

**The Role of the Science Media Centre and the Insurance Industry in ME/CFS:
the facts behind the fiction**

Professor Malcolm Hooper September 2013

Some of the content of this document is already in the public domain; it was, however, commissioned for lawyers and high-profile others who had no knowledge of the background behind the ME/CFS controversy specifically to provide for them in a single document the facts relating to the Science Media Centre and its acknowledged campaign against people with ME/CFS, as well as the SMC's relationship with the Wessely School and their relationship with the permanent health insurance industry.

This document is in 6 sections:

Section 1 sets out the facts behind the Science Media Centre (SMC).

Section 2 considers the link between the SMC and key players in the ME/CFS controversy (whose own links with the permanent health insurance industry cause senior Parliamentarians serious concern).

Section 3 considers how the SMC is supporting and publicly promoting in the media certain mental health professionals who are acting in contravention of Department of Health policy.

Section 4 provides evidence of the SMC's campaign to discredit people with ME/CFS.

Section 5 provides evidence of the SMC's misrepresentation of the PACE trial results to the media.

The Conclusion considers how the SMC can credibly claim to represent "science" when it ignores so much science.

Section 1: The Science Media Centre (Founder Member: Simon Wessely)

The Science Media Centre (SMC) began work in 2002 under New Labour to operate like a newsroom for national and local media when science stories hit the headlines. It is funded by, amongst others, the pharmaceutical and chemical industries. Its Director is Fiona Fox. Its origins lie in the House of Lords Science and Technology Committee's Third Report (Session 1999-2000) which identified a breakdown of trust in the public's understanding of science and wanted to renew that trust.

The public increasingly have legitimate concerns about industry's corporate control over scientific and medical matters and they are right to be concerned.

For those not blinded by the SMC's dazzling aura, it appears that its covert purpose is to ensure that journalists and the media report scientific and medical matters only in a way that conforms to Government and industry's "policy" on the issues in question. To that end the SMC provides "training days" for journalists so that what they report on scientific and medical issues is effectively influenced and controlled by the SMC – indeed, Health Editors of various broadsheets have on numerous occasions confirmed that they will only publish items on ME/CFS research that emanate from the SMC.

The SMC provides off-the-record briefings with key figures at the centre of controversial issues (such as ME/CFS) who want to communicate with the media without being quoted directly but who nevertheless wish to ensure that their message receives maximum publicity.

It has close links with The Royal Statistical Society, whose members provide a "Before the headlines" service for it (<http://www.sciencemediacentre.org/working-with-us/for-journalists/headlines-for-journalists/volunteers/>); given that the majority of UK medical statisticians are bound by their institutions' mandatory allegiance to NICE, an effective circle of closed ranks exists when misleading statistics are challenged, as individual statisticians are fearful of speaking out, and some have admitted this to be so.

In March 2002 the SMC released its Consultation Report; its reassuringly-worded Executive Summary claimed: "The overall goal of the Centre is to help renew public trust in science by working to promote a more balanced, accurate and rational coverage of the controversial science stories that now regularly hit the headlines....It will aim to gain a reputation with the media for a fast, accurate and media-friendly response...The SMC will promote

itself to news-desks of national and local media as the place to come for information, comment and interviewees on science stories that hit the headlines...It will offer to refer journalists to appropriate specialists on the story; to offer fresh sound-bites and comments from key people; to offer opinion pieces for comment pages (and) will facilitate events in the SMC that will bring scientists and journalists together...(it will offer) a free venue for press briefings or interviews in central London”.

However, LobbyWatch (founded in 1998 by Jonathan Matthews to expose the complex web of pro-corporate lobbying and to keep track of the Living Marxism (LM) network – a political group that engages in infiltration of media organisations and science-related lobby groups in order to promote its own agenda) reported that within just months of its launch the SMC was embroiled in controversy over its activities: it was accused of employing “some of the clumsiest spin techniques of New Labour” and Professor David Miller of Strathclyde University was amongst the SMC’s critics: “The SMC is ...not as independent as it appears. It was set up to provide accurate, independent scientific information for the media but its views are largely in line with government policy....Its independence was supposed to be guaranteed by the fact that no more than 5% of its funding comes from any one source; yet 70% of its funding comes from business which could be said to have similar interests” (<http://www.lobbywatch.org/profile1.asp?Prid=121>).

Ten years ago, George Monbiot (winner of the United Nations Global 500 Award 1995 – a Roll of Honour which recognises environmental achievements of individuals and organisations) described how “a cultish political network became the public face of the scientific establishment” and said that Fiona Fox has used the SMC to promote the views of industry and to launch fierce attacks against those who question them (Invasion of the Entryists. George Monbiot: The Guardian 9th December 2003).

