

Tweets from first 2nd set of 100 posts in S4ME thread:
Michael Sharpe skewered by @JohntheJack on Twitter



Lucibee

Senior Member
(Voting Rights)

Messages: 248

Likes Received: 2,510

Location: Mid-Wales

dave30th said: ↑

Let's also remember this quote from Professor Sharpe in his 2011 interview with Norman Swan on the ABC network in Australia not long after The Lancet published the first results

Why won't Prof Sharpe answer my question? He keeps saying, "It's just a trial, it's just a trial"



Lucibee

@_Lucibee



Interesting. So why did you let [@richardhorton1](#) state that, "they were really stepping back and comparing two philosophies, not just two treatments, two philosophies of what chronic fatigue syndrome was."? [@thelancet#PACEtrial](#)

michael sharpe [@profmsharpe](#)

No. The PACE trial was a clinical trial - all a trial does is compare treatments. That's it. It is not a policy or a conspiracy. Just a trial..

2:21 PM - Apr 8, 2018

♥ 27 👤 See Lucibee's other Tweets





Lucibee

Senior Member
(Voting Rights)

Messages: 248

Likes Received: 2,510

Location: Mid-Wales

He's still going...



Cheshire @cheshfr

9 Apr

Replying to @profmsharpe

Dear Michael,

Like many patients, I read the "actual papers", to make an informed decision.

What matters to me is:

- To be able to improve significantly my walking capacities

- To go back to work.

What I discovered in the PACE papers wasn't really convincing:



michael sharpe

@profmsharpe



Glad you read it. And I understand your wishes. However those were not the primary outcomes. It is a trial not a policy. The results are what they are.

9:43 AM - Apr 15, 2018



See michael sharpe's other Tweets



Lucibee, Apr 15, 2018 [Report](#) [Bookmark](#)

#108 [Like](#) [+ Multiquote](#) [Reply](#)



Indigophoton
Senior Member
(Voting Rights)

Messages: 674
Likes Received: 7,167
Location: UK



uab9876 @uab9876

15 Apr

Replying to @profmsharpe @cheshfr

So if PACE doesn't answer important questions was it badly designed? It just seems to answer can CBT/GET change how patients record perception of fatigue, certain physical tasks. Measuring those doesn't give sufficient information to make decisions.



michael sharpe

@profmsharpe



Well. That is how the illness is defined. I am inclined to believe patients.

2:46 PM - Apr 15, 2018



See michael sharpe's other Tweets



uab9876 @uab9876

15 Apr

Replying to @profmsharpe @cheshfr

Tell someone they will get better if they ignore symptoms and think they can do stuff. Then ask how do you feel, what can you do. You will likely a reporting bias so results based on this are unreliable. Its not a case of believing/disbelieving patients.



michael sharpe

@profmsharpe



Sorry. I disagree

4:37 PM - Apr 15, 2018



See michael sharpe's other Tweets



I find this quite odd. Apparently it makes sense to believe what patients said during the trial, but to dismiss what they say otherwise, even when published in peer-reviewed journals.

Indigophoton, Apr 15, 2018 Report Bookmark

#128 Unlike + Multiquote Reply



Lucibee

Senior Member
(Voting Rights)

Messages: 248

Likes Received: 2,510

Location: Mid-Wales



uab9876 @uab9876

15 Apr

Replying to @profmsharpe @cheshfr

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michael sharpe

@profmsharpe



Well. That is how the illness is defined. I am inclined to believe patients.

2:46 PM - Apr 15, 2018



See michael sharpe's other Tweets



Sharpe: "That's how the illness is defined."

No. That's how you've chosen to define it, Prof Sharpe. You've defined it by a measure that you have devised to be so amenable to subjective suggestion that you can easily (or not so easily *cough*) fix it and report you have fixed the underlying condition. Win win win!

Lucibee, Apr 15, 2018 Report Bookmark

#134 Like + Multiquote Reply



Barry

Senior Member
(Voting Rights)

Messages: 2,281

Likes Received:
14,681



Sten Helmfrid

@StenHelmfrid



Professor Michael Sharpe of the #PACEtrial team confirms the importance of Dr David Tuller's work. #MECFS

twitter.com/profmsharpe/st...

michael sharpe @profmsharpe

This is what researchers who are studying aspects of CFS/ME that activists don't want studied are up against. occupyme.net/2018/04/07/ret...

8:01 PM - Apr 8, 2018

♡ 77 💬 18 people are talking about this



Sten Helmfrid @StenHelmfrid · Apr 12

What conflict of interest?

