

A SKEPTICAL LOOK AT THE PACE CHRONIC FATIGUE TRIAL

JAMES C. COYNE PHD

16 NOVEMBER 2015

Part 1

00:00 Slide 1: A skeptical look at the PACE chronic fatigue trial

I'm Jim Coyne, I go by Jim and you can interrupt me at any time or we could go through the slides and have a discussion afterwards, we can just play it by ear.

But the title is "A skeptical look at the PACE chronic fatigue trial"

00:31 Slide 2: Special thanks

And as I go to my . . . among the things that you'll learn about me, is I'm a bit dyslexic and I notice my first misspelling, of Tom's last name, dropped the L. Tom, forgive me. There are a lot of people I should be giving special thanks to including the group that organised this. And at the risk of leaving lots of people out, I just wanted to name some people associated with me getting involved.

For a while I've been working with Julie Rehmeyer, you saw her Slate article recently, and I've been working on some positive psychology book that she's working on, and her illness never came up that much before. She began mentioning it and I mentioned that I'd been learning about it from Tom and it was on my list to eventually get around to writing about, but I was going to be concentrating more on positive psychology, how much pseudo-science is involved in positive psychology, how many of the practitioners, the coaches, don't get any formal training in psychology or in research, but they're going out and finding research findings. I thought, there are groups to be educated about that.

I took advantage of a trip to Australia to give a keynote at national skeptics gathering on positive psychology and I was working on my e-book and then Julie started agitating me in a gentle way and I made contact with David Tuller and then it just happened, Michael Sharpe pissed me off with a tweet and I announced that I was going to jump into the fight.

Now Michael Sharpe and I have a bit of a background, he was at the Royal Ed and I remember going out and between us we drank two bottles of wine and he said he was going to patch up my relationship with Simon who was angry at me when I was poking fun at him in an article about his military work, history work about PTSD - Simon Wessely - and he's a key figure in this.

And so Simon had written some stuff, that he'd gone through all the records from the Boer War and found in the medical records no mention of there being anything looking like PTSD and maybe it was a recent invention. And so I poked fun at that and said, I'll bet the records didn't mention any of the British troops masturbating – so maybe they were just good old boys who hadn't discovered that yet – if you have to go literally with what's in the record. And that there was a problem with that methodology. It was more just as a joke but he took it very seriously and so Michael said he'd resolve Simon's dislike for me. But Simon insists that he's forgotten about that.

3:37 Slide 3: Government orders release of PACE trial data

Anyway, but then came the October 27th decision by the Information Commissioner's Office to release the PACE data and I thought that was an historic moment. That once it had gotten so public that the data had even been withheld there was no turning back. And then there was a petition.

4:04 Slide 4: St. Nicholas Church open to all

And I spend a lot of time in Leipzig and the sign is still there on the church: "St Nicholas Church Open to All", and it was an historic moment in which that was put up in, I think it was 1989?

And so what happened is the crowds were gathering out there, they were protesting the East German government in its oppressiveness, and they were agitating and just wandering around out there, and they started beating then, and the Secret Police came and started taking some away and the pastor just hung the sign out, the church is now a refuge, the church is open. And it was sort of unclear with what authority the East German government did recognise the church but it was declared in mediaeval terms a refuge, and that would set off a series of events where the protestors were protected and then the Secret Police came in and they wanted to stop being Secret Police and the wall came down within days.

And I think a similar thing is going on. It doesn't matter whether the decision is appealed by the Commissioner. It doesn't matter whether this (?) publishes the letter and I'm not sure they will, but I think the conversation has changed, and people are going to be treated differently and words are going to take on a different meaning.

And it just was at that moment that I was stepping in not knowing any of these events were going to happen. I blogged a couple of blogs which I'll come back to.

5:41 Slide 5: Mind the Brain

The first one talked about the fatal flaws in the PACE chronic fatigue trial. The second one made an argument that the scientific community needed the PACE data released.

5:57 Slide 6: Where did this come from?

Before that, all people knew about me, certainly in the patient community, was this tweet: "I've had it. Sharpe quotes are offensive. Will lay waste to PACE" and so here I am and I'll explain a little bit more about how I got here.

6:13 Slide 7: About me (1)

I've published over 350 papers; I have over 35,000 citations. I think these kind of metrics are very silly but people take them very seriously. I've... that H index of 84 ranks me above many Nobel Prize winners just because they have different patterns of publishing. Certainly ahead of all the PACE investigators, but I'd like to think I'm not being an intellectual bully because there are more of them.

And I certainly agreed that they all could come to a debate that Mental Elf was going to hold, but they somehow couldn't fit it in their schedule. But I do have a standing, I do have a credibility and that makes me different than the patients who have been so neutralised. And it's really frustrating to me that many of the things that I'm saying that are taken so seriously are things that patients have said before and they weren't taken seriously. And that's something we've got to change. It pisses me off.

I'm an academic editor of PLOS One, that's not a big deal, it's an open access journal, there are 4,800 of us editors, we turned out 24,000 papers last year; 6% of all the papers published in PubMed are published in our journal. But I've used my role as editor to push them about issues, and what I've just done is file a formal request for the data from the PACE trial cost-effectiveness that was published in PLOS, and PLOS has teeth and they enforce the data policy.

And I just an hour ago got a message that my request had been turned into a Freedom of Information Act request and would be acted on within 20 days. PACE investigators know not to fight on the turf of PLOS. There is no withholding data. They had to make a commitment to sharing data when they published it. They've a problem if they're not ready to do that, and they'll face consequences. They know that.

I'm a promoter of open access on PubMed comments, I'll say more about that. I know that Tom and other patients have made effective use of PubMed comments. It's a place where anybody who has ever published anything at all in the 26 million eligible publications can go there and comment on any article that is published in PubMed, and be there for public view. When people go to PubMed to look up an article, they'll find the comments and it's an effective means of strengthening post publication peer review in taking stuff out of the hands of journalists who control pre-publication peer review.

9:10 Slide 8: About me (2)

I teach scientific writing and critical skills, critical quality... There's another one of my dyslexic things: "quality of the quality". "Be critical of the quality of the scientific literature". When I'm writing these things I can't see the problems that I have. What I often do is I write on my lap-top and then I put it up on my iPad, and I take it to the cafe and with the different format I can sometimes see things I didn't see. So you'll see these things come up. Thanks, I appreciate it that some of the members of the patient community have taken to proof-reading my blogs for me and send me discreet messages. I appreciate that and I welcome people doing that.

I blog with Science-Based Medicine, that's a pretty scary place where a lot of pharmacologists go who hate quackery.

11:38 Slide 9: I live in Philadelphia

And now I live in Philadelphia and the interesting thing about Philadelphia, that's where S. Weir Mitchell lived. Do people know who he is?

There was an epidemic of post viral fatigue in the United States at the turn of the century - the 19th century - and he became an expert in, uh...he prescribed extreme bed rest to the women and a stay on a dude ranch to the men. And Theodore Roosevelt was one of his patients but one of his women patients was someone who eventually became a feminist. She fired her doctor, fired her husband who had referred her and started writing children's books, uh...Charlotte Gilman Perkins....do I have her name hyphenated right, anybody know? [note: Perkins Gilman is correct]

I highly recommend her book called 'The Yellow Wallpaper' where she was describing her enforced rest cure and doing nothing but staring at the wallpaper and her... Weir Mitchell had decided that her fatigue was due to competing with her husband and that she should give up her aspirations and just stay in bed. He did something similar to William James's sister, Alice James, and she stayed in bed pretty much until she died of breast cancer thirty years later. It was a pretty horrible treatment but that's a famous spot [indicating the slide]. I walk by there getting my espresso and I carry my iPad to go read what I've written, to find the mistakes, and it really strikes me. There's an excellent book about that period, 'The American Nervousness', and you see some of the struggle even then to

decide whether it was neurasthenia or whether it was something post viral. It was clearly tied to a known outbreak of flu that occurred about the same time. OK [turning to next slide].

13:39 Slide 10: I'm a skeptic

I'm a skeptic: I believe that controversies are resolved by looking at available evidence but I'm well known for my scepticism about the quality of that evidence.