In his article, Monbiot set out the background to the SMC and its infiltration by vested interest groups: “One of the strangest aspects of modern politics is the dominance of former left-wingers...There is a group which has travelled even further to the extremities of the pro-corporate right. Its tactics (involve) entering organisations and taking them over (and) members of this group have colonised a crucial section of the British establishment. The organisation began in the late 1970s as a Trotskyist splinter; it immediately set out to destroy competing oppositional movements. In 1988 it set up a magazine called Living Marxism (known as) LM.In the late 1990s the group started infiltrating the media, with remarkable success. In 2000, LM was sued by ITN after falsely claiming that (its) news journalists had fabricated evidence of Serb atrocities against Bosnian Muslims. LM closed, and was resurrected as the web magazine Spiked.

“What seems to be a new front in this group’s campaign has come to light. Its participants have taken on key roles in the formal infrastructure of public communication used by the science and medical establishment.

“The scientific establishment appears unwittingly to have permitted its interests to be represented to the public by the members of a bizarre and cultish political network. Far from rebuilding public trust in science and medicine, this group’s repugnant philosophy could finally destroy it”.

LobbyWatch notes that the Living Marxism network members often hide their affiliations and engage in infiltration of media organisations in order to carry out advocacy for the corporate bodies by whom they are funded. According to Monbiot, these people are “industry lobby groups, they are not science lobbyists...Their ideology bears very little relation to science. It actually bears a close relation to corporate demands and where those demands are consistent with science they will claim to be on the side of science and where those demands are inconsistent with science they will keep quiet about it....We should not be at all surprised to find the corporate press embracing these people. They are putting out exactly the message that the corporate press wants people to hear....Clearly theirs is not a scientific position...it is a pro-corporate position and they will adapt their claims to what science is and isn’t around the demands of that pro-corporate position”.

Referring to the lack of transparency, Monbiot said that even more important is: “the way in which they stage debates which claim to be objective and even-handed debates but are totally controlled and managed. And this is what the Institute of Ideas specialises in” (see below).

As Monbiot points out, it is very hard to believe that the Living Marxism network and its successors (ie. the SMC, Sense about Science, “spiked”, the Institute of Ideas etc) includes a network engaged in corporate advocacy across a wide range of issues, taking a wholly pro-industry line, which makes things doubly difficult for critics.

Indeed, anyone foolhardy enough to criticise the SMC would face immediate ridicule and the opprobrium of virtually the entire UK scientific and medical establishment (and the organisations that fund them). The esteem in which the SMC is held, and its influence throughout the media, is invincible, as is clear from a short film it commissioned to celebrate its 10th anniversary in 2012 (<http://www.sciencemediacentre.org/film/>).

The text in the film informed viewers that: *“The SMC is funded by 80 different organisations across science and the media...(it) now has 2,400 science and engineering experts, and hundreds of press officers, on its database. It works to support 350 national news journalists.....Working in collaboration they ensure the media and public receive the most accurate, evidence-based information when science is in the headlines”*.

Fiona Fox herself says on the film: *“When a story breaks, within minutes, in the in-boxes of every single national news outlet will be an email from us which will generally include the availability of anything between 5 and 20 very, very eminent, trusted scientific experts willing and available to adapt fantastic science to the needs of this hungry 24-hour news beast....The SMC has privileged access to about 10-15 scientific journals in advance of the embargo lifting and we basically go to the database and seek third party experts who can put those studies into context....We really are genuinely a kind of altruistic set-up, trying to get good, accurate, evidence-based scientific information out there in the public domain”*.

This means that virtually the entire UK scientific and medical establishment, the UK nationals and the BBC unquestioningly believe what they are fed by the SMC. Such corporate control of science is scarcely believable.

The SMC produced a line-up of luminaries to extol it, including Sir Paul Nurse, President of The Royal Society; Professor Colin Blakemore, an Oxford neuroscientist and former CEO of the Medical Research Council; Professor David Spiegelhalter, Professor of the Public Understanding of Risk, University of Cambridge; Professor Giles Oldroyd, a plant scientist from John Innes; Dr Allan Pacey, a fertility expert from the University of Sheffield and Professor Adam Finn, a vaccine specialist from the University of Bristol. In addition there were well-known and respected journalists, including David Shukman (Science Editor, BBC); Nick Collins (Science Correspondent, The Daily Telegraph) and Kate Kelland (Health and Science Correspondent, Reuters). Others who praised the SMC included Lord David Sainsbury (Labour Minister for Science and Innovation 1998-2006) and Natasha Martineau (Head of Research Communication, Imperial College, London). Their unified praise of the SMC was fulsome, for example:

Natasha Martineau: *“The broad representation they have across the scientific community enables people to see the full picture without being dominated by any particular party line”*.

Professor Colin Blakemore: *“(The SMC) has taken a clear, pro-science view, not a kind of doctrinaire unconsidered pro-science view”*.