💬 1



michael sharpe @profmsharpe · Apr 12

Seeking money to promote a particular view point.

💬 3



♡ 2

In which case what **other** interest(s) of @dave30th's does MS have a problem with? An interest cannot be in conflict with itself; there have to be at least two for there to be any possibility of conflict between them.

Barry, Apr 15, 2018 [Report](#) [Bookmark](#)

#137 [Like](#) [+ Multiquote](#) [Reply](#)



Barry

Senior Member
(Voting Rights)

Messages: 2,281

Likes Received:
14,681



Cheshire @cheshfr

9 Apr

Replying to @profmsharpe

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@profmsharpe



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9:43 AM - Apr 15, 2018



See michael sharpe's other Tweets



Yes, the trial's results are indeed what they are, but:

- The published results are an interpretation of the trial's results, and that interpretation was deeply skewed.
- The trial's results were arrived at from a trial

Lucibee

Senior Member
(Voting Rights)

Messages: 248

Likes Received: 2,510

Location: Mid-Wales

Because you're not on Twitter?

News just in... another blockage:



Sten Helmfrid
@StenHelmfrid



Svar till @profmsharpe och 7 till

You have no objective measures of adherence. The lack of improvement in fitness suggests that patients cannot follow the exercise program.

04-15-18, 20:02

3 GILLANDEN



Sten Helmfrid
@StenHelmfrid



Blocked by Professor Michael Sharpe for this comment about measurement of harm in the [#PACEtrial](#). He just doesn't like criticism. [#MECFS](#)

7:57 PM - Apr 15, 2018

♡ 92 💬 30 people are talking about this

Lucibee, Apr 15, 2018 [Report](#) [Bookmark](#)

#145 [Like](#) [+ Multiquote](#) [Reply](#)

Indigophoton

Senior Member
(Voting Rights)

Messages: 674

Likes Received: 7,167

Location: UK

I don't think it's who it is, but the level of argument he is presented with that's the problem. Despite directly challenging people, he seems to drop out of every conversation when people take up his offer and attempt to pin him down on specific points.

For example, on the trial itself,



michael sharpe @profmsharpe

8 Apr

Replying to @MECFSNews

And your evidence for your very serious and libellous allegation of fraud is ?



Paul Watton

@thegodofpleasur



Libellous allegation?

Dr Sarah Myhill & colleagues appear to have had no problem evidencing

it.drmyhill.co.uk/drmyhill/image...

The ball would appear to be in your court.

So what's your response ?

Will you please address the criticisms of PACE directly for once?

4:39 PM - Apr 15, 2018

♡ 15 👤 See Paul Watton's other Tweets





michael sharpe @profmsharpe

15 Apr

Replying to @thegodofpleasur @MECFSNews

Can you be specific please. ?



Paul Watton

@thegodofpleasur



How much more specific can I be?

The criticisms of PACE have been well publicised, but you seem to want to pretend that you've answered those criticisms and that there's no problem.

You could start by addressing the overlap between entry criteria and your definition of recovery

5:00 PM - Apr 15, 2018



7



See Paul Watton's other Tweets



Another attempt to get answers from Clare Lagan, who describes herself as a medical scientist in the areas of pathology and the microbiome,



Claire Lagan @LaganClaire

8 Apr

Replying to @profmsharpe

It's not that 'activists' don't want certain aspects of CFS/ME studied. It's just they don't want the results to be made up to try and validate the authors hypothesis.



michael sharpe

@profmsharpe



Do you really think that we would do that?
Or that in the context of a regulated clinical trial that would even be possible. Really?

12:33 PM - Apr 15, 2018



See michael sharpe's other Tweets



michael sharpe @profmsharpe

15 Apr

Replying to @LaganClaire

Do you really think that we would do that?
Or that in the context of a regulated clinical trial that would even be possible. Really?



Claire Lagan

@LaganClaire



Can you answer me a couple of genuine queries about the study?

4:55 PM - Apr 15, 2018

And physicist Sten Helmfrid has been blocked, as @Lucibee noted,



John Peters @johnthejack

15 Apr

Replying to @StenHelmfrid

Yes, as soon as I mentioned subjective outcomes in an unblinded trial he blocked me as well. Obviously a little sensitive.



Sten Helmfrid

@StenHelmfrid



A scientist who doesn't dare to defend his work in an open debate. What a disgrace.