13:39 Slide 11: I don't think these are controversial statements

And I don't think these are controversial statements. Many findings, perhaps most, in the biomedicine and science literature are ultimately exaggerated or found out to be false and there's a crisis in the trustworthiness of the scientific literature.

14:10 Slide 12: Evidence based is.....

We talk a lot about evidence-based treatment but I'm very suspicious of that being a branding not a hard earned designation and too often investigators get that branding of their treatment based on weak evidence that's generated by the promoters of the treatment who have a conflict of interest and who are supposed to ignore that.

Among the many fights I've gotten into recently, there's a physician, Philip Wilson, in Aberdeen, a GP, and he was running a trial in Glasgow of 'Triple P Parenting' and he began getting suspicious of the evidence base despite the millions of pounds that were being spent on it.

He wrote a paper attacking the conflict of interest in the literature that had evaluated, that had led to the trial. There was an attempt at retaliation. I went after the developers of Triple P Parenting and between us we collected 54...so far...corrections and erratum to their articles because of undisclosed conflicts of interest.

I got disinvited from a talk a couple of months ago in Australia because the other person doing keynote had made millions off Triple P and then I'd just publicised that I got disinvited and a group put together the funds for me to go there and do the talk at the skeptics convention as a replacement. So I do get into fights.

15:47 Slide 13: Quotation attributed to Ben Goldacre

Now, I'll say more about Ben Goldacre as the evening goes.

He's been a guiding force in a lot of the stuff that I've done and his stand about it's appropriate to pick apart dodgy claims. It's an acceptable activity. It's not just being a pest. And unfortunately he's refused to get involved in this fight and I'll have something to say about that in a little bit.

We had a very nasty set of exchanges going on back and forth, direct messages on Twitter. He thinks that I'm organising a group of patients to harass him. Those are very familiar words in England. Those fussy Brits, I don't know. But he thinks that I'm part of a conspiracy and he refuses to comment on PACE because he hasn't read the trial. Now if you go back in Twitter you found that he's commented before and very negative about patients. And, so, it's a cop-out. We'll have, more to say about that.

16:50 Slide 14: Targets of skepticism

So, my 'targets of skepticism'. I've been refining them; Questionable Research Practices, and PACE is full of them, but also Questionable Publication Practices. How did the PACE findings come to our attention? What went on in the peer review and in the relationships with the press? So a lot of people when they look at bad research, they look at methodological issues and questionable research practices but I think we need to look at the institutional agenda that provide reward for bad practices.

17:30 Slide 15: Politics

So it comes around to politics. Bad science is being published with exaggerations of its significance without challenge. This can only be understood by reference to politics. I have a constant fight with PLOS about my blogging getting too political and they'll have to decide and have a parting of the ways that we need to. They are certainly under pressure from the British Psychological Society to silence me. Like other institutions are.

18:00 Slide 16: Politics

So politics aside, what gets into what publications, in which forums, who's invited to forums, who's invited to the public or the secret meetings, who can be critical and be heard, and who gets ignored, and who suffers retaliation and by whom? It's all about politics. You can't understand what ends in our lap as a peer reviewed scientific claim unless you understand the politics around it.

18:31 Slide 17: Developing Citizen-Scientists

I've been developing the idea - before I got into the PLOS thing - that we need to develop citizen scientists. These are people who are faced with scientific claim that impact on their life. They're either things that they're supposed to do or that their health care providers are supposed to do with them, or that their public health policy sets. So I wrote a whole series of blogs about efforts by the British government to put restrictions on food at fast food outlets as a way of controlling obesity. It's a totally rubbish idea but people who want to curry favour with the British government tortured the results to make it look that way for publishing in the BMJ.

So the idea of the citizen scientists, it's a person who has learned to trust their basic mathematical and scientific knowledge to make a judgment: do they need to probe an article or find a more trusted source before accepting a claim? And a lot my blogging has been organised around disseminating skills and encouraging skepticism about the claims we all deal with.

I originally was developing this idea around positive psychology coaches but I think now it really applies to people like Tom Kindlon and all the members of the community who are desperately looking to interpret the scientific literature that they have a well based skepticism about the quality of it, the trustworthiness of it.

20:11 Slide 18: Journalists and the media

Journalists have a role to play. They should be, ideally, they should filter material. They should not be at the mercy of what investigators want to tell them to publicise. They have an ethical commitment to avoid churnalism. Churnalism is a word I use a lot in my blogging. That refers to just gullibly accepting what is told by the investigators about what happened in their trial. Ideally, they need to filter exaggerated claims.

We know that most junk scientific claims in the media start with exaggerated claims by the investigators and their press officers. Most bad press coverage of science starts with a bad abstract and a bad [?] abstract that claims significance there isn't a basis for claiming. And the journalist's responsibility is to filter that by introducing independent evaluations.

You saw me go after - those of you who are on Twitter - go after the Mental Elf recently, where I had expected them to get independent evaluations by clinicians, by other scientists, of the clinical trials they evaluate. So who do they get for PACE when they couldn't set up a debate? Simon Wessely and that's hardly an independent source and so I indicated they are now under a boycott and I would not tweet them with a little alpha sign so that they wouldn't pick up my tweets anymore and I sent them - Andre - a note "you just fucked up but we can't talk about it now" because I felt he was developing a role using clinicians and independent junior investigators to interpret the scientific literature to the larger community, when people don't have time, inclination or competence. They can go to these trusted sources and he just blew it.

22:12 Slide 19: My activism (1)

OK, my activism. I just don't write, I do things. I identify and I try to correct practices. I promote open access and data sharing. I've been involved in a number of complains to the US government about researchers who won't share their data.

There's one situation I'll be blogging about where investigators put their data up on the web, allowing the scientific community to access it. My graduate student and I accessed the data and we showed that the results they claimed were rubbish. They then altered their data, took it down, altered it and put it back up, put up another paper saying that we didn't understand their data. Fortunately my graduate student was very careful and he kept the altered data and the original data and they are now facing ethics complaints in the United States.

I work hard to strengthen post-publication peer review. The idea is that all of the data that are out there that everybody collected, typically from clinical trials using patients, it should be available, and all of it, and we should evaluate it after it gets available and the data should be available for re-analysis. And the idea [is] that we take the power away from an editor and two or three cronies and give it to the scientific community and the citizen scientists who earn their way into it by writing competent critiques.

And I tried working on some crowdsource post-publication peer review. Working with one of the medical journals now that realised there were computational mistakes in reporting a large clinical trial. And if only more people had looked over the tables carefully and prepared articles they would see some real discrepancies being developed and being amplified. So the idea is that for a period after data become available that people scrutinise it and have a forum and a reward for finding, in a collaborative way, the faults in the literature, some of them which are perfectly honest mistakes but have important clinical and public health implications.

24:30 Slide 20: My activism (2)

So I go after bad science, but also go after bad editorial policies. A lot of journals have had policies that they would not publish a critique if the authors wouldn't respond. So authors got veto power over anything that you could say. And journal by journal I go after that and change that policy. And I've gotten erratums like I said. I think 54 now, with Phil Wilson, about Triple P Parenting and about other promoters of particular therapies to apologize in print as a condition of the paper not being retracted.

Needless to say, I've made a few enemies. I've tried a number of attempts to get papers retracted. That's a lot harder to do, that, and we've got to be realistic. There's a real reluctance not only of authors but of journals to admit that they've published faulty science. And things are stacked against you if you try to do that. Let's be realistic. But it's very important to try anyway and to fail, and to publicise the failure. That in itself is progress. We are not lying dead when an effort fails like that. We're publicly reporting and it's a move in the game. It's a move in the game that ultimately will change things.

25:56 Slide 21: My skeptical engagement with positive psychology of cancer care

I got into scepticism when I became head of behavioural oncology at the University of Pennsylvania and I realised that there was literature out there that encouraged patients to adopt a particular attitude in facing their cancer. And there was some literature out there that suggested going to support groups and expressing positive emotions would affect not only their sense of wellbeing but the actual disease processes of the cancer - they would live longer. Now, I'm all for support groups for people who want to go to them but they ought to be honestly presented to them: "this will not change your outcomes" - the biological outcomes.

26:41 Slide 22: I Took on Claims Psychotherapy Promoted the Survival of Cancer Patients

So I took on these claims.....

