



December 17, 2021

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National Center for Emerging and Zoonotic Infectious Diseases
Centers for Disease Control and Prevention

Dear Dr. Unger,

Thank you for hosting an informative ME/CFS Stakeholder Engagement and Communication call on December 16. We noted and appreciate your provision of a written [summary](#) of CDC program updates in advance of the call and your willingness to extend the call to allow sufficient time to answer participants' questions.

In light of #MEAction's [previously raised concerns](#) with the [EPC draft systematic review](#) of ME/CFS treatments, **we support CDC's appropriate decision not to submit the review for publication in a peer-reviewed journal**, either by CDC or independently by EPC.

However, we are concerned that CDC's plan to post the final review on its website may still confuse healthcare providers and harm patients. Most readers are unlikely to [examine in depth](#) the limitations of the EPC review. As you have acknowledged, the review does not provide sufficient evidence for treatment recommendations, and it states that quality of evidence is very limited and includes many caveats about study findings.

But the reality is doctors and patients are often desperate for ME/CFS treatment answers, and they have historically been recommended treatments like graded exercise therapy (GET) and cognitive behavioral therapy (CBT), which experienced ME/CFS clinicians understand are not appropriate and are often harmful. Few clinicians are well-informed on ME/CFS despite its high prevalence and increased incidence due to Long COVID. In light of the history of misinformation and stigma that colors clinician attitudes and impacts patient care today, CDC must be especially mindful in how information is presented to the public.

#MEAction appreciates that you want the EPC review that is posted to the CDC website to be put in "appropriate context" so that healthcare providers and patients are clear that:

1. CDC does not recommend GET or CBT for people with ME/CFS,
2. CDC does not endorse the studies of GET and CBT contained in the review,
3. CDC's clinical definition of ME/CFS differs from the broad definitions of chronic fatigue utilized by the GET and CBT studies

#MEAction supports CDC's intention to link to the United Kingdom National Institute for Health and Care Excellence (NICE) updated treatment guidelines and systematic reviews especially



because the NICE systematic review differs with the EPC review about the [“directness”](#) (e.g. applicability or generalizability) of GET and CBT study findings to people living with ME/CFS. It also includes a [comprehensive synthesis](#) of the experiences of people who have had GET for ME/CFS, as captured through qualitative studies.

Given the above issues and the [widespread community concern](#) over the EPC review, we requested on yesterday’s call that CDC hold a community meeting to dialogue with stakeholders about how the systematic review information could most appropriately and effectively be communicated that would help alleviate our concerns. **We appreciate your response that CDC will consider our request for a community meeting about how the information is presented on the website.**

If the CDC ME/CFS program is not be able to organize such a community meeting, then #MEAction will be happy to organize a community meeting on this topic and invite you and any other CDC representatives as panelists. We will then collate the feedback from the public meeting and provide it to CDC in a written summary. We understand you are in the process of finalizing the EPC review, so naturally it will be helpful to obtain the amended copy of the review prior to the community meeting.

We know that you have the interests of the patient community at heart, and we have confidence that you will consider and respect input from patients and advocates prior to posting the review.

Sincerely,

Ben HsuBorger
U.S. Advocacy Director
#MEAction