8:06 PM - Apr 15, 2018



39



See Sten Helmfrid's other Tweets



Indigophoton, Apr 15, 2018 Report Bookmark

#147 Like + Multiquote Reply



Indigophoton

Senior Member
(Voting Rights)

Messages: 674

Likes Received: 7,167

Location: UK



Jonathan Edwards
Senior Member
(Voting Rights)

Messages: 1,139

Likes Received: 13,326

Why doesn't Dr Sharpe call me out for my conflict of interest?



Is it that as a professor at Oxford University he is used to arguing with those he considers lesser mortals and prefers to stick with that? (I found Oxford a bit stuffy as a student so moved to the University of London.)

Pretty much everything David has put out has been cross checked with multiple senior academics. In many instances he has facilitated communications from those academics. What conflicts of interest do us academics have then? The Biobank people do try to make sure there are sandwiches at meetings, but last time we had to make do with instant coffee! (The cakey things were good though.)

Jonathan Edwards, 15 minutes ago Report Bookmark

#140 Like + Multiquote Reply



Anton Mayer

@MECFSNews



Jonathan Edwards take on Sharpe's tweets
s4me.info/threads/michae...

8:17 PM - Apr 15, 2018



26



See Anton Mayer's other Tweets

Indigophoton, Apr 15, 2018 Report Bookmark

#149 Like + Multiquote Reply



Sly Saint
Senior Member
(Voting Rights)

Messages: 1,206

Likes Received: 9,614

trials and gave up after a few months. Done
d now I've learned to live with and understand
ed it to people who suffer with this.

an hour or 2 in the hospital and 2 busses back,
ated by people who have no understanding of

My initial blood tests showed some signs of infection and inflammation so I was sent for another set which apparently didn't, so I could be accepted into the trial. The assessment/criteria forms which had to be filled out at the before and during the trial, did not mention symptoms after exertion or delayed onset fatigue, there was very little attention paid to pain and cognitive/mental issues were very blurred.

At the start of the trial, I had to wear an accelerometer thing for a week, presumably to measure activity levels. But at the end of the trial, this wasn't repeated. The fitness tests measured the number of steps I could do in a set amount of time, but paid no attention to the fact that I usually couldn't walk for 2 days after these assessments.

The 'handbook' I was given contained an incredibly flawed model, which GET is based on, which basically goes 'felt a bit ill - led to resting too much - led to deconditioning - led to the ME/CFS symptoms'. This completely ignores the fact that the vast majority of people don't rest early on and carry on pushing themselves despite severe pain and fatigue.

pls and they didn't help me. What is very worry
st for people with mild to moderate M.E. and not S
s are still too often being referred to clinics to take
Whilst pacing can help patients they are often push
aving a relapse. I read just recently about a man w
trials and ended up being bedridden for a year an

d) After I told the therapist that I was disengaging from the trial, he phoned me 3 times to attend a meeting with him - although it states that you can leave the trial at any time and don't even have to give a reason. Although the therapist had said the purpose of the meeting was to wish me well for my future, he was very angry and defensive at the meeting due to me disengaging; he obviously had pressure on him to keep his numbers up - but that was no reason to treat me in such a way.

e) It was quite apparent during the 6 sessions I had with the therapist that he was more interested in his research findings than genuinely helping me and my CFS. All in all I found the whole experience to be quite damaging, particularly as my expectations were falsely raised and the therapist behaved quite unethically at the last meeting - no doubt due to pressure upon him to get the desired results via his research subjects. I think it is incorrect for Action for ME to support and endorse such a trial, and am most disappointed that it does so.



Adam
@Adam_Bombe



More comments from participants of the PACE trial...

thinking of you Michael...

11:11 PM - Apr 15, 2018

♡ 73 🗨 46 people are talking about this

Sly Saint, Apr 16, 2018 Report Bookmark

#160 Like + Multiquote Reply



Art Vandelay

Established
Member (Voting
Rights)

Messages: 32

Likes Received: 376

Location:
Adelaide, Australia



Cheshire @cheshfr

9 Apr

Replying to @profmsharpe

Dear Michael,
Like many patients, I read the "actual papers", to make an informed decision.

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- To be able to improve significantly my walking capacities
- To go back to work.

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michael sharpe

@profmsharpe



Glad you read it. And I understand your wishes. However those were not the primary outcomes. It is a trial not a policy. The results are what they are.

9:43 AM - Apr 15, 2018



See michael sharpe's other Tweets



Sharpe is trying to absolve himself of further responsibility here, however he and his fellow authors should also be held to account for their conduct after the trial was released.