26:44 Slide 23: Review article clippings from Journals

.....and I wrote a series of review papers in which I really couldn't find much evidence that psychological interventions.....yeah? [indicating audience]

Audience: That's a really central dichotomy in psychotherapy approaches. What the patient believes can be beneficial, you can't assume it will be but if you don't offer promotion of that idea, then they're not going to have the benefit. So the only way of getting benefit is to be biased.

Exactly, except there are ways of testing ideas. And one of the things that PACE didn't do - now I have a future blog coming out about their inadequate control group, that they encouraged a lot of positive expectations about their favoured treatments. The so-called standard medical care, or sometimes they called it specialist medical care, it was often no care at all, delivered with no positive expectations. So that all of the positive expectations in their trial were centred on the treatments that

they were offering. An adequate control group would have provided positive expectations, maybe supportive counselling, maybe talking nicely to patients and finding out about their needs but they had none of that. So what their supposed active ingredient, cognitive behavioural therapy, the graded exercise, that was confounded with positive expectations that weren't in the control group. That was a bad trial and no one seemed to be noticing that. I'll get back to that.

Audience But interestingly, as far as support groups goes: from what you're saying, they're supposed to help people with breast cancer. With ME you're not allowed to be in a support group. If you're in a support group, that encourages you to think you're ill. So, I mean, it's unbelievable.

Well the problem is that a lot of the groups have been done with metastatic cancer and there's very little that's changed in 25 years in the treatment of metastatic breast cancer. Why they think that attitude would affect it.... and you can just look at the data...randomly put people in the support group or not and see what difference there is in survival time, what difference in time recurrence. There are no difference across the trials. And so....

29:15 Slide 23: "Fighting Spirit?"

...and then 'Fighting Spirit' - that started in England - the idea. There was a very small study that suggested that patients who adopted a fighting spirit, that they lived longer but it was a very small, flawed study. When they moved onto a larger study, they found absolutely no evidence. One of the investigators, Maggie Watson, said "I'm greatly relieved at this finding; now patients don't have to blame themselves for not having a fighting spirit" and her....Greer, the other investigator, got angry with her and said "I know that I published a paper in which we said that but I didn't read the paper and I want to take it back" but he couldn't because they'd published it. But it developed an attitude.

0:00 Slide 25: Loved Ones Recall Man's Cowardly Battle with Cancer

This is a fake article. It's from The Onion in the United States. But it's so close to reality. The patient ... [continued in Part 3]

PART 2

0:00 Slide 25: Loved Ones Recall Man's Cowardly Battle with Cancer

[The first few seconds of this slide are on the end of Part 1]

This is a fake article. It's from The Onion in the United States. But it's so close to reality. The patient died and his physician said [reads from slide] *'it's rare that you see someone give up that quickly and completely. Cancer's a powerful disease but most people can at the very least delay its spread by maintaining a positive outlook and mental attitude. This was not the case with Charles, Charles had a yellow streak a mile wide.'* And again, this is fake but it's very believable. I had another slide, I left at home, but it's Lance Armstrong demanding a rematch with cancer, because he'd taken it out the last time, now he's had so many problems he needs to bounce back, so he wants cancer to come and get him and he'll beat it again.

Audience The thing is you can't police somebody's attitude towards their illness in that you can't police someone's attitude towards anything in their life. Our attitudes depend on a lot of things, it's absurd.

Exactly, you've got it.

0:50 Slide 26: Barbara Ehrenreich and the Negateers

You're speaking like my good friend Barbara Ehrenreich. She wrote a book called 'Nickels and Dimes'. What she did is that she dropped out of graduate school and started cleaning houses and working at K-Mart, big box stores, to learn what it's like to be poor, and it was awful. And they actually made a play out of her book and it was a bestseller. And she was working on another book and then she developed breast cancer, and it was so inconvenient when she wanted to get her book done to have breast cancer, so she went to a support group and said "I'm mad as hell to be here, it's keeping me from doing the things I want to do". "No, no, no, no, if you have that attitude, your cancer will progress", so she wrote a book called 'Bright-Sided' about it, about how the relentless promotion of positive thinking was undermining America, but then she wanted to publish it in Britain, they said "that won't work in Britain, call it 'Smile Or Die'", which I like as a title actually better, so the idea the pressure was that if she didn't smile she would die quicker. And she and I really promote a liberationist view.

1:54 Slide 27: A liberationist view

If people want to say "fuck cancer", let them, it's not going to affect their physical outcomes, if that's their natural attitude than let them have it. You can't change the attitude and it won't make a difference. And a full range of patient styles of coping need to be accommodated to cancer care.

People may be familiar with the English writer John Diamond, he thought he had a non-fatal cancer and contracted to write a series of articles on it, and it ended up being a quite serious fatal cancer and he wrote a book called 'Even Cowards Get Cancer'. He describes at one point everyone was telling him to have a positive attitude, look on the benefits of having cancer, he said he was tempted to send out Christmas cards, "Merry Christmas man, you get cancer this year and get the benefits that I have". He said, whatever benefits he found – and sure he discovered the some people really cared for him - but he was soon gonna lose contact with his wife and kids, he was gonna be dead and there's no benefit to that. And I think that's a very profound book, written with great humour.

3:16 Slide 28: A Lancet study...

So, I was writing about positive psychology and then this report came out, 'Understanding Psychosis and Schizophrenia' from the British Psychological Society. And it was radically denialist from my point of view; it denied that there was any biological aspect to schizophrenia and at the same time a paper came out about CBT in The Lancet...

3:37 Slide 29: Schizophrenia headlines

...and it was promoted that talking therapies were as effective as drugs and in 'Science' of all places, the title was 'Schizophrenia - Time To Flush The Meds?'. Something you need to know about the media before you beat up another journalist - journalists often write bad articles, but they don't get to choose the titles and editors choose them without their permission and I sometimes really batter the journalists for good reason, but I went after them because of their title, not because of what they said in the article. In these particular cases these were terrible headlines and Professor Tony Morrison from Manchester was giving them this rubbish interpretation of this trial, so I began blogging about it...

4:25 Slide 30: A skeptical look at the Lancet CBT study

...and when I looked at the Lancet paper, there were actually fewer participants stuck in the intervention group than there were authors at the end. They had, em, the comparison treatment was ill defined, but some of them simply were thrown out of routine care because they wouldn't take their meds. So there was no comparison, certainly no control for expectations. A substantial portion of patients assigned to CBT were getting medication by the end anyway, which was supposed to be the other condition. There was no evidence that response to cognitive therapy was comparable to that achieved with anti-psychotic medication. This was totally a sell job. When I started attack...

Audience: just, you know, on this point, it's become common knowledge that the British government is now intending to put CBT therapists into job centres. Dame Carol Black has been given terms of reference to go around, to basically do another job which is policy based evidence rather than evidence based policy. It contravenes the UN CRPD about enforced treatment. I just think that this is, like, one of the most pernicious things that's happening in the UK at the moment, because basically they're telling people with, a lot of people with severe and enduring mental health [unintelligible] that if they don't accept this so-called help then they will be made destitute, homeless and [unintelligible]

OK let's put the social justice issues aside for a moment... which are overwhelming. Let's look at it from a therapeutic point of view. It makes no sense to try to attempt, try to establish a therapeutic relationship, a therapeutic alliance under those circumstances. It's absolutely idiotic from a clinical trial point of view, a service delivery. But it's been pushed for political reasons. It's an evidence based treatment, but there's no evidence it'll work for that purpose.

Audience: Well, we're hoping that the psychological community, you know...

They won't, they'll weakly take a stand against it but they see the opportunities, the job opportunities. There's a real problem with the training of clinical psychologists in the UK. They basically have to work for free. Maybe if they have this pressing need for CBT therapists, they'll start paying for the training. I keep badgering them to take a stand against it and say they'll boycott it, and they keep ignoring me.

Audience: Well, the only group that has emerged has been the Psychologists against Austerity. They're doing what they can.

Right. And they normally get involved, Peter Kinderman, the president elect, normally gets involved in that but he's careful not to bite the hand that hopefully will feed him. Boy, I'll bet he'll be writing to my university about that comment. Hey, Peter! I'll give the email of my Dean!