Worth noting is what Professor Blakemore said about the swine flu pandemic: he enthused that the Science Media Centre had provided *“a fantastic briefing for the media which just changed the whole course of the coverage”* and this was indeed so. However, on 20th September 2013 it was announced in the UK that: *“Swine flu jab carried a risk”* and that, after four years’ insistence that the vaccine was not harmful, the Secretary of State for Work and Pensions would announce that the Government has reversed its policy. A lawyer said: *“The damages paid out by the Government and GlaxoSmithKline, which made the vaccine, could reach £1 million for each victim”* (Oliver Moody; The Times, 20th September 2013) but it appears that the SMC failed to give this important science news due prominence.

Professor Adam Finn: *“Trust is the watchword for the communication about science. Overwhelmingly, people need to know that they’re hearing from somebody they can trust. The Science Media Centre has been able to become a focus. They have established a reputation, so that I think they’d be the natural place, certainly for science and health correspondents to go to when they want to engage on these kinds of stories”*.

Nick Collins (Daily Telegraph): *“They’ll have four or five people, really authoritative figures on the subject. They’re at the end of the phone for pretty much anything you could possibly ask of them, whether its getting hold of an expert to talk to you about a paper, getting hold of the author of the paper, getting you background information on a subject that you haven’t been able to find elsewhere. Really they’ve just been extremely helpful on every count”*.

Kate Kelland (Reuters): *“The Science Media Centre briefings provide access to so many of the important players in a scientific study at the same time in the same room. By the end of a briefing, you understand what the study is and why its important. The SMC is almost unique in being able to provide that for you”*.

David Shukman (BBC): *“What the Science Media Centre does, very effectively, is guide science journalists like me in where the centre of gravity lies in particular endeavours of scientific research....In terms of trying to get a handle on where the science stands, what the Science Media Centre does can be really valuable....When you’re under time pressures and dealing with something very controversial, it’s really nice if, among the people you’re dealing with, are those who are enthusiastic, highly responsive, incredibly professional, and that is what you find at the Science Media Centre – in spades”*.

In order to understand the SMC's activities in relation to ME/CFS, it is important to be aware of this background, and also of the background of the Director of the SMC, Fiona Fox.

Fiona Fox

Fiona Fox's track record is illuminating. In 2010, at the request of ex-Labour MP Jim Devine who apparently wished to intimidate his office manager Marion Kinley, Fiona Fox made a fake phone call to Kinley by pretending to be a journalist investigating her financial affairs; Kinley subsequently received £35,000 damages; Fiona Fox admitted that it was she who made the fake and harassing phone call (Employment tribunal hears of bizarre hoax phone call –The Director of Britain's Science Media Centre pretended to be a journalist investigating MP's staff expenses: Ian Sample: theguardian.com; 15th October 2010). Ian Sample commented: *"There are many wonderful things about being a science journalist....Now and then a grim story crops up. This is one of them"*.

Fiona Fox's long-term involvement with Living Marxism is a matter of record: she was a political activist defending the rights of Sinn Fein/IRA and indeed was head of the Irish Freedom Movement which supported the IRA in its armed struggle against *"British imperialism"* (she says she met her husband, Kevin Rooney, a socialist republican from West Belfast, at a protest in 1989 marking the first anniversary of the broadcast ban on Sinn Fein).

Notwithstanding, in June 2013 Fiona Fox (with no scientific training whatsoever but having been afforded the status of science "expert") was awarded an OBE for *"services to science"*. It is perhaps curious that she accepted such an honour, because she is on record stating: *"I was rather pleased when a friendly civil servant revealed that he had removed my name from an invitation list to a Buckingham Palace garden party, knowing that I would rather stick pins in my eyes"*.

She did, however, accept this honour but was at pains to give her reasons. She said that: *"what appeals to me about revolutionaries I now find in science"* and that she accepted it, not because it comes from: *"the royals or the state but from science; it was scientists who wanted to recognise me and the award is for my services to science....I also accepted it because I think this gong can only be interpreted as a vote in favour of scientists speaking out"*.

LobbyWatch is unambiguous: *"The activities of Fiona Fox and her friends have been public knowledge for years and they should have been shamed into permanent obscurity after the ITN/Living Marxism libel trial and the uproar over Fox's hypotheses about Rwanda (she denied the genocide in Rwanda). But instead they're still riding high and living off the fat of the land at the Institute of Ideas, Spiked-Online, Science Media Centre, King's College, the BBC, The Times etc"* (http://www.lobbywatch.org/lm_watch.html).

