Medical Education Work Group Report and Recommendations to CFSAC

June 2018

Beyond ME/CFS: Redefining an Illness

IOM/NAM evidence based review and recommended diagnostic criteria 2015

- ME/CFS affects 836,000 to 2.5 million Americans.
- 80% with ME/CFS have not been diagnosed. Those who are diagnosed wait years to get a diagnosis.
- U.S. economic burden: $17 to $24 billion/year
- ME/CFS is rarely included in medical school curriculum and medical textbooks
- Patients with ME/CFS are marginalized and are often subject to improper care or hostility by medical providers
- Recommendation 1: A new code should be assigned to [ME/CFS] in ICD-10 that is not linked to “chronic fatigue” or “neurasthenia”

https://www.ncbi.nlm.nih.gov/pubmed/25695122

Medical Education Work Group
January-June 2018

- ICD-9, ICD-10, ICD-11 diagnostic coding (U.S. and WHO)
- Brief report on the ME/CFS Expert Clinician Summit
- State level initiatives to disseminate medical education
- Federal level initiatives to develop and disseminate medical education
- Tele mentoring and exploration of Project ECHO as an efficient cost-effective method to broadly disseminate ME/CFS medical education
- **Work Group Recommendations to CFSAC**

*ICD-10-CM (U.S.)
ME/CFS diagnostic coding issues

- WHO ICD-10 classifies ME, CFS and postviral fatigue syndrome (PVFS) in the neurological chapter at **G93.3**.
- ICD-10-CM eliminated ICD-9-CM CFS 780.7 and search engines now default to *Chronic fatigue, unspecified* (R53.82). Moved from ICD-9 "*Symptoms, signs, and ill-defined conditions*" section to the ICD-10 section "*General symptoms and signs*"
- In ICD-10-CM, the **G93.3** code can only be reached by searching for *postviral fatigue or myalgic encephalomyelitis,* terms less familiar to clinicians.
- Three proposals have been submitted to ***NCHS** since 2011 to move CFS back to the neurological chapter and away from *Chronic fatigue, unspecified*. The **latest proposal,** submitted in July 2017 by **IACFS/ME,** was **rejected** from consideration at the Sept 2017 and March 2018 meetings.
- Waiting to hear from Donna Pickett, NCHS: Will the IACFS/ME proposal will be added to the September 2018 agenda?

*ICD-9 CM=International Classification of Diseases, Ninth Revision, Clinical Modification

*NCHS= National Center for Health Statistics

*WHO ICD-11
ME/CFS diagnostic coding issues

- WHO ICD-11 is under development, and currently classifies **CFS, ME, and PVFS in the neurological chapter**. But **a proposal** has been submitted to move CFS from *neuro codes* back to the *Symptoms section* of musculoskeletal disorders. WHO has stated they will not reclassify the terms in question until they complete an evidence-based review. We do not have an update on the status of that review.
- Donna Pickett, NCHS, met with our WkGp in Feb to discuss issues. She is taking this proposal into consideration (to reclassify back to Symptoms in WHO ICD-11) before making her decision about whether to add the IACFS/ME proposal to the ICD-10-CM meeting.
- The MedEd WkGp (via Mary, Gustavo) sent Ms Pickett a document detailing the disputed issues and concerns. **We are waiting for a response from Ms. Pickett**

*World Health Organization International Classification of Diseases, Version 11

Three day ME/CFS Clinician Summit 3/2018

13 ME/CFS Clinical Experts
Invited guests and observers

SUMMIT GOALS:

- Lay foundation for ongoing collaboration as an Expert Clinical Coalition
- Develop and disseminate ME/CFS clinical knowledge to medical providers
- Share clinical knowledge with researchers

YouTube summary video

https://www.youtube.com/user/OFFERUtah

Future collaboration anticipated

- Established a Listserv so ME/CFS expert clinicians can share ideas and pursue projects. For example:
  - Group consensus statements
  - Publications
  - ECHO project
  - Clinical trials group
- Group teleconferences to accomplish interval goals.
- Yearly in-person ME/CFS clinician meetings
- Expand and strengthen the collaboration to increase the number of ME/CFS experts with a goal to host CME conferences.

State level initiatives that serve as a model and encouragement for others

- **New York State:**
  - State Dept website
  - Unrest screenings in collaboration with NYC and NYS Dept of Health, Univ of Rochester
  - NYS Commissioner letter to 85,000 medical providers
  - Articles in FP journal, PC bulletin, County Med Soc web page
- **Massachusetts:**
  - Unrest screenings, panel discussions at State Dept Public Health, a hospital, two colleges, MA state house. More planned at Mass General, BU School of Pub Health, Dartmouth med school
  - Presentation on ME/CFS Diagnosis and Management was given at Massachusetts Academy of Family Practice annual conference.