7:25 Slide31: Critique of a flawed Lancet study of CBT and its promotion

So I started going after the 'Understanding Psychosis', and.... the book.... and The Lancet and there was one blog about how little evidence there was in the Lancet paper. I got into a fight with The Lancet because I accused them of publishing a paper that was... the trial was registered after the start of the trial, and they said that was libellous and then I said, please check with the date of the registration and they apologised to me and allowed me to state that in a letter.

And so, but then, this ridiculous thing that's caused me lots of problems. I found that the president elect of the British Psychological Society believed that Nazis are promoting a biomedical model and... that's traceable back to Nazi Germany and that he was worried about being castrated, not because he was Jewish and the Nazi psychiatrists would get him, but because he had a brother who was odd, and maybe he would be castrated as a way of sterilising them and after all, the Right is rising in Europe.

And so I found this particular thing and started saying that he was trivialising the Holocaust and that's when he wrote to my university, saying that I was rude and offensive, and he threatened legal action against the dean at Groningen paying my salary if I wasn't muzzled. He similarly threatened Stirling and it caused a big laugh among my colleagues in The Netherlands. "What court are they going to sue us in? Does that mean we have to go over to London and face this ridiculous man? If he thinks that someone's going to cut his penis and balls off because his brother's odd, he maybe needs psychological help." And so it didn't go over but it pissed me off.

And then ultimately he came out and said, this advocating CBT for psychosis was not about CBT, it was about the politics of psychologists getting control from the physicians for the treatment of schizophrenia. And I don't know why he says these things. But I [unintelligible] on that. And so now, stay tuned.

9:56 Slide 32: Challenging Oxford's Psychiatry Department

OK. But I have a history of attacking members of the Psychiatry Department at Oxford. Not because they're members of the Psychiatry Department at Oxford but because they say dumb things. There was a trial of mindfulness-based therapy which they claimed was ready to roll out to prevent relapse and recurrence and I pointed out on my blog that from the clinical trial's point of view it did nothing of the kind - it was just hype on the part of the self-promoting author. He then contacted the British press and said I had deviant American views and that he could recommend people who'd be more appropriate to comment on his mindfulness trial.

And then they came out with a trial which they claimed that an anti-worry treatment would reduce paranoid delusions and the author of that, Freedman is his name, [actually Daniel Freeman?] writes for the Guardian and puts out promoting his treatment and his self-help book in the Guardian and so I went after the media....

11:09 Slide 33: Challenging UK Media

...and the Guardian is now reconsidering their oversight of mental health treatment, the BBC changed their headline three hours after my blog attacked them. So I don't know, maybe just random events not related to what I'm doing but I keep going at them.

11:30 Slide 34: What is PACE? (Investigators answer)

So, I'll skip the slide about PACE. This is just a description that's provided by the investigators. Much of it is controversial but it's treated as if it's not controversial, it's treated as factual. I just did that in case there's anybody here who didn't know about PACE. Much of what is said there is untrue, at least anything of substance.

11:55 Slide 35: Bad science of PACE

PACE really attracts my attention because it's so goddamned bad. It's bad in its conduct, it's bad in its reporting, and it's fascinating that it's going unchallenged. And it's uncritically being passed on by journalists and the media with clear harm to patients. And there's murky politics around it all. So it's as if something... I was ready to drop my interest in positive psychology and focus on PACE as an opportunity to teach people who have no interest in chronic fatigue or ME or post viral syndrome but are interested in how to interpret a clinical trial. It's grist for the mill.

I can hopefully imagine sending my blog to graduate students studying clinical trials and they'll learn how to conduct one badly and how to get away with reporting one badly. It's a great case study.

13:00 Slide 36: What makes PACE long-term follow-up results uninterpretable? [1]

So my first blog post pointed out... and you have to understand, there's nothing that I'm saying in my blog post that the patient-groups haven't been saying already. But I've got more of a standing somehow in this messed-up system that I get taken seriously.

So the first non-controversial point that I raised is that if you do a clinical trial, you don't look at within-group differences, you look at between-group differences, and if the investigators had paid attention to that in the follow-up study, they had nothing to report because the group differences had gone away in the follow-up period. And to me it's shocking... and I don't believe that the PACE investigators are incompetent. They know how to run a clinical trial. They knew what they were doing.

13:48 Slide 37: What makes PACE long-term follow-up results uninterpretable? [2]

So the other aspects is they did some really dodgy things. They randomly assigned people to groups, and then they're doing a follow-up based on the initial randomisation but in between the end of the treatment and the trial and the follow-up, they let people go to other treatments. So they weren't being evaluated on their initial assignment, they were evaluated by what was happening two years... in a group that was really... that was very difficult to describe what was going on.

And they also attempted to influence participants' reports of outcomes prior to their collecting of the data. They sent some newsletters that had glowing reports of how well people were doing. Now we know that the people assigned to the standard treatment, the specialist treatment, they didn't like that. A significant minority, I think about 41% said they had no expectation of being helped by that. So there was obviously a lack of balance to begin with, that was compounded by a lot of people switching treatments and by the letters.

These are terribly dodgy things to do, that anyone who's ever taken a course in clinical trials knows that you don't do those things.

15:08 Slide 38: What makes PACE long-term follow-up results uninterpretable? [3]

And so they reported the data based on the initial assignment, not on the treatment that people were getting at the end of the follow-up. And then they used voodoo statistics to try to correct for all of this. A statistician would tear their hair out, looking at what they did.

15:29 Slide 39: Keith Laws Dystopia Blog (1)

So then Keith Laws jumped in and pointed out the dissatisfaction with the standard medical care, which was really no care for a lot of patients with this condition. They were desperate to try something new, they were attracted on the promises that were made about the treatments being preferred by the investigators and there was no positive expectations or hope in that condition. So it violated the condition, the basic condition of a clinical trial: there was no equipoise. Ethically and clinically, you expect there to be a balance between treatments and if there isn't a balance, then you shouldn't be doing a clinical trial. It's not ethical.

16:18 Slide 40: Keith Laws Dystopia Blog (2)

OK. And then he started getting into the mess trying to interpret the outcome variables. And actually, really getting into the tables, the only treatment that showed up not showing an improvement was GET, the Graded Exercise, even people in standard care with the passage of two years had gotten a bit better.

16:49 Slide 41: So what? [1]

So what? What we're accusing the investigators of in our blog and it's upsetting that....we are an established senior facultywe're saying that they inappropriately attempted to influence outcomes, we're saying that they're allowing patients to get other treatments, nullified it as a clinical trial, we're saying that they distorted their interpretations and these are serious charges.

17:15 Slide 42: So what? [2]

So, essentially two academics, we're saying what all the community was already saying, that there is a major mess-up in PACE in the conduct and in the reporting and what's amazing is that no-one was catching it. And they must have known what they were doing. We can only assume they believed that the editor and reviewers at Lancet Psychiatry would let them get away with it....and obviously they did. They didn't get caught in peer review, competent peer review should have caught it, the media should have caught it. They should have gotten somebody independent of PACE to say "does this kinda make sense or is it just an exaggerated self promotion?" and obviously there's something wrong in Britain that this didn't happen.

18:07 Slide 43: So?

And I personally think the PACE investigators were not inclined to challenge the release of their data before. They certainly can't now. They're in a bind; if they try to stop release of their data, they've basically been accused of hiding mistakes and it won't stand, the scientific community won't stand. So I think they can risk further damage to their reputation by fighting the appeal or risk damage by things that are going to be revealed by the data being available. Because it's a Freedom of Information Act, it becomes available not only to that patient who asked for the data, but everybody in the world. PACE is at a real crisis. I think the psychological conceptualisation of Chronic Fatigue, ME, is at a real crisis. The game has changed.

19:08 Slide 44: Why QMUL should not appeal

And so I'm arguing that they shouldn't appeal and they probably won't. They only have a week now, Next Monday, they have to have their appeal in. Otherwise, the data get released I think a week or two later, I think we're going to be seeing the data. There are wonderful things hidden in that data. We can look at the actigraphy data and we can see that there's no relationship between the physiological objective measures. Yep? [directed to an audience member]

Audience: When we do see the data set that is revealed, how can we be confident that this is all of the data set and not a sanitised or selected or altered version?

