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"



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..

0

2:21 PM - Apr 8, 2018



Lucibee Senior Member (Voting Rights)

Messages: 248

Likes Received: 2,510

Location: Mid-Wales

He's still going...



Cheshire @cheshfr

Replying to @profmsharpe

Dear Michael,

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

What matters to me is:

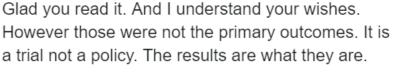
- To be able to improve significantly my walking capacities
- To go back to work.

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



michael sharpe

@profmsharpe



9:43 AM - Apr 15, 2018



See michael sharpe's other Tweets

0

9 Apr

Lucibee, Apr 15, 2018 Report Bookmark

#108 Like + Multiquote Reply



Indigophoton Senior Member (Voting Rights)

Messages: 674

Likes Received:

7,167

UK Location:



uab9876 @uab9876

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



15 Apr

@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

0



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)

248 Messages:

Likes Received:

2,510

Location: Mid-Wales



uab9876 @uab9876

15 Apr

Replying to @profmsharpe @cheshfr So if PACE doesn't answer important questions was

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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!

Lucibee, Apr 15, 2018 Report Bookmark

#134 Like + Multiquote Reply



Barry Senior Member (Voting Rights)

Messages: 2,281 Likes Received:

14,681





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

 \bigcirc 77 \bigcirc 18 people are talking about this





Sten Helmfrid @StenHelmfrid · Apr 12 What conflict of interest?

Q 1 1



michael sharpe @profmsharpe · Apr 12 Seeking money to promote a particular view point.

Q 3 17 0 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

Replying to @profmsharpe

Dear Michael,

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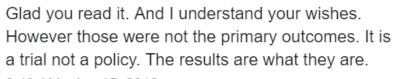
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michael sharpe

@profmsharpe



9:43 AM - Apr 15, 2018



See michael sharpe's other Tweets

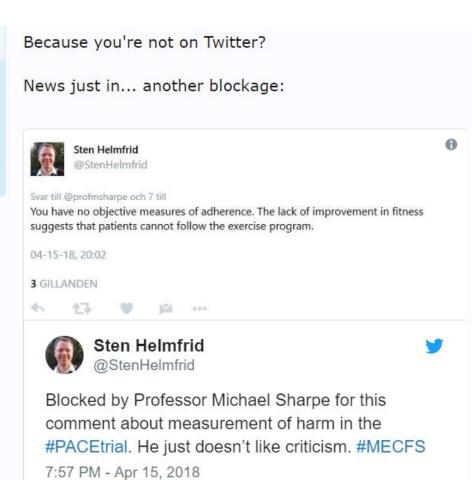
0

9 Apr

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





92 930 people are talking about this

#145 Like + Multiquote Reply

Lucibee, Apr 15, 2018 Report Bookmark

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

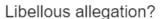
Replying to @MECFSNews

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



Paul Watton

@thegodofpleasur



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?

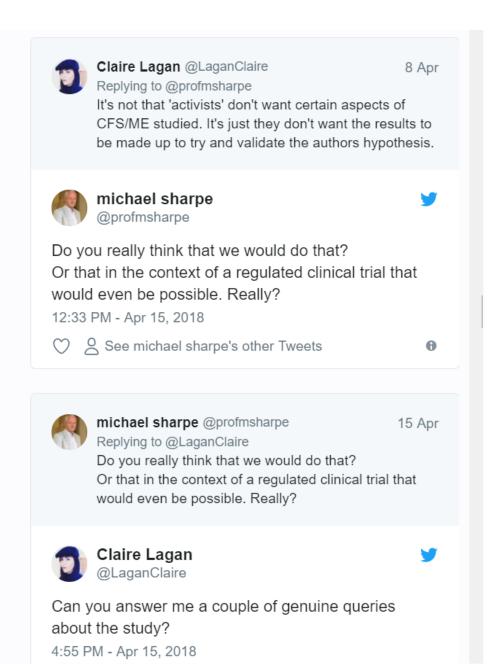
Will you please address the criticisms of PACE directly for once?

