

## **Strawman announcement for the letter to AHRQ**

On February 3, 2016, a group of patient organizations and advocates sent [a followup letter](#) to the Agency for Healthcare Research and Quality (AHRQ) further detailing concerns with the 2015 AHRQ Evidence Review and reiterating their request, originally made in November 2015, to reanalyze the conclusions of AHRQ's Evidence Review in light of the long-known concerns with PACE and with the Oxford definition.

### Background

In November 2015, a group of U.S. organizations sent [a letter](#) to the U.S. Health and Human Services (HHS) requesting a review of the concerns raised with PACE in a [series of articles](#) by journalist David Tuller. Based on these concerns and the call by the National Institute of Health (NIH) Pathways to Prevention report to retire the Oxford definition because it could “impair progress and cause harm”, the letter recommended the following steps as appropriate and necessary to protect patients:

- The AHRQ revise its evidence review to reflect the issues with PACE and with Oxford studies in general;
- The Centers for Disease Control and Prevention (CDC) remove findings based on PACE and other Oxford studies from current and planned medical education;
- HHS use its leadership position to communicate these concerns to other medical education providers;
- HHS call for *The Lancet* to seek an independent reanalysis of PACE.

### The Agency Responses

In [AHRQ's response](#), the authors of the evidence review noted that the review had already considered some of the concerns raised by Tuller and that the additional information would not change the review's conclusions. Yet, the evidence review ranked PACE as a “Good” study with “undetected” reporting bias, a rating that is not consistent with the long-known concerns with PACE but one that could presumably influence conclusions. Further, AHRQ's response did not address the concerns with using Oxford studies as the basis of recommendations of treatment benefits and harms for ME/CFS patients. The February 4, 2016 letter from patient organizations and advocates details these concerns and reiterates the request to reevaluate the evidence review conclusions.

[CDC's response](#), further clarified by a followup email, stated that the IOM and P2P “have placed the findings of the PACE trial in an appropriate context for moving the field forward.” They stated the need for research and that CDC would be conducting a collaborative initiative to prepare new medical education materials. However, CDC's response did not address the question of whether findings and recommendations based on Oxford studies would be allowed in new medical education materials for this disease. The CDC has been asked to specifically respond to this question. That response will be shared when it is available.

HHS did not respond to the request to call on *The Lancet* to seek an independent review.

If you have not done so, please join in with us and sign [this petition](#) calling for AHRQ and CDC to act to protect patients.