



Invest in ME

PO Box 561, Eastleigh SO50 0GQ, Hampshire, UK

Web: www.investinme.org

Email: info@investinme.org

Charity Nr 1114035

Dear BBC,

Invest in ME is a UK charity funding and facilitating biomedical research into Myalgic Encephalomyelitis (ME or ME/CFS).

In your recent article '**Exercise can help with ME, scientists say**' on 14 January [[1](#)] you state –

"A team of British researchers found behavioural and exercise therapies were better at reducing fatigue and disability than adaptive pacing strategies. And a separate analysis by scientists from London and Oxford suggests these treatments work by helping people overcome fearful thoughts and behaviours - such as avoiding exercise in the belief it could make things worse. Researchers say both beliefs and behaviours play a part in perpetuating fatigue and disability."

We would like to point out that the original PACE trial [[2](#)] did not show any objectively measurable improvements.

The trial claimed only modest improvements when comparing self-reported outcomes for Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET), Adaptive Pacing Therapy (APT) and Standard Medical Care (SMC) – and that was after changing the entry criteria once the trial had already started, as well as redefining recovery so that patients could enter the trial with a SF-36 PF score of 65 and yet be deemed to be recovered with a score of 60 at the end of the trial [[3](#), [4](#)].

Despite this the results were so poor that the self-rated clinical global impression showed only a modest 10-16% improvement.

Therefore, if the current study claims that 60% of the improvement was accounted for being less fearful then the results would still be very poor and would involve a very minor group of patients.

The results would not justify headlines such as that which the BBC used without challenging the scientists' claims. This you have not done.

There are a whole host of other flaws in the original trial which you may wish to investigate [[4](#)].

For example, the very broad and fatigue only based Oxford definition used in the PACE trial has now been recommended to be discarded for research into ME by the USA National Institutes for Health initiated Pathways to Prevention (P2P) workshop [[5](#)].

The NIH report says

"The Oxford criteria (published in the Journal of the Royal Society of Medicine in February 1991) are flawed and include people with other

conditions, confounding the ability to interpret the science. The lack of a consistent, specific, sensitive diagnostic test and set of criteria has hampered all downstream research on pathogenesis and treatment, causing harm and preventing ME/CFS from being considered as a distinct pathologic entity."

and

"Specifically, continuing to use the Oxford definition may impair progress and cause harm. Thus, for needed progress to occur we recommend (1) that the Oxford definition be retired, (2) that the ME/CFS community agree on a single case definition (even if it is not perfect), and (3) that patients, clinicians, and researchers agree on a definition for meaningful recovery."

Using these criteria for ME reflects even more adversely on the already poor results for this trial.

As such the PACE trial was completely flawed and is now worthless and any other paper coming out of that trial data has, therefore, to be considered as suspect.

Your headline refers to ME.

Yet, in a response to a complaint made to the Lancet by Professor Malcolm Hooper in 2011, a letter by Professors White, Sharpe and Chalder that was sent to Dr Richard Horton (Editor-in-Chief of The Lancet) on behalf of all the co-authors of the PACE trial stated the following [6] -

"The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME".

Yet in In the PACE Trial Patient Clinic Leaflet, Professor White et al state:

"This illness is also known as post-viral fatigue syndrome, myalgic encephalomyelitis (ME) and myalgic encephalopathy (ME). Medical authorities are not certain that CFS is exactly the same illness as ME...but we will be calling this illness CFS/ME".

This very strange and confusing inconsistency seems to have been overlooked. What is certain is that your headline should not refer to ME – that is misleading.

You also only have a quote from Action for ME in your article. That organisation was part of the PACE trial management group so you should declare a conflict of interest when quoting them. Invest in ME have a vastly different view on this trial and all claims coming from it so perhaps you need to reconsider the balance in the article.

To avoid unhelpful and even serious setbacks to ME patients by the Science Media Centre orchestrated media reporting we would like to ask the BBC to review this latest research objectively.



Invest in ME

You may find Invest in ME's recent response to the NIH P2P workshop helpful [7].

You may also like to document that Invest in ME has initiated two of the most important research projects in the UK – biomedical research projects –

A UK rituximab clinical trial [8]

A UK gut microbiota study [9]

In order for the BBC to be considered as a fair and impartial journalistic source perhaps you might mention this research by the charity.

We have several times invited BBC health reporters to our annual international conference [10] but have never received a reply let alone any interest in accepting. Perhaps you can pass this on to your health reporters – the invite is still there.

We would also request that you attach the Invest in ME website link in your **Related Internet Links** section of the article mentioned – as this would allow the public to be better informed.

The BBC has a proud tradition of unbiased reporting to uphold. But poor or inadequately researched reporting makes many ME patients aware of the bias that still seems to exist amongst establishment organisations,

Yours Sincerely,

The Chairman and Trustees
Invest in ME

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1. <http://www.bbc.co.uk/news/health-30795506>
 2. <http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2811%2960096-2/abstract>
 3. <http://www.effectivehealthcare.ahrq.gov/ehc/products/586/2004/chronic-fatigue-report-141209.pdf>
 4. https://www.whatdotheyknow.com/request/pace_trial_recovery_rates_and
 5. <https://prevention.nih.gov/docs/programs/mecfs/ODP-MECFS-DraftReport.pdf>
 6. <http://www.investinme.org/Article427%20Initial%20response%20by%20Hooper%20to%20undated%20letter%20by%20White%20to%20Horton.htm>
 7. <http://www.investinme.org/IIME-Newslet-1501-01.htm>



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8. <http://www.ukrituximabtrial.org/home.htm>
9. <http://www.investinme.org/LDR%20newslet%201312-01.htm>
10. <http://www.investinme.eu>