Commenting on Fiona Fox being honoured with an OBE, GMWatch notes: *"What they do not say is that... Fox led a double life. It's one which seriously undermines the SMC's claims to be open, rational, balanced and independent, not to mention its being in the business of ensuring that 'the public gets access to all sides of the debate about controversial issues'. It's a double life that connects the SMC's Director to the inner circles of a political network that compares environmentalists to Nazis...More disturbingly it is a network whose members have a long history of infiltrating media organisations and science-related lobby groups to promote their own agenda.....Her use of the Fiona Foster alias (the name she used in her writings for the Revolutionary Communist Party) may have reflected a need to keep her Living Marxism connections hidden....This background has to be an immense cause for concern in relation to Fox's role as Director of the SMC. Fox's Green College Lecture was titled 'The truth, the whole truth, and nothing but the truth: so where does that leave journalism?'. But neither Fox nor the Science Media Centre have been willing to disclose any of the truth about her long years of involvement with a network of extremists who engage in infiltration of media organisations and science-related lobby groups in order to promote their own agenda....Fox's own journalism might also suggest that she is non too fussy about either truth or openness when it comes to pushing her agenda. It is perhaps revealing that someone whose own journalism has been called 'shoddy' and 'an affront to the truth', and proved enormously controversial, has been selected as the Director of an organisation which claims the role of making sure that controversial scientific issues...are reported accurately in the media"* (http://gmwatch.org/index.php?option=com_content&view=article&id=14913 15th June 2013).

Another activist in the network is Fiona Fox's sister, Claire Fox; she is a prominent former member of the Revolutionary Communist Party and, like her sister, uses an alias (Claire Foster). In 2002 when Living Marxism was sued out of existence, Claire Fox founded The Institute of Ideas, of which she is Director. She is a regular panellist on BBC Radio 4's "The Moral Maze" and is known for her belief that bullying in schools could be a good thing because it teaches children how to cope in a survival-of-the fittest world. She regularly comments across

the whole range of media outlets including BBC Question Time; BBC Any Questions and BBC Breakfast; she writes regularly for national newspapers and for a range of specialist journals; she was number 64 in Time Out's 2006 list of London Movers and Shakers and she was named as the capital's No. 3 activist. She also features in the Daily Telegraph's list of Britain's most influential people on the Left (http://www.instituteofideas.com/people/claire_fox.html).

Claire Fox says of her sister Fiona: *"A lot of science stories in the paper will have come through her"* (Claire and Fiona Fox, sisters: Interviews by Caroline Scott; The Sunday Times 28th May 2006). This is undoubtedly true, and it has had a devastating impact upon those with ME/CFS and upon how the disease is perceived.

Section 2: The SMC, Wessely School psychiatrists, the Permanent Health Insurance industry, and ME/CFS

The SCM is closely associated with the online magazine "spiked" (www.spiked-online.com) which is militantly opposed to ME/CFS being accorded the status of an organic disorder; "spiked's" health writer is a London GP, Dr Michael Fitzpatrick, renowned for his perverse and immoderate attacks on those with ME, and especially for his disparagement of the UK Chief Medical Officer's comment on the 2002 Report on ME/CFS. Speaking in support of those with ME/CFS at the launch of his Working Group's Report, Professor Sir Liam Donaldson, then Chief Medical Officer, said on the record: *"CFS/ME should be classed as a chronic condition with long term effects on health, alongside other illnesses such as multiple sclerosis and motor neurone disease"* (BBC News/Health: 11th January 2002), only to be vilified by Fitzpatrick: *"The CFS/ME compromise reflects a surrender of medical authority to irrationality. The scale of this capitulation is apparent when Professor Donaldson claims that CFS/ME should be classified together with conditions such as multiple sclerosis and motor neurone disease. The effectiveness of the ME lobby reflects its middle-class base"* (spiked: Health: 17th January 2002: "ME: the making of a new disease").

Supporting Fitzpatrick, psychiatrist Professor Michael Sharpe (one of the PACE trial Principal Investigators who works for the permanent health insurance industry and so has a vested interest in categorising ME/CFS as a behavioural disorder, as "functional" disorders are excluded from benefit payment) said in the BMJ that doctors would not accept a particular strategy just because the CMO's report recommended it (BMJ:2002:324:131).

Psychiatrist (now Professor Sir) Simon Wessely, Founder Member of the SMC and listed as a member of its Scientific Advisory Panel (after whom the "Wessely School" is named: Hansard: Lords: 9th December 1998:1013), is also associated with "spiked". Wessely is Professor of Epidemiological and Liaison Psychiatry at King's College, London and of The Institute of Psychiatry (which is part of the South London and Maudsley NHS Foundation Trust; the Maudsley Charity funds the SMC). In its previous Notes for Editors, "spiked" said that Professor Wessely was available for comment or interview and could be contacted through Sandy Starr at "spiked" (0207-269-9234).