Well, it's possible but then it moves into the criminal realm. Altering clinical trial data is a very serious offence, and I think that the commissioner has already indicated that it's now going to be contempt of court. They've had an order, and if they alter it that's not consistent with the spirit of the order, they'd be in danger of criminal contempt. I'm not a British lawyer but as an American I would be scared shitless of that possibility. Having caught some Americans altering data that was shared, I know the bind they're in, and these are prominent people in the United States. I would not want to be a British investigator...Yeah?

Audience: This has really been their last bite of the cherry anyway in doing analysis of the data. So the stuff they are publishing now is as far as they can go because, you know, the data has its limits. It'll all be after the fact anyway.

Yeah, this whole thing about intellectual... the thing I run up against in the States when I try to get data is that they'll say, "It's intellectual property rights, we're going to publish more data". Hell, it's been a long time since initial publication. Go on with the additional follow-up, but you're not doing additional follow-up. You've got the follow-up, you've got the initial data. What intellectual property is at stake? It's a rubbish argument.

Now that they're being criticised by the scientific community, the game has changed. They can't get away with that

Audience: Well, I've got a question and I'd like to make a comment. The question is about the relationship between Mansel Aylward and Simon Wessely, the whole so-called biopsychosocial model and the excellent work that you're doing but in terms of.... people.. disability grass-roots campaign. (unintelligible). It's important that this gets out into the public domain.

Absolutely.

Audience: And that's not something that academics are best placed to do. It's something that we are experts in as campaigners. I'd look to if I could just share a letter which we wrote to the Guardian, which is less than 200 words which was published on September 12th, 2012. So I'll be as quick as I can.

Speak up: for posterity this is going to be on Youtube. You want to get closer to this? [indicating the audio recorder]

Audience: Yes that would be very helpful. Thank you. So it's a letter to the Guardian published at 21 hundred hours 12th September 2012 and it says: "This week the sixth International Forum on Disability Management, IFDM 2012, takes place at Imperial College London. It is sponsored by some of the world's largest medical insurance companies, Unum among them, and speakers include DWP chief medical adviser Dr Bill Gunyeon and Professor Sir Mansel Aylward, formerly DWP chief medical adviser and director of the Centre for Psychosocial and Disability Research at Cardiff University, which was sponsored by Unum from its inception in 2003 until 2009. Unum's website states that during this sponsorship period "a series of papers was published, identifying the range of factors that determine why some people become long-term absentees". The Cardiff papers advocated a "biopsychosocial model" of disability which Unum says "informed its approach to medical underwriting". It is the same approach upon which the current Atos work capability assessment (WCA) is based. Concomitantly, the company were advising the UK government on welfare reform. On 4 September, during an emergency debate on Atos and the WCA held in parliament, Labour MP Kevin Brennan demanded to know if DWP minister Chris Grayling was as concerned as he was "that Atos's chief medical officer is one Professor Michael O'Donnell, who was previously

employed as chief medical officer by the American insurance company, Unum, which was described by the insurance commissioner for California, John Garamendi, as an 'outlaw company' that has operated in an unlawful fashion for many years, running (disability) claims denial factories. We condemn the Royal Society of Medicine's decision to host IFDM 2012. By so doing, it has lent an aura of legitimacy to a pseudo-scientific approach to disability that is as far from evidence-based medicine as it is possible to imagine. It is an approach that continues to devastate the lives of patients, scores of whom are tragically no longer with us as a direct result. These for-profit corporations should never have been permitted to sequester such power and influence over public health and social policy. There may be clear conflicts of interest at stake, and the public interest now demands an urgent and thorough independent public inquiry into the relationships between, and roles played by, senior Unum, Atos and DWP staff in the creation of the current government disability assessment regime. Signed by John McArdle and Dr Stephen Carty, Black Triangle Campaign, and 449 co-signatories, [em with a link](#). Just to say that this guy Dr Bill Gunyeon has now jumped ship and he is now chief medical officer with Maximus who have taken over the contract from Atos.

I think it's very important... that's an excellent letter, and I think it's very important that activists like you keep following the money, keep following the people.

Audience: We're about protecting people from harm. This is it.

You know, once I started to get into this PACE thing, it reminded me so much of the Jack Nicholson movie, Chinatown, where everything is connected to everything, and you think somebody has one role but they have another role, but they switch roles.

And to me, it's so amazing, to an outsider, that this shit goes on in the UK: undeclared conflict of interest.

Audience: It's the privatisation of our welfare state. It began with Labour under Tony Blair in 2001 and this is the logical end game.

But see, as an academic, for me, I have to translate this into undisclosed...

Audience: we have to translate your work into stuff that's going to change social policies.

But I'm only, you know, one 68 year old guy with dyslexia, I can't do everything, but I'm willing to work within limits,

Audience: We couldn't do what you do.

But I'm a sharpshooter, don't ask me to drive a tank. That is, I can take down a badly done trial, I can point out that it's badly reported...

Audience: It's good you are taking it down because nobody else is. Sure as hell, nobody else is. Apart from patients and patient charities.

Yeah, but it's going to get more trendy to do what I'm doing...

Audience: But you know on a personal note, I'm bored stiff with ME because I've had it for 33 years. I'm bored with but I can't... I have to talk about it because I was diagnosed as a 19 year old, albeit, it was poorly understood, the mechanism wasn't understood, but it was a neurological illness diagnosed by a consultant neurologist. 33 years later psychiatrists have taken over my illness. They've taken it over. They've distorted it and that's why we've got nonsense like PACE because they had their results before they started. They had their results before they started.

But I think what's happening now, think of that sign... Saint Nicholas's Church is open. The game has been changed.

Audience: They wonder why patients are hostile. They wonder why patients are hostile. We've already had our lives ruined to indifference. What these people are doing, I mean I don't...The PACE trial, I just know, I mean I know it's dodgy just because it is without having to go into all of this. It's been dodgy before it even started.

But the spell has been broken.

Audience: So thank God for people like you because no one here is listening

Keith Laws is a Brit, I'm an American.

Audience: I'm a militant. I mean, there's really no one more peaceful than me but I'm a militant because I comment on my illness with honesty and lived experience. But I'm a militant

Good for you.

Audience: I mean the fact that you examined the methodology as you said...the very work that you are doing to complain about journals em, about papers that are written that, you know, are methodologically unacceptable, you know, to raise those things are absolutely critical to the work that we do.

29:01 OK, but I'm just getting started. Anyone know what MEOOW means? It's an American term. It's not the sound a cat makes. It's a MEOOW for me right now.

29:09 Slide 45: What next for PACE and me?

The moral equivalent of war. It comes from William James, and ironically, William James referred his sister for treatment of her neurasthenia to Weir Mitchell...

29:24 Slide 46: Moral Equivalent of War

But the idea is that...

29:29 Slide 47: From William James

It's from William James... I was already busy shooting up bad clinical trials, I was busy going after journals, now I'm going to refocus the activity on PACE and the associated ideology.

And I'm only one person. It's not a war against people, it's a war against practices and assumptions. And rather than doing the positive psychology thing, the focus of my work is to see how much we can degrade bad science being badly reported.

30:05 Slide 48: My existing goals and activities refocused on

I'll expose more of the bad science, the QRPs [Questionable Research Practices] of PACE; establish culpability of journal editors and reviewers in questionable practices, in getting it out there; educate the media and journalists on the responsibilities that they have not exercised in reporting PACE. They've got to be called to task.

Audience: How are you going to do that? If we try and educate, and you have to remember, we're all, I mean I seem feisty sitting here but I mean I'm ill. I shake after a week of all of this and I'm crying at yet another bloody article demeaning me and people with my illness. It destroys us. It's appalling.

Well, you know, I'll tell you. So my recent fight with Prospect... eh, with The Spectator. The editor won't apologise but you can be damn sure he won't be talking about the "patient trolls" any more. That's one thing. I stepped up and I called him an asshole and called his associate editor a bitch and got slapped on my hand. [unintelligible] I should have said it was a bitchy thing to do, rather than that she was a bitch.

Audience: Your comment was "it was a bitch comment" which was basically 'it's a bitchy comment' which is how any reasonable person would have taken it.

