

Tweets from 8th set of 100 posts in S4ME thread: Michael Sharpe skewered by @JohntheJack on Twitter



Indigophoton
Senior Member
(Voting Rights)

Messages: 688
Likes Received: 7,492
Location: UK

For sure. He's still absolutely wedded to the conviction that it was a good trial, and it's just a few people being partisan and emotional that is the problem:



FionaPWME @FionaPWME

2 Jun

Replying to @profmsharpe and 2 others

Which trials don't? I presume you mean primarily the PACE trial - which has been exposed for (among other things) lax patient selection, and changing the outcome parameters midway through so patients could be worse than when they started and still be recovered?



michael sharpe
@profmsharpe



Actually it hasn't. That has been alleged by those who don't like the findings.

2:49 PM - Jun 2, 2018

1 See michael sharpe's other Tweets

He knows, he just dismisses the majority of the academics as unqualified to judge, and biased - full (start) of thread for context, not that it makes any difference -



Jacquie Wilson 🦋
@MEwarrior_au



This article is bloody BRILLIANT!!! I couldn't agree more!
[#MillionsMissing](#) [#PWME](#) [#PACEtrial](#) [@WesselyS](#)
[@profmsharpe](#) Peter D White, Esther Crawley, Trudie Chalder

Tapanui 'Flu ('Tui Tapanui') @TapanuiFlu

Just tumbled across this excellent 2007 letter to the BMJ, written by a retired Wellington #NZ psychiatrist responding to Peter White et al. Yet #Wellington neuros are still ignoring #MyalgicE & our local health board only offers #CBT & #GET to #pwmeNZ 🙄 bmj.com/rapid-response...

1:06 PM - May 30, 2018

3 See Jacquie Wilson 🦋's other Tweets



michael sharpe @profmsharpe

31 May

Replying to @MEwarrior_au @WesselyS

Thank you. Do you think that ME activism is the new anti-psychiatry?



Jacquie Wilson

@MEwarrior_au



I've nothing against psychiatrists if they stick to their field. As the article in BMJ says, "We as psychiatrists should spend more time helping patients with a mental health problem instead of wasting valuable time and resources on a neurological illness."

4:48 PM - May 31, 2018



1



See Jacquie Wilson 's other Tweets



CFS Research @cfs_research

31 May

Replying to @MEwarrior_au and 2 others

Actually, depression is very common in MS (20% annual and 50% lifetime incidence), and CBT is helpful.



Jacquie Wilson

@MEwarrior_au



CBT can be helpful for many things. But NOT as is used in PACE Trial to rid oneself of (so-called) 'false illness beliefs'. ME is a biological disease as is constantly being proven by research.

6:02 PM - May 31, 2018



See Jacquie Wilson 's other Tweets





Jacquie Wilson  @MEwarrior_au

1 Jun

Replying to @cfs_research and 2 others

The results of the PACE Trial were found by many, many scientists to be flawed. Read David Tuller's blogs at:virology.ws/mecfs/

So if that's what you are suggesting, @cfs_research then, no thanks!! Too many I know have got worse on GET.



michael sharpe

@profmsharpe



Well a subset of scientists, mostly not experts in trials, at least some of who have pretty strong feelings about the findings. How many trial experts do you think find it a good trial - not perfect but good?

1:46 PM - Jun 1, 2018



3



See michael sharpe's other Tweets



I was quite astonished by that remark.

Eta: quote.

Last edited: Jun 4, 2018

Indigophoton, Jun 4, 2018 Report Bookmark

#703 Like + Multiquote Reply



Esther12

Senior Member
(Voting Rights)

Messages: 1,608

Likes Received:
12,787

That David Jameson account comes out with some stuff.



Janelle Wiley @janwly

4 Jun

Replying to @janwly and 8 others

However, CBT and GET have been studied repeatedly in trials. And unable to demonstrate any realistic good effect, such as return to work, less need for home help or medical care, able to walk a clinically important amount (after PACE, less than avg in Class III heart failure).



CFS Research

@cfs_research



PACE didn't look at work status, but @profmsharpe's 1996 study found that CBT significantly improved employment status. For a review, see citeseerx.ist.psu.edu/viewdoc/download...

5:44 PM - Jun 4, 2018



1



See CFS Research's other Tweets





strategist

Senior Member
(Voting Rights)

Messages: 511

Likes Received: 5,210

Assuming there is a plan and goal behind Sharpe's activity on twitter, it's probably related to this (it's today by the way)



#MEAction Network UK

@MEActNetUK



Watch Parliament Live tomorrow from 2.30pm!