Sandy Starr, aka Alexander Starr, is listed by LobbyWatch as being involved, along with Dr Michael Fitzpatrick, Dr Phil Hammond (GP; comedian; writer and broadcaster) and Claire and Fiona Fox, as lobbyists for the Living Marxism network and its successors "spiked" and the Institute of Ideas.

Also listed as a member of the network is Tracey Brown, Director of the SMC's sibling organisation Sense about Science, another prominent "science" lobby group which lists Professor Sir Simon Wessely as a member of its Advisory Council.

The Permanent Health Insurance Industry

The extensive biomedical evidence-base on ME/CFS cuts no ice with the permanent health insurance industry for which so many members of the Wessely School work as Chief Medical Officers, medical advisors and as visiting assessors of claimants.

Obtaining the pension to which they have contributed and to which they are legitimately entitled is a huge issue for people with ME/CFS. Before the SMC came into existence, newspapers frequently carried distressing reports of the struggles that people with ME were having with their permanent health insurers and a compendium of this evidence still exists.

The incidence of ME/CFS is known to be rising: in order of insurance costs, ME/CFS came second in the list of the five most expensive chronic conditions, being three places above AIDS. A report written on 4th April 1995 by Dr

Carolyn Jackson for the insurance giant UNUM states: *“UNUM stands to lose millions if we do not move quickly to address this increasing problem”*.

The situation was so bad that in 1999 Members of Parliament were gravely concerned about the difficulties their constituents with ME/CFS faced with the insurance industry, especially with UNUM, as recorded in the House of Commons debate chaired by Sir Alan Haselhurst on 21st December 1999 (Hansard 147WH – 166WH). Some of the concerns voiced by MPs were that: *“All claimants are sent to a psychiatrist, whose diagnosis is subject to questionable decisions”*; *“It shows that insurance companies are prejudging the causes of and the treatments for ME”*; *“If they have been treated by an ME specialist who favours another method of diagnosis and treatment, they may find that their disability insurance payments cease”*; *“Several patients were forced to attend named psychiatric clinics and to receive cognitive therapy, graded exercise and psychoactive drugs. They were told that if they did not they would lose their pension rights”*.

In 2001 the insurance industry was increasingly worried: *“The first claim for Permanent Health Insurance (income protection) because of CFS or ME arose around 1987. CFS/ME is now one of the four commonest reasons for claiming income protection. Poor prognosis with CFS/ME has been found to be precipitated by certain illness beliefs and receiving a disability pension”* (Insurance Medicine, 3rd July 2001).

Following publication of the Chief Medical Officer’s Working Group Report on ME/CFS in January 2002, the medical insurance industry was alarmed and set about tightening control of such claims with heightened self-preservation. The following quotations come from an article in “Health Insurance Daily” by Peter Pallot:

“Official recognition has not brought clarity for insurers. Insurers see the devil in the long-term nature of CFS. Take for instance a 30-year-old City high flier who succumbed aged 30 when earning £75,000 a year. (He) might be in line to get two-thirds salary -- £50,000. Over 35 years, if the condition never resolved, the insurer would be paying out £1.75 million. Renaming the condition CFS and discarding earlier labels, including myalgic encephalomyelitis (ME), was helpful”.

Problems with the insurance industry are recorded in the Minutes of the All Party Parliamentary Group on ME held on 14th December 2004 which was addressed by James Millar Craig from Royds, a solicitor who at that time had 15 years experience of representing PHI claimants including those with ME/CFS:

“I have represented a fair number of clients with ME in PHI dispute with most of the principal insurers...in my experience they are getting more hostile to claimants generally and ME sufferers in particular....These insurers are powerful with extremely deep pockets and there are certain types of medical experts who are very happy to do insurance work...Needless to say, certain doctors have been extensively supported by the insurers and (their) names...appear repeatedly”.

The insurance industry’s continuing concern about ME/CFS claims was featured in the ME Association’s magazine “ME Essential” (February 2005 pages 12 – 15):

“It has been five years since the House of Commons last debated Permanent Health Insurance (otherwise known as income protection or replacement policies), as they affect people with ME/CFS. Little has changed in the intervening five years – if anything it is now more difficult for people with ME to persuade their insurance companies to pay out. MPs’ postbags bulge with complaints, and horror stories continue to pour in. The stories are legion, and known to many of us.

“Some policies contain exclusion clauses which relate to a diagnosis of a mental health problem. Despite the fact that both ME and CFS are classified by the World Health Organisation as neurological disorders and the UK Department of Health accepts this classification, we know of cases where this exclusion clause has been used to cover ME/CFS on the basis that the insurer’s medical expert believes that ME/CFS is a psychiatric disorder”.

Such was the national concern about the behaviour of the insurance industry and the denial of rightful claims, including people with ME, that on 4th April 2005, ITV broadcast a documentary (Tonight with Trevor McDonald) which addressed the issue.

