

Public Comment
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Thank you to the CFSAC for allowing me to speak. My name is Andrew Bokelman.

A majority of the leading American ME/CFS experts sent a letter to the HHS urging them to adopt the Canadian Consensus Criteria for ME/CFS. These criteria are based on a consensus of ME/CFS experts with years of experience, and recently more experts added their names to the consensus.

Despite this, the HHS continues down the path to a one million-dollar literature review that will create new criteria. The contractor for this task is Institute of Medicine (IOM). They recently admitted that they have no experience with criteria development. But the IOM did develop a treatment guide for Gulf War Syndrome which includes a section about Chronic Fatigue Syndrome. I read this section to see the quality of their work. I was not impressed.

For example, they recommend graded exercise. And to support this, they reference three web sites that offer no citations to back up their claims. The IOM also cites two journal articles. The first is called The Neuroendocrinology of Chronic Fatigue Syndrome. It says nothing about graded exercise helping CFS patients. The second paper, called Endorphins and Exercise, doesn't even deal with CFS.

I also looked at their coverage of pharmaceutical treatments. They only mention pain control and sleep. In contrast, the Canadian Consensus document includes a section on pharmaceuticals for a much wider range of symptoms. I also know of two books that cover a wide range of pharmaceuticals. Both include citations. It's remarkable that the IOM panel wasn't able to discover any of this.

The IOM points out that there will be a different panel this time. And that's true. But the panel will be chosen by the same people. And the actual project will use the same method for quality control.

It is also important to note that the IOM will not test the criteria to see if they can actually differentiate ME/CFS from similar illnesses. With no validation testing, there is no evidence the criteria work, and therefore no evidence-based criteria. All they will have is an evidence-based hypothesis, and claiming that it's more than this takes liberties with the truth.

But the problem here is not only with the IOM. It is with the idea that one can take evidence from research based mostly on weak criteria, and then use this to create strong criteria. Illness criteria are supposed to differentiate one patient group from another. And in the absence of reliable biomarkers, the only way to improve criteria is through observation by expert ME/CFS clinicians, who are familiar with the research, and who have ongoing communication with other clinical and research experts. This is exactly

what the Canadian Consensus authors do. And they have been doing it for many years with less money than other illnesses receive.

But it's clear that the HHS doesn't want to simply accept the Canadian Consensus Criteria. So I suggest that instead of spending one million dollars to circumvent the experts, they meet with the experts as colleagues. Work out a mutually agreeable way to perform validation field-testing on the Canadian Consensus Criteria. See how well these criteria select patients. Then proceed from there. This is a much, much better solution than paying one million dollars to a research group that has demonstrated an inability to adequately research CFS, and who admits they have no experience with criteria development.

Thank you for letting me speak.

Bibliography

Canadian Consensus Document

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. Carruthers et al., Journal of Chronic Fatigue Syndrome, Volume 11, Number 1, 2003.

IOM Gulf War Syndrome Treatment Guide

Gulf War and Health: Treatment for Chronic Multisymptom Illness. Washington, DC: Institute of Medicine of The National Academies, 2013.

Two books that cover pharmaceuticals and include citations

Reviving the Broken Marionette: Treatments for CFS/ME and Fibromyalgia. Haavisto, 2008

Chronic Fatigue Syndrome: A Treatment Guide, 2nd Edition. Verrillo, 2012.