The application by @CMonaghanSNP

to the Backbench Business Committee of the House of Commons

for a debate on #ME is live on parliament TV tomorrow.

It would be AMAZING if this were granted![#canyouseeMEnow parliamentlive.tv/Event/Index/50...](http://canyouseeMEnow.parliamentlive.tv/Event/Index/50...)

9:20 PM - Jun 4, 2018

♡ 105 💬 77 people are talking about this



We have to remember that what we observe is not nature in itself, but nature exposed to our method of questioning.

strategist, Jun 5, 2018 Report Bookmark

#719 Like + Multiquote Reply



Lucibee

Senior Member
(Voting Rights)

Messages: 259

Likes Received: 2,694

Location: Mid-Wales

Another reminder that this thread is publicly viewable:



Anton Mayer @MECFNews

5 Jun

More #pacetrial comments by Prof. Jonathan Edwards: on the reason for the difference in responses between treatment arms. pic.twitter.com/iKPynFCi8t



michael sharpe

@profmsharpe



'He does not get scientific methodology' What a bizarre and offensive comment for a (long retired) medical academic to make about any colleague.

7:58 AM - Jun 5, 2018

♡ 1 👤 See michael sharpe's other Tweets



Lucibee, Jun 5, 2018 Report Bookmark

#722 Like + Multiquote Reply



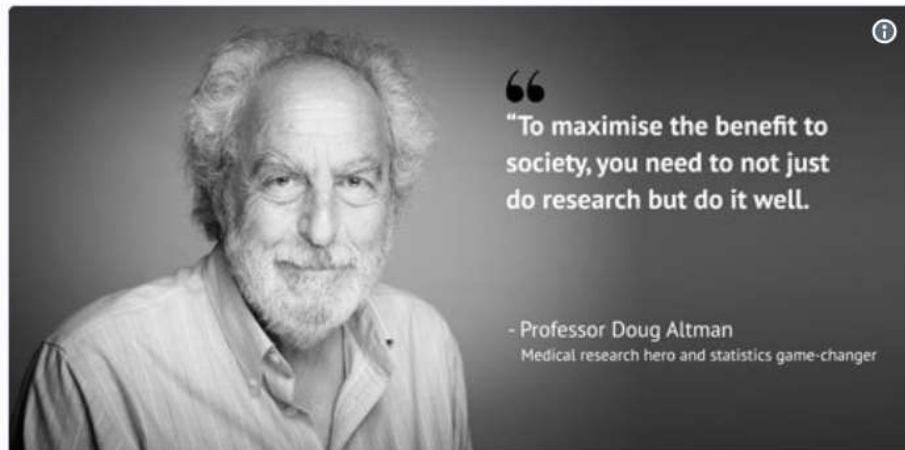
Sly Saint

Senior Member
(Voting Rights)

Messages: 1,217

Likes Received:
9,713

retweeted by Simon Wessely:



NDORMS

@ndorms



It is with great sadness we share the news of Professor Doug Altman's passing. Medical research and statistics have lost one of their greatest. Thank you, Doug, for all you gave to research and the world.

5:11 PM - Jun 3, 2018

♡ 900 💬 745 people are talking about this

again.....as with Sharpe quoting Feynman....

"

The scandal of poor medical research

Pechius

Established
Member (Voting
Rights)

Messages: 45
Likes Received: 287

They may be beginning to realise it slowly, but just refuse to admit it to themselves due to various reasons. I think they will never ever change their opinion on it, because that's what they believed all their life. It's almost impossible.



FionaPWME @FionaPWME

2 Jun

Replying to @profmsharpe and 2 others

Which trials don't? I presume you mean primarily the PACE trial - which has been exposed for (among other things) lax patient selection, and changing the outcome parameters midway through so patients could be worse than when they started and still be recovered?



michael sharpe

@profmsharpe



Actually it hasn't. That has been alleged by those who don't like the findings.

2:49 PM - Jun 2, 2018



1



See michael sharpe's other Tweets



Anton Mayer @MECFNews

1 Jun

Replying to @pechius and 4 others

It's just an ordinary placebo response that the authors refuse to interpret as such.



michael sharpe

@profmsharpe



But. First what do you mean by placebo? Second the PACE Trial compared 3 time and credibility matched interventions and got a differential response. Why ?