4:39 PM - Apr 15, 2018

0



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



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



John Peters @johnthejack Replying to @StenHelmfrid

15 Apr

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

0

Indigophoton, Apr 15, 2018 Report Bookmark

#147 Like + Multiquote Reply



Indigophoton Senior Member (Voting Rights)

674 Messages:

7,167

UK

Location:

Likes Received:

(Voting Rights) 1,139 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



Jonathan Edwards

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 uls and they didn't help me.What is very worry of a now I've learned to live with and understand for people with mild to moderate M.E. and not S is are still too often being referred to clinics to take whilst pacing can help patients they are often push an hour or 2 in the hospital and 2 busses back.

an hour or 2 in the hospital and 2 busses back, trials and ended up being bedridden for a year an ated by people who have no understanding of

My initial blood tests showed some signs of injection and inflammation so I was sent for another set which apparently didn't, so I could be accepted into the trial. The assessmentscriteria forms which had to be filled out at the before and during the trial, did not mention synthesis after certain or adelayed onter flugiate, there was very little attention poid to pain and cognitive/mental issues were very blurred.

At the start of the trial, I had to wear on occelerometor thing for a week, presumably to measure activity levels. But at the end of the trial, this wasn't repeated. The finess 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 wolk for 2 days after these assessments.

The 'handbook' I was given contained an incredibly flowed model, which GET is based on, which basically goes 'fet a bit III - led to resting non much - led to decenditioning - led to the ME/CFS symptoms'. This completely ignores the fact that the vast majority of people dos's rest early on and carry on pushing memselves despite severe pain and fatigue.

d) After 1 iold the therapist that 1 was disengaging from the triat, he phoned ne 3 rines to attend a meeting with him -adhough it states that you can leave the trial or any time and don't even how to give a mann. Although the therapist had said the purpose of the meeting was to with ne well for my future, he was very analy and definitive at the meeting due to me divergaging; be 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 apported during the 6 sessions I had with the therupist that be was more interested in his research findings than genuinely halping me and my CFS. All in all I found the whole experience to be quite damaging, perfectability as my expectations were foliative reased and the threpsite belowed quite untrivially of the last meeting—no dudued 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 an most disappointed that is 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



Member (Voting Rights)

Messages: 32 Likes Received: 376

Location:

Adelaide, Australia



Cheshire @cheshfr

Replying to @profmsharpe

Dear Michael,

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What matters to me is:

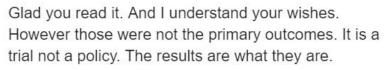
- To be able to improve significantly my walking capacities
- To go back to work.

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



michael sharpe

@profmsharpe



9:43 AM - Apr 15, 2018



See michael sharpe's other Tweets

0

9 Apr

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:

Likes Received:

Location: UK

7,168

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

0

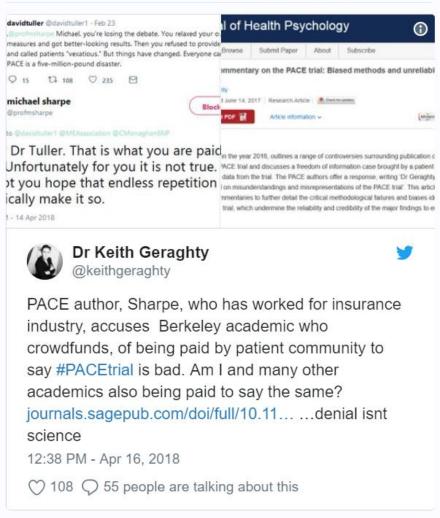
And @Adam pwme has been blocked,



#182 Like + Multiquote Reply

#183 Like + Multiquote Reply





Indigophoton, Apr 16, 2018 Report Bookmark



Robert 1973

Senior Member (Voting Rights)

Messages:

Likes Received:

1,836

Location:



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/CQ8yCWywre

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. View image 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.

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







. @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

v



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

0

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/10.117

Thank you pic.twitter.com/hZMOnvnyfH

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



tna / /+ aa /=\/|+a2hhhn



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







Robert McMullen @RobertHMcMullen Replying to @RobertHMcMullen and 3 others

16 Apr

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 actomter 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