Exactly. You know, the problem is that you can't say it's an asshole comment to a woman because there's a gender thing about insulting people. I was tempted the other day to say to Ben Goldacre, who sent me a nasty message, "that was a bitch comment" and it was very appropriate but it's an odd thing to somehow... a gender specificity to "bitch" and "asshole".

But anyway, the issue was that I got slapped on the wrist, but who cares? A patient didn't get slapped on the wrist. And I'll survive that.

Audience Yeah, but if we try and educate them on Twitter they block us. We're blocked as if we're suicide bombers.

I got blocked by Isabel but I didn't give a shit. I don't need her to follow me.

Audience: But the sad thing about Isabel..... she is a young journalist. She's naïve. She was trying.....

But she shouldn't be on the same editorial board with Ron whatever his name is...

Audience: I would like to question the ethical position of people like Wessely and Aylward.

In time.

Audience: We confronted him at that particular conference and I've got film of it and he lied to us- we have it on film – I mean he couldn't sue me for saying that – Mansel Aylward, you lied to us - because I've got film of you saying that you were reconsidering your position regarding the biopsychosocial model and the harm that it's been doing. These people are in the pockets, I mean, it seems to me that their number one priority is profiting private, profiting themselves and their own academic careers at the cost of human life. If he ever sees this, I accuse you of it, sue me.

Well, change is going to take a while...

Audience: Meanwhile people are absolutely perishing

I know,

Audience: That's how urgent it is...

I know, all I've got is my pen and my type...

Audience: It's no criticism of you, it's just that I tend to get quite upset about these things because...

You have a right to be upset

Audience: I see the suffering that my friends are going through

You have a right to be upset, and what we've got to do is focus it...

Audience: You're work is incredible important but there should be more interaction between us.

It'll get more trendy to attack PACE, there's a guy, Johan Denollet in the Netherlands, who had a theory of Type D personality causing people to have a shorter lifespan once they got congestive heart failure, and I started attacking that. He got so upset he took out two pages in the national newspaper, saying the Americans were invading and attacking a Dutch idea. And now the idea's dead, you know, and John Ioannidis, the famous methodologist, wrote a paper about my taking down this model, the decline effect. And he talked about the politics that were maintaining it, it was a dead idea and how it would go away.

And these things happen, and it's to me frustrating that what I'm doing, it's nothing that different than patients haven't tried to do. They're saying the same thing.

Audience: You know it's very frustrating to us that Wessely is now the president of the Royal College of Psychiatry.

Yeah, I know, but we'll take down some other targets of convenience. Who's this guy, Crick, he's part of the game promoting the psychosomatic model. He's got an article coming out this week or next in the Journal of Psychosomatic Research. I'll be waiting for it to come out and it'll be down there on the floor.

Audience: Well if you could publish your article to our website that would be most welcome.
The Creative Commons license....people need to know this: the Creative Commons license of my blogging is I don't give a shit what you do with it. You can translate it, you can chop it up, you can give it away for free, as long as you say where it came from. Take it. Yeah?

Audience: Have you any idea how many people are taking your material and using it to get a positive effect anywhere as opposed to just creating [unintelligible]

I get notes from people using it for discussion in journal club. I get notes of people thanking me for it. They said it was embarrassing to them that they'd presented one of the articles before to the class and everybody approved of it and now they felt so shocked, they couldn't avoid seeing the problems that I'd pointed out.

But I'm one person, I just keep blogging away. But it is something that I'm committed to doing.

Audience: I'd like to thank you for the work your doing, personally, as an activist and a person with disabilities....

36:07 Slide 49: My existing goals and activities refocused on

Thank you. Well, it's a lot more meaningful than taking on the damn coaches of positive psychology and their crap self-help books. There's a time and a place for that but right now I'm taking care of that. I want to expand to other questionable research practices. Like it's fascinating that the largest trial before...Pardon?[directed to an audience member]

Audience: Sorry, I'm just talking to myself. I'm just agreeing with that wee top bit about the 'maintained illusion that there's validity to psychosomatic model for treatment of ME'.

Well, my next targets, after I discuss the control group problem, and once I get through discussing it, everybody will see, and will say, "Whiskey, Tango, Foxtrot", you know? How did they get away with not having an adequate control group?

But my next target is... the largest trial before.....

PART THREE

0:00 Slide 49: My existing goals and activities refocussed

.....PACE was a null trial.....

Audience: FINE

What's her name?

Audience: Wearden

Wearden. And why isn't that mentioned? It's striking that the initial PACE trial is cited 300 times. That's cited 30 times and mostly by her and her colleagues. Yeah?

Audience: Because people involved have been doing other work based on what they do in the FINE trial and ignoring the results of the trial.

But there's an ethical responsibility to summarize the literature that led to you feeling that there was enough ambiguity to do another trial and they failed in that responsibility. That's a bad publication practice that science recognises, when a selective citation, creating a false authority. There is a BMJ paper about that. When people see the relevance, they start poking further.

Audience: These are clinician researchers and what they've done is they've gone on to develop clinical services. So they're not doing more research.

But you have to cite relevant literature. They didn't play the science game the way they are supposed to and there are people who don't give a shit about chronic fatigue, who don't like the game being played badly and they now have a dog in the fight. I'm trying to appeal to the scientific community who, I'm sorry they don't know enough about your condition to care. They're going to learn about it gradually but I'm more interested in taking down the bad science and getting them to take down the bad science. I'm sorry, I don't have - I'm 68 years old - I don't have the time to learn, to protect six months of my time and learn about your condition but I can fire away the bad science and you can take what I do and use it the way you want. And you don't answer to me. I will give you advice. But there isn't a movement that has the paranoid fantasies of the Science Media Committee, whatever..

Audience: The Science Media Centre.

Yeah, yeah, yeah, we'll get to that.

Audience: I wish you would take them on.

One target at a time.

Audience: They're a piece of work

2:09 Slide 50: The story of PACE will be rewritten to

So I think the story of PACE will be rewritten. I don't understand the lack of patient participation in the design/interpretation. It's so against modern practices. It's so pre-2000 and there are really important guidelines in the UK to have patients involved in clinical trial. They violate those guidelines and they're gonna say "Well, we're from Oxford, we can get away with it." What are people gonna say? Hey, I don't know about PACE and I don't know about Oxford but you broke the rules. And it's an object of study in my seminar that you broke the rules because we don't like people breaking the rules. So we we're getting people [who are] relevant pissed off about what's going on, who don't know and don't care about your condition.

Audience: A key player in their time in the '90's, before this, was the King's Fund, so they were in support of these policies in general - the biopsychosocial imbalance - instead of pacing, they were actually developing an understanding and developing costly disease recognition and treatment.

I mean the whole psychosomatic model, it's ... In the United States they have the American Psychosomatic Society and they are very pained that they have a journal called Psychosomatic Medicine because they realize how tainted the idea ...because it assumes the psychological causation. You know the root of psychosomatic medicine is a German-American psychiatrist who believed that psychosomatic conditions were metaphors for psychological conflicts. So the reason why women get more migraines is they don't have penises and they have penis envy and their head is like a blood engorged penis. It's a metaphor. I mean, this is the shit that you would find in these journals. And they are so embarrassed by it. They don't want to say...oh, so you look... they had a big fight and they decided to change the title of their journal a little bit to indicate that they were now doing more behavioral medicine and this is the kind of shit...people got away with that.

Audience: I mean, the PACE trial was destined to fail because the scaffolding's so shaky.

There are so many reasons why...

Audience: It had to be flawed in order for it to.. In their... as far as they're concerned it's respectable, which of course it isn't. But it had to be flawed in order to appear to be respectable because it was never going to work because it's built on the scaffolding that people with this illness, even if it is caused by virus, that it's maintained by false illness beliefs and a wee bit of CBT....

There's no evidence, that's an assumption ...

Audience: Yeah I know, but that's their.....

Well, but it's going to exposed to have no evidence...

Audience: but they're in charge in the UK.

But you're just a patient and have a vested interest and I'm not a patient. I've never had the condition and I still think it sucks as a theory and I'm going to say "where's the evidence?"

Audience: There's no evidence. It's based on their beliefs.

Absolutely. It's their false beliefs.