In September 2006, James Millar Craig was quoted in an article “Quids out: the health insurance minefield” in InterAction (pages 30-33), the magazine of the charity Action for ME:

*“ ‘When it comes to PHI, the stakes are very high for all concerned. If an individual contracts a debilitating chronic illness in their 30s, a successful claim can result in payouts of hundreds of thousands of pounds. From an insurer’s perspective, ME/CFS is a particularly worrying illness....**Sadly for those affected there are still doctors prepared to assert that ME/CFS is a treatable psychiatric condition, thus giving insurers a pretext not to pay out’***

“He went on to raise the matter of supposedly independent doctors routinely hired by insurers...Far from being independent, he says, these doctors ‘tend to support the viewpoint that many ME sufferers are malingerers and are prone to mislead and/or exaggerate their symptoms’

“(James Millar Craig) talks about phone tapping using wireless scanners....Another persistent issue is the mystery of ‘lost’ forms and letters...A strong pattern emerges. There are too many similar stories of chronically ill people being systematically mistreated at the hand of PHI insurers for this to be mere coincidence. Indeed, one medical magazine sums up PHI insurers’ behaviour as ‘hardball tactics designed to wear claimants down and make them give up’ ”.

Following publication of the NICE Guidelines on CFS, on 22nd February 2009 “Health Insurance News” stated: *“This sounds like a physical problem, doesn’t it? However the NICE guidelines suggest that it is a psychiatric condition rather than a physical one....Because of the NICE guidelines, private health insurance companies are within their right to refuse to cover if an applicant’s policy does not include psychiatric cover”.*

That the Department of Health itself is concerned about the vested interests of the insurance industry in relation to ME/CFS patients is set out in a letter dated 24th November 2009 from a Senior Policy Manager, Mrs Lorraine Jackson, who wrote to Mr Nick Starling, Director of General Insurance and Health at the Association of British Insurers:

“I am writing about concerns that have been raised with Ministers and officials at the Department regarding the assessment of people with (CFS/ME) who are seeking payment of benefits under their insurance policies.

“Patient groups suggest that the insurance sector is interpreting the clinical guideline published by the National Institute for Health and Clinical Excellence (NICE) on the diagnosis and management of CFS/ME... to mean that CFS/ME is a psychiatric rather than a physical illness. As a result, they claim that many insurance companies are opting out of making payments to people with CFS/ME where there is a psychiatric exclusion clause in the contract.

“The Department of Health accepts the World Health Organisation’s (WHO) classification of CFS/ME as a neurological condition of unknown cause. The Department also accepts that CFS/ME is a genuine and disabling illness that can have a profound effect on those living with the condition”.

Thus there can be no doubt that the insurance industry is extremely exercised about ME/CFS, or that the SMC supports those psychiatrists and others who work for it and who recommend denying claims by people with ME/CFS on the grounds that it is a functional (mental) disorder. For the avoidance of doubt, extensive written evidence exists of such denials by those who promote themselves as “experts” on ME/CFS.

Section 3: The SMC is supporting and publicly promoting mental health professionals who are acting in contravention of Department of Health policy.

It will be recalled that Professor Sir Simon Wessely is a Founder Member of the SMC and a member of the SMC’s Scientific Advisory Panel (and listed as such in their literature).

It can readily be shown that Wessely has a proven track record of denying the existence of chronic disorders such as ME/CFS which might cost the insurance industry a considerable amount of money, a stance that sits squarely with the SMC’s *raison d’être* and which brooks no challenge to the insurance industry’s agenda: neither biomedical scientists, certainly not the public, and emphatically not patients, must be permitted to raise any doubts about ME/CFS being a behavioural disorder; if they do, they must be publicly ridiculed and discredited not only in the media but also in medical journals. Any dissenting evidence must be dismissed as “biased”, as was the case with the 2007 NICE Guideline on CFS: when irrefutable evidence of the organic nature of ME/CFS was submitted to NICE, the Guideline Development Group (advised by the Wessely School) deemed it to be of little value and it was discounted (J Inf 2007;55:6:569-571). Indeed, the GDG were specifically instructed not to consider the totality of the evidence about ME/CFS.

