



# **Invest in ME Research**

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Professor Mark Baker  
Centre for Guidelines Director  
National Institute for Health and Care Excellence

## **NICE Guidelines for Myalgic Encephalomyelitis (ME)**

17 January 2018

Dear Professor Baker,

Thank you again for your reply to our letters.

We apologise for taking up more of your time but there is one issue that has now arisen which we feel needs clarification and action.

At the Stakeholder engagement workshop meeting yesterday you were reported as saying that the existing NICE guidelines would be "torn up" and new guidelines developed.

Yet yesterday, just a few hours before that meeting, you wrote to us and stated –

"In our most recent review of the guideline, and cognisant of the controversies regarding the interpretation of the PACE results and methods, we assessed the evidence with, and without, the PACE results and the trial made no difference to the conclusions"

and that you would

"give some consideration to whether we need to modify or omit any of the existing recommendations during the development of the new guideline"

These remarks seem to us to be contradictory.

If you are now telling participants at yesterday's meeting that the existing guidelines will be torn up then you are effectively stating that they are of no value.

Therefore, there is no logic in retaining the existing guidelines any longer, which you have previously stated were not effective and which you are now alleged to have said will be completely removed in any case.

If you decline to take action in issuing the addendum that we have requested then the most logical action that NICE must now take is to withdraw the existing guidelines completely, immediately, and inform all doctors across the UK that the existing guidelines are not fit for purpose and the recommendations in those guidelines are not to be used.

This notice should also be communicated around the world to any foreign organisations that have misguidedly used the existing NICE guidelines for their own healthcare systems.



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It is better to have no guidelines than to have guidelines that will potentially harm patients.

Although withdrawal of the guidelines may be embarrassing for NICE this action would avoid the need to add the addendum that we previously requested and would serve patients – the very people that the guidelines should help at the end of the day.

This action could also demonstrate that your words mean more than the meaningless platitudes that patients in UK have long been accustomed to from establishment organisations over the last decades. You can change that – Tear It Up!

Failure to withdraw these now would invite speculation that you are leading patients down one of the longest garden paths in history,

Yours Sincerely,

Kathleen McCall

Chairman Invest in ME Research  
and the Trustees of Invest in ME Research