

**Public Comment**  
**CFSAC | December 2014**  
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In less than one week, the AHRQ Evidence Review will be released and the P2P Workshop will be held. I send you information one month ago summarizing advocate concerns with these initiatives and asked you to take a strong position on those concerns at this meeting. I note that HHS did not provide a spot on the agenda to discuss this topic and ask that you please carve out time in your discussion periods.

Today, I will speak specifically to the AHRQ Evidence Review.

We would all say it is unscientific and unethical to recommend diagnostics and treatments for cancer patients based on studies in multiple sclerosis, even though they both cause fatigue. Why? Obviously, they are different disease processes.

And yet that is exactly what has been done in AHRQ's Evidence Review. Eight disparate definitions with dramatic differences in inclusion and exclusion criteria have been treated as though they represent the same disease process, based solely on the symptom of medically unexplained fatigue.

But look at this collection of definitions. The most basic scientific reasoning tells you that Oxford, which requires nothing more than medically unexplained chronic fatigue and includes primary psychiatric illness cannot possibly represent the same disease process or patient cohorts as the ME-ICC or the Canadian. That same reasoning also tells you that a collection of definitions centered on nothing more than the ubiquitous and ill-defined symptom of fatigue plus the current state of our medical knowledge is scientifically nonsensical since it is unlikely to encompass a set of biologically related diseases.

Such scientific reasoning should have caused the AHRQ Evidence Review team to cry foul when asked to compare diagnostics and treatments across these eight definitions. But they didn't. They barged ahead - without a shred of proof - with the fatally flawed assumption of definitional equivalency. And based on that faulty assumption, the Evidence Review then concluded that PACE style CBT and GET, studied in Oxford patients, is also appropriate for ME-ICC and Canadian patients. PACE style CBT and GET are used to convince patients they do not have an organic illness and to reverse the deconditioning presumed to be causing symptoms. Given that ME-ICC and Canadian both describe an organic disease characterized by exercise induced pathologies, such recommendations are unethical and create an undue risk of substantial harm for ME patients.

Obviously, AHRQ's Evidence Review is likely to create significant misunderstanding and bias about the nature of this disease in the uninformed P2P panel, especially given how many studies on biomarkers, treatments and pathophysiology were excluded.

But my bigger concern today is with the other uses of the final version of the Evidence Review. AHRQ has stated that the Evidence Review may be used as the basis of clinical guidelines and

reimbursement and coverage policies. Using the kinds of conclusions seen in the draft Evidence Review for these purposes is medically dangerous for ME patients and must be addressed. It is medically irresponsible to release such flawed conclusions, knowing the deleterious impact that these recommendations can have on ME patients.

For the sake of patients, I ask you to please act on this issue today, before the AHRQ Evidence Review is issued, and call on AHRQ to not publish this Evidence Review until it address these and the other substantial concerns raised with this Evidence Review.

For further information on the concerns with the AHRQ Evidence Review, please see: Please review at least this [summary](#). The full submission submitted by a group of patient advocates can be found here: ([Part One](#) and [Part Two](#)). [SolveMECFS](#) also posted their concerns [here](#)