In accordance with the dismissal of all evidence that challenges the Wessely School’s view about ME/CFS, the SMC website carries an article “A Collapse of Respect of Authority or Expertise” which claims that whilst a minority of those consulted: *“saw the growth of public questioning of scientific expertise as a largely positive development....a larger group of those consulted feel that the declining trust in and respect for scientists is a worrying development...and an area of concern. Professor Simon Wessely echoed the views of many when he said: ‘The current trend towards equating all sources of knowledge as of equal value is very dangerous. We need to defend scientific expertise as a basis for sound policy decisions’ ”.*

This contrasts sharply with UK Department of Health policy: it was in September 2001 that the DoH produced “The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century” which

promised to utilise the knowledge and experience of patients themselves and promised that patients with chronic illnesses could become key decision-makers in the treatment process in partnership with healthcare providers. The publication stated: *"The era of the patient as the passive recipient of care is changing and being replaced by a new emphasis on the relationship between the NHS and the people whom it serves, one in which patients are empowered with information"*. Its key recommendation was to *"promote awareness and create an expectation that patient expertise is a central component in the delivery of care to people with chronic disease"*. The timetable for the full implementation was given as a six year period from 2001, with the programme to be mainstreamed throughout the NHS by 2007.

In defiance of this DoH policy, the SMC enthusiastically supports the Wessely School whose members consistently refuse to heed ME/CFS patients' evidence, but this is in direct contradiction to DoH policy requiring that patients with long-term diseases are to be acknowledged as experts in their own conditions.

What is *"very dangerous"* is the SMC's failure to fulfil its promise in its 2002 Consultation Report, which was to help renew public trust in science by providing accurate and balanced information via the media. Conforming to Wessely's edict that *"equating all sources of knowledge as of equal value is very dangerous"*, the UK mental health researchers who specialise in psychosocial disorders and who work for the permanent health insurance industry continue to ignore the significant evidence-base of over 6,000 published scientific papers that demonstrate the biomedical (neuro-immune) status of ME/CFS which invalidates their own view that it is a behavioural disorder, yet the SMC are overtly and covertly supporting them in this major deception.

These psychiatrists' views have often been legitimately challenged so, apparently in order to strengthen their own position, they resort to claiming in the media that they have been "harassed" by a "hate campaign" run by the ME/CFS community. This has afforded the SMC the opportunity to exploit the situation, to the significant detriment of ME/CFS sufferers.

Section 4: The SMC's campaign against ME/CFS patients

On its own admission, the SMC works closely with the Medical Research Council's PACE trial Investigators and with the MRC itself, so it is worth noting the involvement of the MRC in the campaign to discredit people suffering from ME/CFS.

The PACE trial statistician, Dr Tony Johnson, was until recently Deputy Director of the MRC's Biostatistical Unit (BSU), and the "Statistician Clinical Trials Unit (CTU) Division of Psychological Medicine Ref No: 06/A09" was described as the "Johnson_Wessely_Job" (07/07/2006) at The Institute of Psychiatry, so what Johnson wrote about people with ME/CFS during the life of the PACE trial was noted with concern, especially as his co-authors were the three Principal Investigators (PIs) of the PACE trial, Professors Peter White, Michael Sharpe and Trudie Chalder, all of whom are supported by the SMC and all of whom work for the permanent health insurance industry.

The Medical Research Council's BSU Quinquennial Review of 2006 was placed on the MRC's website and it said:

"Our influence on policy-makers has largely been indirect, through scientists' work on advisory committees, in leading editorials, in personal correspondence with Ministers, Chairs or Chief Executives (such as of Healthcare Commission or NICE), Chief Medical Officers and Chief Scientific Advisers, or through public dissemination when the media picks up on statistical or public health issues that our publications have highlighted".

Hence the influence of the MRC at the highest levels is far-reaching, so it was a matter of concern that Johnson's own Report within the Quinquennial Review stated:

"CFS is currently the most controversial area of medical research and characterised by vitriolic articles and websites maintained by the more extreme charities supported by some patient groups, journalists, Members of Parliament, and others, who have little time for research investigations".

Johnson's Report was an important official communication. **Coming from such a senior figure within the MRC, and considering his level of involvement with the PACE trial, Johnson's adverse comments about ME/CFS patients and charities would have carried considerable authority and influence.**

When asked to provide evidence in support of his comments contained in his Report, it took Johnson seven months to reply: on 7th November 2006 he wrote: *"I regret the words that I used"* and, remarkably, he was unable to supply any evidence to support his claims on the MRC website; he stated in his letter: *"I did not have*

specific individuals or groups in mind and consequently, I cannot provide you with the names and details of the charities, patient groups, journalists, Members of Parliament, and others, who I believed had little time for research. I do not have, and I have never thought about, attempting to compile such a list. Similarly, I do not possess, and have never possessed, a list of vitriolic articles and websites, so I cannot provide these”.

From this whole episode concerning Dr Johnson’s MRC Report, the ME/CFS community was left in no doubt about the bitter contempt for sufferers, some ME/CFS charities, and those MPs who support them that exists at the MRC, or that the seam of Wessely School dismissal and denigration does indeed run deep.