Indigophoton

Senior Member
(Voting Rights)

Messages: 674

Likes Received: 7,168

Location: UK

Some more of the ongoing conversation, for those not on Twitter.



Robert McMullen @RobertHMcMullen

15 Apr

Replying to @profmsharpe and 2 others

Please could you explain why you decided to drop actigraphy as an outcome measure?

Please could you also respond to Prof Edwards's criticisms – particularly his concern about the trial's reliance on subjective outcome measures?

journals.sagepub.com/doi/full/10.11...

Thank you pic.twitter.com/hZM0nvnyfH



michael sharpe

@profmsharpe



Actigraphy was dropped to reduce participant burden. Patient rated outcomes were used because that is how the illness is defined. Truly objective outcomes don't exist. The key finding is DIFFERENCE between arms - e.g. GET and pacing even though pacing was more credible.

7:26 PM - Apr 15, 2018



See michael sharpe's other Tweets



And @Adam pwme has been blocked,



Adam @Adam_Bombe

15 Apr

Oh dear blocked by Michael...
[twitter.com/adam_bombe/sta...](https://twitter.com/adam_bombe/status/984123456789012345)
pic.twitter.com/A6TzuA4xGz



Anton Mayer
@MECFSNews



The blocked by Sharpe club is growing rapidly.
9:23 PM - Apr 15, 2018

7 See Anton Mayer's other Tweets



Indigophoton, Apr 16, 2018 Report Bookmark

#182 Like + Multiquote Reply



Indigophoton
Senior Member
(Voting Rights)

Messages: 674

Likes Received: 7,168

Location: UK

davidtuller @davidtuller1 - Feb 23
@profmsharpe Michael, you're losing the debate. You relaxed your criteria for publication, got better-looking results. Then you refused to provide data and called patients "vexatious." But things have changed. Everyone can see PACE is a five-million-pound disaster.

15 108 235

michael sharpe
@profmsharpe

to @davidtuller1 @MFAssociation @CMonaghanSNP

Dr Tuller. That is what you are paid to say. Unfortunately for you it is not true. But you hope that endless repetition will eventually make it so.

1 - 14 Apr 2018

Journal of Health Psychology

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Commentary on the PACE trial: Biased methods and unreliability

14 June 2017 | Research Article | Check for updates

PDF Article information

In the year 2016, outlines a range of controversies surrounding publication of the PACE trial and discusses a freedom of information case brought by a patient data from the trial. The PACE authors offer a response, writing 'Dr Geraghty on misunderstandings and misrepresentations of the PACE trial'. This article commentaries to further detail the critical methodological failures and biases of the trial, which undermine the reliability and credibility of the major findings to date.



Dr Keith Geraghty
@keithgeraghty



PACE author, Sharpe, who has worked for insurance industry, accuses Berkeley academic who crowdfunds, of being paid by patient community to say #PACEtrial is bad. Am I and many other academics also being paid to say the same?
journals.sagepub.com/doi/full/10.1181/0962280217701611111... ..denial isnt science

12:38 PM - Apr 16, 2018

108 55 people are talking about this

Indigophoton, Apr 16, 2018 Report Bookmark

#183 Like + Multiquote Reply



Robert 1973
Senior Member
(Voting Rights)

Messages: 125
Likes Received: 1,836
Location: UK



michael sharpe @profmsharpe

7 Apr

No. The PACE trial was a clinical trial - all a trial does is compare treatments. That's it. It is not a policy or a conspiracy. Just a trial..



Robert McMullen
@RobertHMcMullen



So was Richard Horton wrong when he said that it was a test of two philosophies – whether CFS is “an organic disease” or whether it is “entirely reversible” with CBT? meassociation.org.uk/2011/04/profes...
pic.twitter.com/CQ8yCWywe

2:25 PM - Apr 8, 2018

Richard Horton is Editor in Chief of The Lancet.

Richard Horton: We were delighted to get this trial, it was eagerly awaited. It was a remarkable study because the investigators stepped back and were willing to do an experiment comparing conventional treatments for chronic fatigue, cognitive behavioural therapy for example against treatment which was very much endorsed by parts of the patient community but very sceptically received by the more scientific community and that was the adaptive pacing therapy. So they were really stepping back and comparing two philosophies, not just two treatments, two philosophies of what chronic fatigue syndrome was.

[View image](#)

Norman Swan: In other words whether or not you can be rehabilitated to some extent and whether or not you should actually just adapt to the condition.