Federal initiatives to create and disseminate ME/CFS medical education

CDC

- Medscape CME, CDC Website updates, Roundtable in fall
- Reaching out to UpToDate, Healthwise, Mayo and others

AHRQ

- Annals of Internal Medicine will publish the 2016 Addendum to the 2014 AHRQ ME/CFS Evidence Review

HRSA – appointing a new representative on CFSAC.

- Tele mentoring experience, including Project ECHO

Tele mentoring and exploration of Project ECHO:

- The core goal of Project ECHO is to unlock AND SHARE expert knowledge to increase the number of knowledgeable medical providers who can care for medically underserved populations…

A perfect fit for ME/CFS.

Moving Knowledge Instead of Patients and Providers

Project ECHO

Project ECHO® is a lifelong learning and guided practice model that revolutionizes medical education and exponentially increases workforce capacity to provide best practice specialty care and reduce health disparities through its hub-and-spoke knowledge sharing networks

People need access to specialty care for complex conditions

Not enough specialists to treat everyone.

ECHO® trains primary care clinicians to provide specialty care services

Patients get the right care, in the right place, at the right time.

More about the ECHO model:

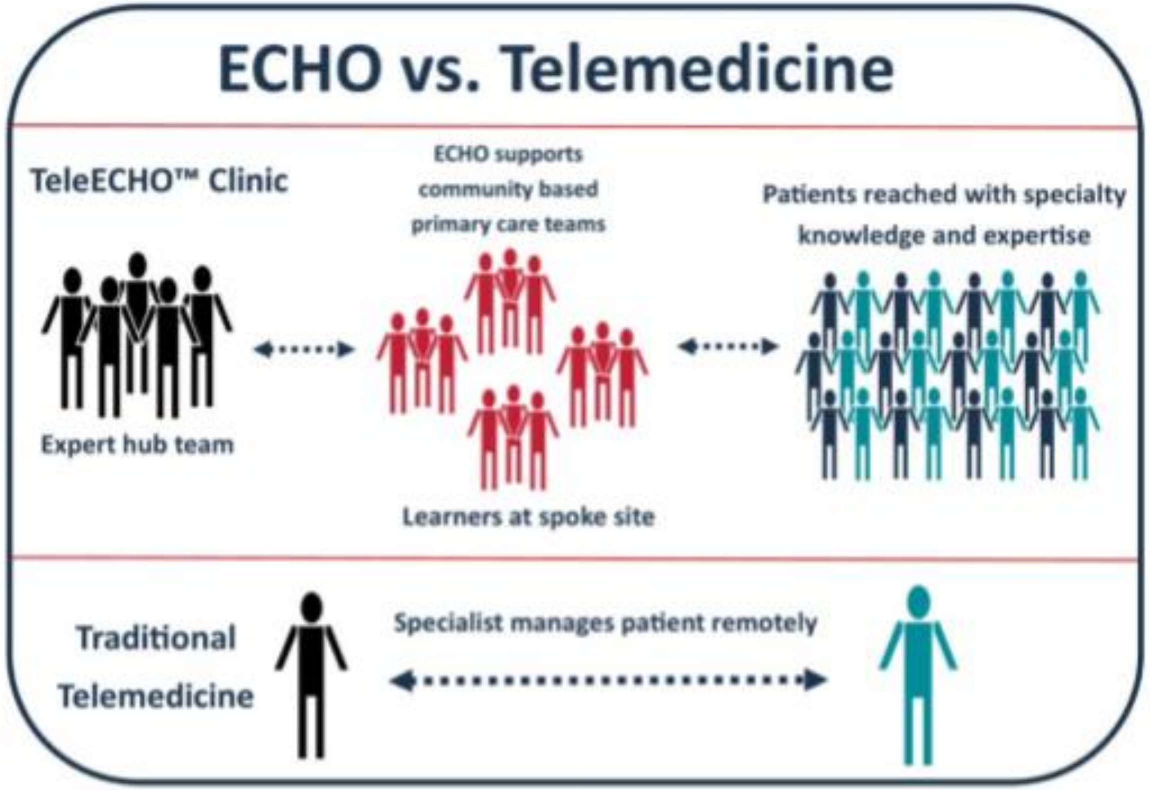
- Share the best practice of medical care
- Reduce disparities in quality of care
- Use cases as examples—**case based** medical discussions and medical learning
- Use modern technology to reduce costs
- Monitor the outcomes to measure the impact

HUBS:

Expert(s) who prepare and deliver the medical education (107 HUBS in the US).