Audience: But why did it gain so much currency? Why did their false beliefs, I mean the fact of what this guy here was saying, it's all back to insurance companies and medical benefits... It must be...

But I think...I've got to get the conversation going and taken for granted that there is no evidence for the false beliefs. It's a false belief of some investigators.

Audience: Of course it's the false beliefs of some investigators.

Audience: The funding in 2004 [i.e. for PACE], whenever it was initially promised, but 2001 onward as it built up, was the biggest fight. It was all the funding that ever came in almost, and it was a political stitch up from a series of things where they had evidence for, so there was more evidence against. There was money put into producing evidence against, more reports. The reports against were always believed; they were always official....

Sure.

Audience:and there was a continuing background of increasing... and so the MRC could get away with funding this because there was so much momentum distorting any consideration of the obvious lack of value. I mean the design was completely criticised, there was never going to be any useful outcome to the trial.

OK, let me use a medical metaphor. It's an anaerobic process. Do you know what that means? Things that can develop because there is no contact with oxygen. The metaphor in this situation, a lot went on because it wasn't pointed out what was going on. Now that we start pointing it out, it gets harder for these processes to continue in the way they were in the past. I think that there's a real game change going on. I put these joke Tweets up that only until midnight tonight, I think, can they refer to patients a certain way. I have no idea who can legislate that but it makes people nervous.

Audience: But it's actually funny and you need to have humor because what you're saying is true: there is a license in the UK media to treat people with ME with utter, utter disrespect and unintelligible].

OK, but we can change that. And sometimes if I have to stop and tell a journalist he's being an asshole and get punished for that, I don't give a shit. I don't live in the UK.

Audience: It will probably change when the science changes. And the science hasn't been funded....

Yeah, but we've made people uncomfortable. You know, Lyndon Johnson said some horribly racist things but when the time came, he pushed through the Civil Rights Act. And I think there are a lot of people, I mean there are some, we won't name names, and please don't name names, there are some chefs, master chefs in this whole thing that dictate recipes, how to do things, but a lot of people are just cooks and bakers following those recipes and they don't have a real investment, they don't know how to do it otherwise. The thing you need to get is...most of the journalist out there, their problem is that they are temporarily able bodied and they don't know it. They haven't thought about it.

Audience: I saw you write that. What did you mean by that?

So a patient I had educated me on this 35 years ago, it stuck with me. He said "you know, I'm here to work on my anger and I've got a penile pump that doesn't work and I got my toe in a box because of all the complications of diabetes and I've been told I'm angry. And you can't work with me because like everybody else, all the other professionals, you're temporarily able bodied and you don't know it. I used to race sports cars and now I.....(racecars)....and I didn't realize I had diabetes and what it would do to me. I had different thought about people who had disabilities."

And now that I'm 67 years old, I know I'm temporarily able bodied. I won't be that way forever but a lot of people.. I bet there was a point in the lives of many sufferers of this condition; it didn't occur to them that they would ever face this. They believed they were able bodied. They had a wonderful life ahead and they made judgments about people who were disabled. And I think you need to have empathy for some of these journalists who don't know a lot. They don't even know about their own mortality. They haven't thought it through. And some of them will come around once the spell is broken.

Audience: The main problem with journalism, as far as I can see, is that it's only the sensational that actually gets advertising. So when you actually have [unintelligible] and it's a balanced argument that losing advertising. So they're not being published.

Yeah, but the journalists, they have to have some claim to journalistic credibility and to ethics. It may be a loose claim, it may be an inconsistent claim. You can't call them out on this consistently without them changing their behavior. When I attacked the Guardian, they started trying to clean up their act. The problem is, the Guardian, like a lot of media outlets is de-professionalised, they fired their paid staff. They're doing stuff on freelance and blogging right now. Some of it is excellent stuff and some of it is really irresponsible and they need to develop a new ethics code for people who are working in those conditions. The freelancers get paid to have sensational stories. They're not working for the patient community, nor are they working for the scientists and they need to be called up on their ethics. Their job is to filter what the scientists say to them because the scientists may have an agenda.

10:52 Slide 51: Upcoming blog posts will be modest steps

(11:10) So, I'm going to speak past the patients on a lot of my blogging because I've got to get the scientific community involved. I need to get them pissed off about bad science, about bad publication practices and the institutions that develop it. Take what I use. Don't be offended if I'm addressing it, if I'm talking past you. You know what I'm talking about and you can use it the way that you want. I'm not hired by you. I don't work for you. You don't work for me. There's no monolithic... You can't report me. You know, they say "vexatious," you know, I love that term. Now I understand why Britain developed Orwell and Monty Python. There's such a pomposity to the language and doing things. You know I say "Shit", as an American, "are these guys serious?" OK, but we're getting there. (12:09)

11:49 Slide 52: Auslander

OK, Auslander, it's a term that means, in German, "outsider." Ben Franklin was a guy who didn't get along with his family. He didn't get along with people in Boston. He came down to Philadelphia. He was aggressive, individualistic but Philadelphia back then was a bunch of Quakers and some Episcopalians and they felt that the culture of Philadelphia couldn't respond to the challenge of that. The Quakers had gotten decimated in the French Indian war because they were pacifists. And they tried to say "I'm sorry, we don't do this war thing" and they'd get scalped because the French were buying the scalps from the Indians. And so the idea is that you need Auslanders, I mean outsiders. And I think the reason it has to be done by outsiders is... all we need to do is look at Ben Goldacre. He's a problem. He really wants to cultivate the favour of the British establishment. He wants desperately to be a full time faculty member. He's not, he supports himself blogging the journals, blogs in the books, seeing patients, part-time faculty. He's not one of the club and it makes him reluctant to criticize Simon and the PACE crowd. He says such inspiring things about sharing data but he won't say it about PACE. But that's because he's playing the game by their rules.(13:30) I'm not.

13:15 Slide 53: Charter of UK CFS/ME Research Collaborative statement

And then this offensive thing. I can't believe this as an American. You've all seen that? That's giving away your free speech. Look at that. Does that mean that if you've signed a petition that is an orchestrated campaign against those ... This is such a load of crap...

Audience: It doesn't mean that...it only means what it can mean in terms of...

It came mean anything they want. I showed that to a lawyer in the United States and they said "Whiskey, Tango, Foxtrot." They signed this?

Audience: But that's the point, that's the point, under the law it can only mean exactly what is already established under law.

Yeah, but it is a form of intimidation. It's make people think twice.

Audience: But it's already been challenged.....

Audience: It's because there's been so much so-called abuse and harassment of the researchers, they have to because "everyone's a militant".

You know, this is also the country that believed Tony Blair about the weapons of mass destruction.

Audience; Well, we didn't believe him, we didn't actually...we protested.

JC: Well it's just as mythical. I don't know about those... Shit, I get trolls all the time...

Audience: George Bush didn't?

Huh? George Bush wanted to believe it.

So I get trolls on my blog all the time and I get sock puppets, people use made up names. I use software to locate those people and they're not patients. They are professionals from the British Psychological Society. And then I send them an e-mail saying "I know who you are." And I'll say, "I don't know for sure that it's you but it somebody within three houses of you. Here's a map of The Meadows, compliments of the internet company." And you know, I don't have a button like Simon does, or a panic button, or I don't X-ray my mail.

Audience: What kind of button has Simon got?

A panic button in his office.

Audience: What's that?

If patients come and get him.

Audience: Oh, right. To call security.

And I don't know. Maybe there is a troll out there but it's not the community. It's not that organised.

Audience: Yeah, it's absolutely disgusting that a patient community with this illness, which is so long term, so devastating, be labeled in this way. It's disgusting. These so called doctors have allowed this to happen.

I think at least some of the hostility from the patients, they created by treating them with indifference.

Audience: Exactly, they did. Not indifference.

It's reflecting of the hostility...

Audience: But I think that guy's unethical from start to finish and I'm supported by tens of thousands of other people who feel the same way.

One step at a time. I still have to have my beer with them. I offered him a single malt, but he says he doesn't drink that.

Audience: You've got to have your professional courtesy but we don't.

Well yeah, but I'm a rude American.

Audience: Well, I'm a rude Scot.

Well, whatever

Audience: And a rebellious one.

