

Public Comment, P2P Draft Report, ME/CFS

by Benita G. Mériaux
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Dear Members of the Panel,

You have my thanks for a job well done, with so little time to grasp the main issues in a field so muddled your efforts were extraordinary. Thank you.

The ME/CFS field has been muddied by so many things: the invention of the misnomer Chronic Fatigue Syndrome, the focus on the symptom “fatigue” even after it was clear that the hallmark symptom is in fact Post-Exertional Malaise (or Post-Exertional Collapse/Crash); the many studies done on a broad patient population with fatigue where results have falsely been promoted as pertinent to the ME/CFS patient population.

I was worried about the workshop and your Draft Report, especially since the AHRQ did not represent the state of knowledge in the ME/CFS field well—mainly because the authors were not tasked with the right questions. The focus should have been on etiology and disease mechanisms, where there are many promising leads—it is far too early to do any evidence reviews on treatment for ME/CFS. Hardly any clinical trials have been done using a well-defined ME/CFS population. In spite of the shortcomings of the AHRQ report, you have in most respects grasped the main issues in the ME/CFS field, which is impressive.

Yet, there are still areas for improvement in the Draft Report, and I will comment on these below.

Name-change

I believe the report should recommend a name-change. The term “Chronic Fatigue Syndrome” needs to be retired. “Chronic Fatigue Syndrome” is as misleading as calling Alzheimer’s “Chronic Forgetfulness Syndrome” or Parkinson’s “Chronic Shaking Syndrome”. It belittles the very disabling organic disease which ME/CFS is.

Please comment on this in your Introduction (lines 1 et seq.). In Future Directions and Recommendations (lines 178 et seq.), I suggest you add a recommendation that the name “Chronic Fatigue Syndrome” be retired. If you do not feel that Myalgic Encephalomyelitis or Myalgic Encephalopathy is appropriate, I suggest “Ramsay’s disease” (named after the ME pioneer Dr. Melvin Ramsay).

Case definition

Referring to lines 105-106 and 202-204:

“A clear case definition with validated diagnostic tools is required before studies can be conducted.”

“Define disease parameters. Assemble a team of stakeholders (e.g., patients, clinicians, researchers, federal agencies) to reach consensus on the definition and parameters of ME/CFS”

I suggest that you recommend that the Canadian Consensus Criteria (CCC) be endorsed as an interim criteria. Please remove lines 105-106, so that research is not halted. It is crucial that a large number of ME/CFS trials be conducted in the near future—there is no time to stall that pending a new set of criteria, when the CCC is deemed by expert researchers to be useful.

Ongoing projects such as the IOM project may feed into the discussion about criteria, but the vital issue is that you recommend a way for research to continue, and increase, in spite of the lack of universally accepted criteria. This can be done by recommending the use of CCC in the interim.

Clinical trials – objective outcomes necessary

Referring to lines 277et seq.: “Improve methods and measures”:

A central problem in clinical trials in the ME/CFS field has been the complete lack of objectively measurable outcomes. This (in combination with other methodological problems) has allowed studies which proclaim to demonstrate effectiveness of a certain treatment modality, but in fact probably only show placebo effect improvements.

It is absolutely necessary that future treatment trials include objective measures of effectiveness. With the new technology opportunities abound, such as actometers. Please include this as a recommendation.

Prioritization of recommendations plus time-table

I believe your recommendations must be prioritized and time-set, in order for any real progress to take place.

Thank you kindly for your consideration of my comments. If the Final Report is even stronger than the Draft, it bodes well for everyone in the ME/CFS community, patients, clinicians and researchers alike.

Yours sincerely

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