SPOKES:

Medical professionals learning in a remote setting

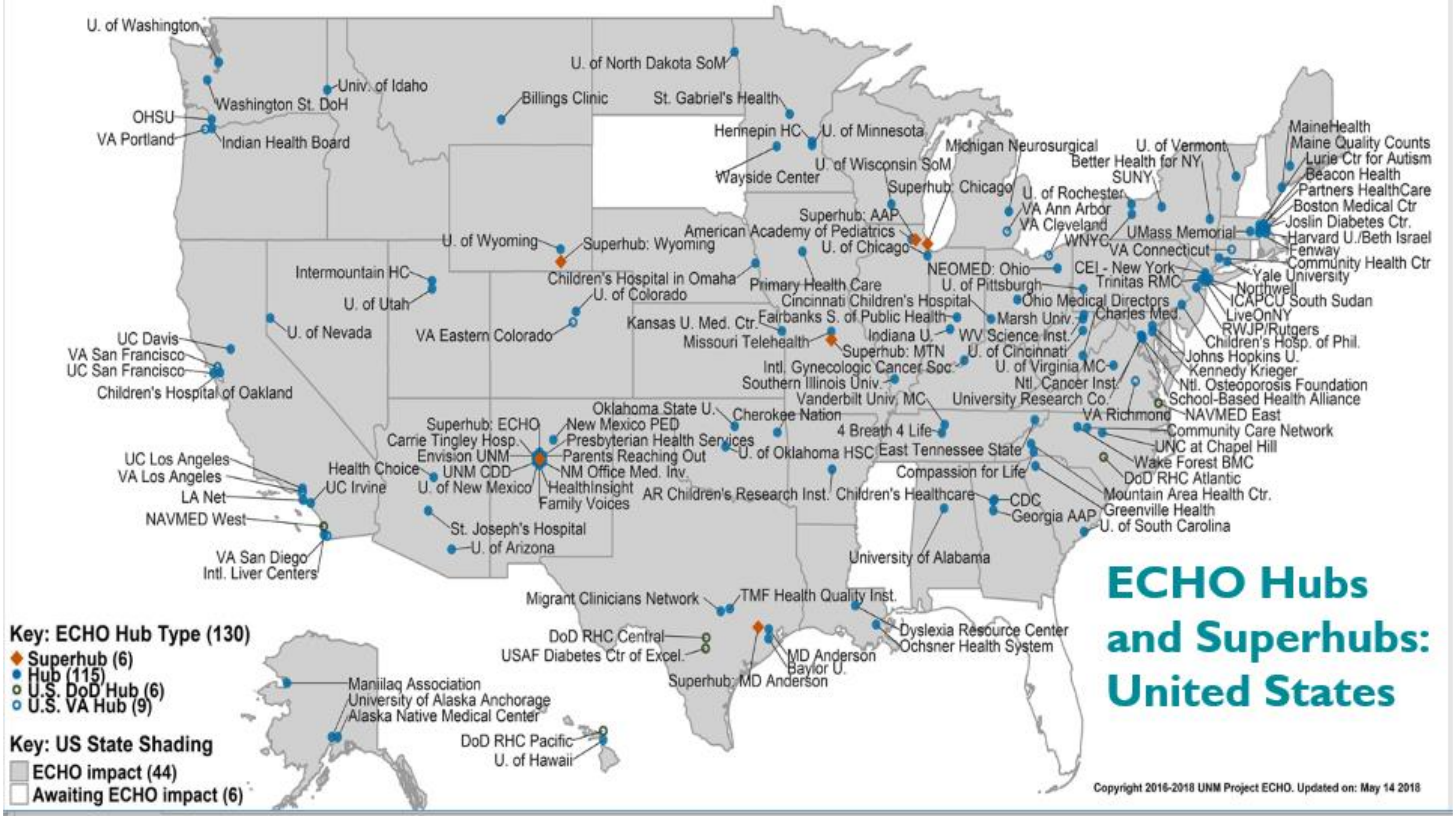


ECHO model **is not 'traditional telemedicine'**.

Treating Physician retains responsibility for managing patient.

Disease Selection

- Common diseases
- Management is complex
- Evolving treatments and medicines
- High societal impact (health and economic)
- Serious outcomes of untreated disease
- Improved outcomes with disease management



ECHO Hubs and Superhubs: United States

Costs associated with creating and maintaining a Project ECHO

- Average costs are $100,000 to $200,000/year but can range from "shoe-string to Cadillac."
- Funds cover program development, expert preparation and content delivery.
- Project ECHO services are provided free, although institutions may charge for CME credits.

