anticipate questions from providers, parents, patients
- Provide downloadable fact sheets

CDC WEBSITE FEEDBACK (CONTINUED)

- No treatment, but treatable aspects
- Acknowledge lack of peer review but provide options (e.g., beta blockers for patients with orthostatic intolerance)
- Start with signs/symptoms; move to case definitions/diagnosis (as per Mayo Clinic example)
- Provide walk-through and questions for clinicians to ask patients with a history of unknown illness and fatigue
- Provide lists of patient organizations and associations

CDC WEBSITE FEEDBACK, CONTINUED

- Emphasize the validity of the condition
- Discuss psychological issues in terms of support (appropriate for coping with any chronic, debilitating illness)
- Describe symptoms such as PEM (similar to American Heart Association model for women and heart attack symptoms)
  - Describe the "energy envelope" limits
  - Distinguish PEM in mild, moderate, and severe illness
  - Replace GET with pacing
- Provide more detailed explanations of the IOM diagnostic criteria
  - Note how ME/CFS overlaps with/mimics other diseases

CDC WEBSITE: WHAT *NOT* TO INCLUDE

- Concerns about tone and pictures
- Perpetuating confusion about 1994 International Research Case Definition (Fukuda) criteria
- Review mention of Adverse Childhood Experiences (ACEs)
  - Reference to child abuse as a risk factor = stigmatizing
  - Replace CBT and GET references with "coping" and "activity management"
- Delete references to overly solicitous caregiving

IMPLICATIONS FOR TODAY

- Focused on:
  - IOM report
  - CDC website
  - Other needed educational materials
  - Diagnosis
- Input on:
  - Topics, messages, content
  - Visuals/photos

PHOTO FEEDBACK

- CDC heard strong message to seek input on website photos
- Folders contain potential images for website
- Make notes during the day directly on the photos, indicating which you like/don't like and why
- Comment on any ideas/images that may be missing
- Will be collected at end of day

THANKS!

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