Richard Horton: Yeah, I mean adaptive pacing therapy essentially believes that chronic fatigue is an organic disease which is not reversible by changes in behaviour. Whereas cognitive behaviour therapy obviously believes that chronic fatigue is entirely reversible and these two philosophies are kind of facing off against one another in the patient community and what these scientists were trying to do is to say well, let's see, which one is right.

♥ 26 See Robert McMullen's other Tweets





Robert McMullen
@RobertHMcMullen



. @profmsharpe Please can you answer this question? Was the #PACEtrial a test of two philosophies? If so, what is the conclusion? Is ME/CFS an organic disease or is it entirely reversible with CBT?

Robert McMullen @RobertHMcMullen
Replying to @profmsharpe and 3 others

So was Richard Horton wrong when he said that it was a test of two philosophies – whether CFS is “an organic disease” or whether it is “entirely reversible” with CBT? meassociation.org.uk/2011/04/profes...

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5:31 PM - Apr 10, 2018

♡ 12 👤 See Robert McMullen's other Tweets





michael sharpe @profmsharpe

10 Apr

Replying to @RobertHMcMullen

A trial can only compare treatments. Treatments may reflect aetiological models. But a trial only compares treatments. A single experiment. That's all.



Robert McMullen

@RobertHMcMullen



Are you saying that Richard Horton was wrong? If so, why didn't you correct him during the interview?

Would you agree that the PACE trial provides good evidence that ME/CFS is not "entirely reversible" by CBT?

10:52 PM - Apr 10, 2018



9



See Robert McMullen's other Tweets



Robert 1973, Apr 17, 2018 [Report](#) [Bookmark](#)

#191 [Like](#) [+ Multiquote](#) [Reply](#)



Robert 1973

Senior Member
(Voting Rights)

Messages: 125

Likes Received: 1,836

Location: UK



michael sharpe @profmsharpe

15 Apr

Replying to @thegodofpleasur @MECFSNews

Can you be specific please. ?



Robert McMullen

@RobertHMcMullen



Please could you explain why you decided to drop actigraphy as an outcome measure?

Please could you also respond to Prof Edwards's criticisms – particularly his concern about the trial's reliance on subjective outcome measures?

[journals.sagepub.com/doi/full/10.11...](http://journals.sagepub.com/doi/full/10.1177/1463426918771117)

[http://journals.sagepub.com/doi/full/10.117](http://journals.sagepub.com/doi/full/10.1177/1463426918771117)

Thank you pic.twitter.com/hZM0nvnyfH

7:10 PM - Apr 15, 2018

Abstract

The PACE trial of cognitive behavioural therapy and graded exercise therapy for chronic fatigue syndrome/myalgic encephalomyelitis has raised serious questions about research methodology. An editorial article by Geraghty gives a fair account of the problems involved, if anything understating the case. The response by White et al. fails to address the key design flaw, of an unblinded study with subjective outcome measures, apparently demonstrating a lack of understanding of basic trial design requirements. The failure of the academic community to recognise the weakness of trials of this type suggests that a major overhaul of quality control is needed.



8



See Robert McMullen's other Tweets





michael sharpe @profmsharpe

15 Apr

Replying to @RobertHMcMullen and 2 others

Actigraphy was dropped to reduce participant burden. Patient rated outcomes were used because that is how the illness is defined. Truly objective outcomes don't exist. The key finding is DIFFERENCE between arms - e.g. GET and pacing even though pacing was more credible.



Robert McMullen

@RobertHMcMullen



Actigraphy would have been an objective measure. Do you concede that dropping actigraphy was a mistake?

12:00 PM - Apr 16, 2018



15



See Robert McMullen's other Tweets





Robert McMullen @RobertHMcMullen

16 Apr

Replying to @RobertHMcMullen and 3 others

Why do the TSC minutes not mention the burden on patients? Why were actometers considered too burdensome for measuring outcomes (when patients were supposedly improved) but not at baseline? (I am severe. I would be happy to wear an actometer but could no way do step test etc.)



Robert McMullen

@RobertHMcMullen



TSC minutes state actigraphy was dropped because the Dutch trial suggested it was not "useful". There is no mention of the burden. Was it considered not useful because it was likely to produce a null result? Please can you explain what was meant by not useful.

12:10 PM - Apr 16, 2018

♥ 25 👤 See Robert McMullen's other Tweets



I will try to get him to answer some of the unanswered questions.

Robert 1973, Apr 17, 2018 Report Bookmark

#192 Like + Multiquote Reply