- Sample Budget included in written report to CFSAC

Work Group suggestions about how to approach creation and support of ME/CFS medical education via Project ECHO

- **Develop a ME/CFS Project ECHO at an existing academically-based Project ECHO site,** and leverage partnerships with federal institutions, expert ME/CFS clinicians/researchers, the NIH funded Collaborative Research Centers, advocacy groups and non-profits.
- **Develop a strong marketing plan** to gain credibility needed to overcome medical community bias, lack of interest or resistance. Start a modest program with a plan to enlarge reach and resources.
- **Seek and create federal funding** to support growth and sustain ME/CFS Project ECHO as a primary route to medical education

University of Utah Project ECHO as a possible site

- ECHO Hub. Currently 8 active ECHO topics
- Welcomes development of ME/CFS ECHO topic
- Willing to implement asap and collaborate broadly
  - Bateman serving as adjunct faculty
  - Inclusion of ME/CFS Experts welcome
  - Many Univ of Utah specialists embracing ME/CFS
    - Neuroimmunology and autonomic specialists. Sleep specialists. Pain and anesthesia.

ECHO Project for ME/CFS next steps/needs:

- **Immediate funding/staffing**
  - ½ time staff, reimbursement for travel/training, content development, expert preparation/delivery
  - Short term 6-12 months donated time from BHC staff/Dr Bateman (a non-profit 501(c)3)
  - Short term infusion of funds will be needed: SMCI? OMF? Crowd-sourcing? Other foundations ?
- **Marketing:** combined efforts of Project ECHO NM and ECHO Super HUBS, UofU Project ECHO, but could be multiplied by help from federal agencies, non-profits and patient advocacy groups
- **Development of sustainable funding sources**:
  - Long term financial support: *HRSA grant, CDC budget item…, grants from other sources, other?*

The "ECHO Act"(Expanding Capacity for Health Outcomes Act)

Passed House/Senate by unanimous vote, November-December 2016
Signed into law by President Barack Obama, December 2016

Asks the Secretary of Health and Human Services to study the impact of Project ECHO on:

Conditions	Mental and substance use disorders, chronic diseases and conditions, prenatal and maternal health, pediatric care, pain management, and palliative care
Workforce	Implementation of public health programs, including those related to disease prevention, infectious disease outbreaks, and public health surveillance
Public Health	Health care workforce issues, such as specialty care shortages and primary care workforce recruitment, retention, and support for lifelong learning
Rural and Underserved Populations	Delivery of health care services in rural areas, frontier areas, health professional shortage areas, and medically underserved areas, and to medically underserved populations and Native Americans

The “ECHO Act” (Expanding Capacity for Health Outcomes Act) of 2016

Discussion:

- Will the Secretary of HHS inform CFSAC about this study and how it might inform medical education for ME/CFS?
- Can we explore how the Secretary of HHS might consider implementation of ME/CFS medical education as a prospective way for HHS to study the impact of Project ECHO?

Medical Education Workgroup Recommendations to CFSAC June 2018

- *CFSAC recommends that the National Center for Health Statistics work with ME/CFS experts and advocates to resolve concerns regarding the IACFS/ME proposal of how to reclassify CFS in the ICD-10-CM and ensure that the IACFS/ME proposal is placed on the agenda for the September 2018 meeting.*
- *CFSAC recommends that CDC add a "diagnostic coding" section to its ME/CFS website for medical providers to explain that the code for "chronic fatigue, unspecified" (R53.82) should not be used for ME/CFS, and direct providers to use the existing code for myalgic encephalomyelitis or postviral fatigue (G93.3) when coding the diagnosis of ME/CFS.*
- *CFSAC recommends that all federal agencies providing ME/CFS information and outreach to medical providers should include this diagnostic coding clarification related to a diagnosis of ME/CFS.*

Medical Education Workgroup Recommendations to CFSAC June 2018

- *CFSAC endorses the establishment of a ME/CFS Project ECHO or equivalent tele-mentoring program, to be conducted by ME/CFS disease experts and established through an existing academic center Project ECHO.*
- *CFSAC recommends that the relevant HHS agencies, including but not limited to CDC, HRSA, and AHRQ, plus the VA and DOD, actively support the implementation of a ME/CFS Project ECHO, once established, by :*
  - *Meeting with CFSAC, or the Medical Education Work Group, to identify potential* ***grant, contract, or other funding mechanisms*** *that could be used to support the development, continuation and expansion of the ME/CFS ECHO program.*
  - *Identifying and implementing* ***mechanisms to actively promote*** *the ME/CFS ECHO Project to the federal and greater medical community, and to* ***encourage participation****. These mechanisms could include sending notice to medical professional societies and their members, requesting that state departments of health disseminate information to their medical providers, encouraging staff at HRSA funded health centers to participate, and posting links to the program on each agency's website.*