16:11 Slide 54: Now live

Anyway, you can keep track of me. There's a web-site. I'm giving everything away right now. You can go there and find out what I'm doing and where. And, you can get pissed off at what I say. And you can tell me to tone down the language – “Brits don't do it that way”.

Audience: Ditch the stereotypes.

JC: Well, yeah but you know, I've had so many hassles with Kinderman and the British Psychological Society. I realize not all British academics are the same but there's some nice people. Hell, the Psychology Department invited me tomorrow despite all of the trouble I'm in. You know, I appreciate that (17:12).

Audience; There are very good British and UK psychologists and psychiatrists who don't buy into all of this nonsense. It's just this very protected little clique...

Yeah, but what I don't get the conspiracy of silence. There's something about Britain that's unusual that, there's a certain lineage, most people have trained together. You know in Montreal they used to say, when I'd be consulting up there.....

Audience: It's a conformity thing.

...yeah, they'd say in Montreal, the psychoanalysts, most have been on each other's beds. That doesn't mean they're sleeping with each other. They'd psychoanalyzed each other. And it was a real...They needed a lot of good funerals before that system broke down because people came in who weren't in that period. I think the UK, there's a weird thing about, there's a pseudo niceness where they don't criticize each other.

Audience: There's also a horrible class thing.

Oh there's a class thing, a hierarchy, and it so offends me as an American and lots of times I get into fights with British academics because I think that they are being offensive in their style and they think I'm introducing the offense into the interaction and their style isn't condescending (18:27).

Audience: It's an established form of entitlement that goes into all layers of society and academics and strata and all the traditions.

You know, we have our own problems in the States. It's not that everything is rosy there but I think you need an outsider who isn't...it becomes part of your way of doing things, you don't even question it. I think that there are some people like Ben Goldacre, who's trying to cultivate acceptance by the establishment and there are other people who don't even think about it, they're just doing what they're supposed to do because everybody around them is doing that. And I don't think it's a conspiracy, I don't think it's that profound...

Audience: But it is also strange here that the doctors, the scientists who know that ME is biomedical, they know that, they've treated a lot of us, they haven't stood up for us enough. There's that aspect of it. Doctors haven't

Well, there's been some retaliation.

Audience... yeah a little but not enough.

Audience: That's why we have a medical adviser to our campaign in Scotland.

A lot of people are academics because they need to be institutionalised.

Audience: I'm talking about medical doctors.

I know but they're in academic medicine because they can't function outside a world.....

Audience: Our campaign got the... You know, it's through our medical adviser that the disabled people in our campaign put forward a motion a couple of years ago to the Scottish local medical committee's conference, national conference in Scotland to have the ... a statement came out that the working ability assessment should be scrapped with immediate effect, to be replaced by a rigorous and safe system that doesn't cause avoidable harm. That became BMA national policy. But you see, since then we've been campaigning with a group of doctors who work with deprivation interest group of about 100 practices around Scotland. Because what we've discovered is that these ignorant and non-evidence based kind of, you know, opinions exist within the medical profession as much as they do within the wider community.

Yeah, but you have to understand the affront that you are to doctors. You come to doctors with your distress and they attempt to treat you. They get invested in it. You become their case and they get frustrated that they can't do anything for you. Somebody is to blame. And at some point you make a wrong move and you do something that offends them. You're to blame. You're a bad patient. It's...

Audience: It's as much a product of their class background and so on...

Maybe but I don't want a revolution, I just want people to talk differently.

Audience: I do! [Laughs]

Well...you know, I just want people to talk differently and think differently about your chronic illness. And if I accomplish that in the next few years, fine. It would be a good fight.

Audience: Public health is...we are in a humanitarian crisis here in Scotland.

I get that.

Audience: And we need to fight back against this narrative.

Right. Well, I'll just do my part and you and you can do what you want with it, what I do and you can....

Audience: We appreciate what you're doing, I hope you appreciate what we're doing.

We don't answer to each other.

Audience: Scientists might know how things work but it's people like activists and patients who know the meaning of it...and the meaning of it, surely, is the best outcome for all of us

Sure. I think that we're already observing some change. We're still faced with a condition that's badly described, the categories aren't right...

Audience: Well, the criteria are a mess and I've lived through those criteria...

But one step at a time.

Audience: No. But I've lived through the criteria being diluted and diluted. I've seen my illness changed from a very specific neuro-immune illness and now the criteria is this size and everyone's got ME. It's nonsense.

But politically you attract more resources if you lump things together.

Audience: Yeah but the only resources they've attracted is psychiatric research and this PACE nonsense. That's all they've attracted.

The IOM report, give it time to take effect.

Audience: Yeah, but I've been ill for 30 years.

Audience: Time is something we do not have.

I realise that

Audience: Are we digressing from the point of what we're talking about, as well, which is really the bad science. Not the medical treatment.

Audience: Are we?

Audience: Up to a point we are, yes, because you're talking about...

I can tell you one thing about my method that is relevant. I'm not going to get caught up in drawing distinctions because I'm better at taking aim at bad science. Some of it will spill into that and great when it does.

Audience: But the criteria is just part, part of the whole big mess.

Agreed. And maybe in going after the PACE, I'll attack the exclusionary criteria, the admission of psychiatric patients into the PACE sample.

Audience: We're getting away from the science...I have to agree

Audience: I think you've got to start by saying the fault is in our research, our understanding of research, our filtering of research and our publication of research.

Thank you.

Audience: You said, it's about politics. I also think it's about vested interests.

Yes.

Audience: They're the same thing sometimes. But if I want to keep my academic position, I've got to observe certain rules. If I want to sell my product, I've got to sell it and selling does not necessarily mean to science. I understand how bad popular reporting might be. I don't think we can blame the journalists, if the stuff that the scientist gives them is not good enough.

Well let's talk about the conflict of interest thing. I'm a certified trouble maker according to the Cochrane Collaboration.

Audience: And thank God for it.

Well what happened is an interesting story. I wrote a paper, BMJ said that is was one of the top papers of the year in 2008, it was in JAMA. It was a paper about screening for depression in cardiac patients. So I went back to JAMA and said "OK, we're on a roll, BMJ said we were a top paper. How about if we do a paper on screening pregnant women for depression?" They said no way, we can't do that right now. I said, why not? They said because we've been really embarrassed. We published some trials that suggest it is dangerous in pregnant women to stop taking their anti-depressants. We published some papers that said it's safe to take anti-depressants for the foetus. And they were caught on undisclosed conflicts of interest. So you would be doing a meta-analysis with conflicts of interest. I thought, wow, we've never thought about that. And so I said, what if we do a survey of meta-analyses, do they code for conflict of interest? They said, well make sure you include New England Journal as well as JAMA, we don't want to be picked on right now. I said, well JAMA doesn't, eh, New England Journal doesn't cover these kind of studies so it isn't relevant. Well, just make it broader, so we did. And we published a paper but one of our authors was from Cochrane Collaboration, so people started attacking us, that we were biased in favor of Cochrane Collaboration because we said they did it better.

So then we did a review of Cochrane Collaboration, and we said no, there was a deficiency in the risk of bias. They didn't adequately take conflict of interest into account. We were published in BJM. We were contacted by the Cochrane Collaboration. We said we reluctantly agree with you and we're going to give you the Bill Silverman Award. I didn't know what that was. He's a certified troublemaker. In the early days of doing their systematic reviews, he was very annoying and forced them to do things differently. You've just forced us to change our risk of bias assessment to include investigator conflict of interest and we're going to give you a thousand pounds, which we gave to the graduate student on the project.

(26:54) So now I'm pushing the issue, despite Ben Goldacre, that we have to be attentive to conflict of interest for non-pharmacological trials and PACE is going to be an example.

Audience: The problem with [or with Cochrane] the limit of analysis, it's about the format of the trial rather than the quality of the trial that you are assessing on. So actually, if you're getting a hold of poor trials which are good format, then that gives you a bias which is contradictory to the actual science.

Sure. But there are rules for evaluating risk of bias and I'll just be insistent on applying them. How about if we take a break for a beer and anybody who wants to keep going, we'll keep going and I'm around and anybody who wants to escape, they won't feel held captive. I appreciate holding your attention. Keep Tweeting. I don't know what's going out in the community.

Audience: Thank you very much! [APPLAUSE]