

Anonymous #7

To the authors of the draft report,

Thank you for managing to within a short time-frame grasp many of the important features of ME and point out many of the shortcomings of the field.

I hereby submit my comments on the areas of the draft report which I believe can be improved further. In these comments I think I echo many other patients and experts who have submitted comments to you. I hope you will take them into careful consideration.

1. Please do not recommend multimodal treatment with psychological therapies.

Referring to:

Lines 92-93: Although psychological repercussions (e.g., depression) often follow ME/CFS, this is not a psychological disease in etiology.

Lines 113-116: Existing treatment studies (cognitive behavioral therapy [CBT] and graded exercise therapy [GET]) demonstrate measurable improvement, but this has not translated to improvements in quality of life (QOL). Thus, they are not a primary treatment strategy and should be used as a component of multimodal therapy.

Lines 282-284: Studies addressing biopsychosocial parameters (including the mind-body connection), function, and QOL should be encouraged.

Lines 362-364: The modest benefit from CBT should be studied as adjunct to other modalities of treatment such as self-management. Future treatment studies should evaluate multimodal therapies.

Lines 384-385: We believe there is a specific role for multimodal therapy.

There have been no objectively measured improvements following treatment with CBT and/or GET for ME patients. The studies have not provided any evidence for that. Concurrently, a large number of patient surveys have unambiguously shown that a majority of ME patients do not benefit from CBT or GET, and – on average – around half of the patients report that GET has caused them harm.

See for example this Norwegian patient survey:

<http://me-foreningen.com/meforeningen/innhold/div/2014/05/ME-Nat-Norwegian-Survey-Abr-Eng-Ver.pdf>

Also, multimodal therapy has been tried here in Scandinavia with no significant benefit. The field here is now turning towards more relevant treatments, such as immune-modulatory treatments, see next section.

I ask you to remove the statement that CBT and GET demonstrate measurable improvement and to remove the recommendations of multimodal therapy.

2. Please change the section about treatments so that it focuses on biological therapies instead of psychosocial therapies

Lines 74-117: [H]ow can we foster innovative research to enhance the development of treatments for patients?

Psychosocial treatments have not helped ME patients, nor has multimodal therapy.

The ME research field is now turning towards more relevant treatments, such as immune-modulatory drugs. Norwegian oncologists Prof Olav Mella and Dr Øystein Fluge have shown in small studies that the B-cell inhibitor Rituximab reduces symptoms (sometimes to the point of completely recovered function) in around 2/3 of ME patients. A large multi-site study in Norway is now underway.

In the US, the immune-modulator Ampligen has been shown to help a subgroup of ME patients.

These and other promising biomedical treatments need to be explored in NIH funded large-scale clinical trials.

I ask you to re-arrange the section about treatment, plus your recommendations, so that they focus completely on biological therapies.

Thank you for considering these comments.