3:59 PM - Jun 2, 2018



1



See michael sharpe's other Tweets



This is a good question from Sharpe. What is placebo??

I'm assuming that in their mind, it's ok to use placebo(forcing patients to think they're ok, believing that exercise will cure them), because hey, patients aren't really sick, right? What's the harm?



Indigophoton
Senior Member
(Voting Rights)

Messages: 688
Likes Received: 7,492
Location: UK



Jonathan Edwards
Senior Member
(Voting Rights)

Messages: 1,366
Likes Received: 15,627

'Well a subset of scientists, mostly not experts in trials, at least some of who have pret strong feelings about the findings. How many trial experts do you think find it a good trial - not perfect but good? '

I think having devised and executed many trials including one where I did both published in NEJM I can consider myself an expert on trials (with absolutely no feelings about the findings, just the way they were obtained). But you do not actually have to be an expert on trials to see that PACE is rubbish - just a bog standard junior registrar who listens at journal club.

I don't know of any disinterested experts on trials who think PACE is competent.

Jonathan Edwards, Yesterday at 11:34 PM Report Bookmark #712 Like + Multiquote Reply



Anton Mayer
@MECFSNews



Prof Jonathan Edwards responds again to a comment by M Sharpe. "You do not have to be an expert to see that the #PACEtrial is rubbish."

1:41 PM - Jun 5, 2018

♡ 56 💬 20 people are talking about this

Indigophoton, Jun 5, 2018 Report Bookmark #746 Like + Multiquote Reply



Indigophoton
Senior Member
(Voting Rights)

Messages: 688
Likes Received: 7,492
Location: UK

Sharpe's logic skewered again by @JohnTheJack:



michael sharpe @profmsharpe

5 Jun

Replying to @Solace92109577

Lot of confusion here. CBT and GET are collaborative treatment where increases in activity are very cautious and gradual and at the patients own pace. This is not enforced activity or just ignoring symptoms. I agree that would likely make people worse.



John Peters
@johnthejack



The pre-trial protocol states the essence of Graded Exercise Therapy is that planned physical activity, and not symptoms, determines what patients are asked to do. So it may be tailored to the patient but it is not at the patient's own pace as that would normally be understood.

5:58 PM - Jun 5, 2018

♡ 17 👤 See John Peters's other Tweets





michael sharpe @profmsharpe

5 Jun

Replying to @Solace92109577

Lot of confusion here. CBT and GET are collaborative treatment where increases in activity are very cautious and gradual and at the patients own pace. This is not enforced activity or just ignoring symptoms. I agree that would likely make people worse.



John Peters

@johnthejack



As for CBT, since the illness is perpetuated by the patient's misinterpretation of bodily sensations, how can they dictate the pace of increase?

6:14 PM - Jun 5, 2018



20



See John Peters's other Tweets



Indigophoton, Jun 5, 2018 Report Bookmark

#749 Unlike + Multiquote Reply



Indigophoton

Senior Member
(Voting Rights)

Messages: 688

Likes Received: 7,492

Location: UK



michael sharpe @profmsharpe · 10 h

In risposta a @MECFSNews

'He does not get scientific methodology' What a bizarre and offensive comment for a (long retired) medical academic to make about any colleague.



1



Jonathan Edwards
Senior Member
(Voting Rights)

Messages: 1,367

Likes Received: 15,642

'What a bizarre and offensive comment for a (long retired) medical academic to make about any colleague.'

When a medical academic persistently makes offensive comments about their patients and refuses to accept that their work has fallen seriously below basic standards of methodology I cannot see anything bizarre or inappropriate about calling them out. Are we intended to infer that the old boy Oxford network should apply and that academics should not blow the whistle on 'colleagues' when needed?

I am not sure that eight years counts as all that long, especially if the last five have been devoted to studying and advising on research in ME/CFS.

Jonathan Edwards, 35 minutes ago Report Bookmark

#747 Like + Multiquote Re



Anton Mayer

@MECFSNews



Even more by Prof. Edwards

5:51 PM - Jun 5, 2018

[View image on Twitter](#)



75



35 people are talking about this



Dr Keith Geraghty
@keithgeraghty



Im not retired and I share Prof Edward's view that the PACE trial was seriously flawed and a poor standard. My recent review of trial meeting minutes has shocked me - methods were crafted as trial went along to fit the whims of the trialist. We can learn from PACE #hownottodoit

Anton Mayer @MECFNews

Even more by Prof. Edwards



michael sharpe @profmsharpe · 10 h

In risposta a @MECFNews

'He does not get scientific methodology' What a bizarre and offensive comment for a (long retired) medical academic to make about any colleague.



Jonathan Edwards
Senior Member
(Voting Rights)

Messages: 1,367
Likes Received: 15,642

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Jonathan Edwards, 35 minutes ago Report Bookmark

#747 Like + Multiquote Rej

8:14 PM - Jun 5, 2018

♡ 186 💬 89 people are talking about this



Indigophoton

Senior Member
(Voting Rights)

Messages: 688

Likes Received: 7,495

Location: UK

I think Sharpe might actually agree with this:



David 'Stix' Trowt @CelticSeaWolf

6 Jun

Replying to @cfs_research and 8 others

I have completed a GET program, recently. I complied with all advice on that program and did not let that my symptoms were worsening stop me trying. I am now far more disabled than I have ever been as a result. I recorded all that I did too, if GET doesn't harm, please explain?



CFS Research

@cfs_research



I agree that the advice to continue with GET and push through symptoms is misguided, although it probably depends on the symptoms (e.g. PEM not ok, DOMS ok to push through a bit). Really need a therapist who truly understands CFS.

4:12 PM - Jun 6, 2018



See CFS Research's other Tweets



CFS Research @cfs_research

6 Jun

Replying to @CelticSeaWolf and 8 others

I agree that the advice to continue with GET and push through symptoms is misguided, although it probably depends on the symptoms (e.g. PEM not ok, DOMS ok to push through a bit). Really need a therapist who truly understands CFS.



michael sharpe

@profmsharpe



I suspect skill in application may explain some of the difference between trial and practice.

4:17 PM - Jun 6, 2018



1



See michael sharpe's other Tweets





Indigophoton

Senior Member
(Voting Rights)

Messages: 688

Likes Received: 7,495

Location: UK



Heath @MEawareness

8 Jun

Replying to @wilshica @johnamuir

The problems for many patients is feeling like a burden & hopelessness. #PACEtrial authors/collaborators created hopelessness using deceit, to incite patient blame & enable policies which deny treatment & support. How #PWME endure disease discrimination is extraordinary.



michael sharpe

@profmsharpe



Whilst I sympathize with those feelings it is not logical to blame it on a trial. If the trial had never happened it would be the same.

8:09 AM - Jun 8, 2018



See michael sharpe's other Tweets



This is taking disingenuousness to a new level.

Why defend it so much if he thinks PACE is of no consequence?

Indigophoton, Jun 8, 2018 Report Bookmark

#785 Like + Multiquote Reply



Lucibee
Senior Member
(Voting Rights)
Messages: 259
Likes Received: 2,694
Location: Mid-Wales

Oh great. SW's joining in now...



Lucibee @Lucibee · Jun 7
Looks like you've unlocked an achievement there...
(but I screenshotted the tweet)



michael sharpe
@profmsharpe

Replying to @wilshica @Lucibee and 4 others

There is no model underlying a trial. The trial compared four treatments each with its own model if you will. Keep up.

6:41 AM - 7 Jun 2018

1 4 14



Claudia Gillberg @DrCSGillberg · Jun 8
What a gem. His tweets lay bare the irrational and unethical mindset behind PACE. A glimpse of 'the banality of evil', considering the many horrendous consequences of that trial.

2 2 7



Simon Wessely
@WesselyS

Follow

Replying to @DrCSGillberg @Lucibee and 2 others

Putting to one side a further example of my school friend @sfnemonic famous Law, what have been the 'horrendous' consequences of the trial, since its publication in 2011? I don't think it changed clinical practice in the UK, but perhaps it did elsewhere?

3:33 PM - 9 Jun 2018

1 1 1



Cheshire
Senior Member
(Voting Rights)
Messages: 503
Likes Received: 5,936



michael sharpe
@profmsharpe

The implicit moral meanings of calling an illness 'mental' that still blight understanding and acceptance

1. Not real or deserving of sympathy.
2. Your own fault you are ill
3. Up to you to get better.

7:47 PM - Jun 9, 2018

12 See michael sharpe's other Tweets

Cheshire, Jun 9, 2018 Report Bookmark

#798 Like + Multiquote Reply