This was further borne out when a formal and fully referenced complaint about the PACE trial was submitted to the MRC, who declined to address it until instructed to do so by a Minister of State, whereupon it was effectively dismissed and key questions remained unanswered; it was subsequently ridiculed by the MRC’s Head of Corporate Governance and Policy, Dr Frances Rawle, in the British Medical Journal (BMJ 2011:342:d3780).

It was not until February 2013 that the SMC admitted that they had been orchestrating the campaign to publicise the alleged harassment by people with ME/CFS of those psychiatrists who regard it as a behavioural disorder.

Many people will recall the plethora of (frequently repeated) UK-based media items claiming that ME/CFS researchers, including Wessely, have been harassed and threatened by the ME/CFS community, with the entire ME/CFS community being likened to animal rights activists.

It is true that, mindful of the quality and extent of the published evidence demonstrating that ME/CFS is not a behavioural disorder, medical scientists, clinicians and patients alike have objected to the endless assertions of Wessely and his small group of colleagues about the nature of ME/CFS, but only a tiny number of extremists have apparently sent hate mail. However, the SMC and those it supports appear to have tarred the entire ME/CFS community with the same brush in that they have conflated legitimate and necessary Freedom of Information requests with “harassment” of the behavioural researchers.

Claiming harassment, vilification and abuse by ME patients is a regular pattern of what seems to be attention-seeking behaviour exhibited by Wessely over the years, usually when yet more published evidence further disproves his belief that ME is perpetuated by patients wrongly attributing their symptoms to a physical disease. At such times, Wessely appears intent on deflecting media attention away from the emerging biomedical science by portraying himself as the victim of endless harassment from vicious and intimidating ME patients.

The international ME community noted that the timing of the well-orchestrated 2011 campaign of media coverage about the alleged threats to Wessely coincided with the publication of the International Consensus Criteria for diagnosing ME that was compiled by 26 researchers from 13 countries (Journal of Internal Medicine October 2011:270:4:327-338; first published online on 22nd August 2011). The sound biomedical evidence upon which those criteria are based completely vitiates the UK psychiatrists’ belief that it a behavioural disorder.

The 2011 tranche of the campaign against ME patients began in earnest on 3rd June 2011 when Ewan Callaway reported Wessely’s telling the world that whilst he was used to being the subject of abuse, other researchers were “*absolutely appalled*” by their treatment, saying: “*This will convince another large group of decent scientists to say: oh no, I would rather go find the gene for homosexuality or do work on images of the prophet Mohammed than do this*” (Nature online:doi:10.1038/news.2011.347).

This was followed on 22nd June 2011 by an invited Feature in the BMJ by freelance journalist Nigel Hawkes, in which Wessely once again claimed he was being vilified and threatened by patients with ME. In it, Wessely publicly denigrated all patients with ME, asserting that they would rather have a disease caused by a retrovirus than admit they suffer from a mental disorder (Dangers of research into chronic fatigue syndrome. BMJ 22nd June 2011:342:d3780).

Hawkes certainly pitched battle on behalf of Wessely and of his like-minded colleagues who work for the insurance industry:

“There are jobs that carry a risk, such as volunteering as a human cannon ball at a funfair....And then there is the job of trying to conduct research into CFS/ME....Patients are incapacitated for years, unable to move, sometimes bedridden and fed through a tube. Yet it doesn’t prevent some people, who claim to be its victims, from conducting a relentless personalised attack on doctors and academics who are trying to discover its cause and improve its treatment. Simon Wessely, professor of epidemiological and liaison psychiatry at King’s College School of Medicine in London, has been the target of such attacks for years.

“It is a relentless, vicious, vile campaign designed to hurt and intimidate”, Professor Wessely says. ‘For some years now all my mail has been x-rayed. I have speed dial phones and panic buttons at police request and receive a regular briefing on my safety....Since PACE was published, this has become more intense’ ”.

Whilst any form of harassment is totally unacceptable, as the PACE trial Investigators persistently refuse to release data when requested (data which they do not own, as this was a trial funded by tax-payers), and as the Investigators refuse to publish the results of the trial according to the approved protocol, there can be little argument that they should be subjected to FOIA requests for information that is owned by the public, but such legitimate and necessary FOIA request cannot be described as harassment.

Hawkes continued: *“The personalised nature of the campaign has much in common with animal rights activists....While the campaigners have stopped short of the violent activities of the animal rights groups, they have another weapon in their armoury – reporting doctors to the GMC....Professor Wessely says: ‘With these people, it isn’t that they don’t want to get better but if the price is recognising the psychiatric basis of the condition, they’d rather not get better’ ”.*

Hawkes concluded his article: *“As for Professor Wessely, he gave up active research on CFS/ME 10 years ago. He now specialises in the problems of war veterans. ‘I now go to Iraq and Afghanistan, where I feel a lot safer’, he says”.*

To denigrate all patients with the devastating neuro-immune disease ME in such a fashion is deplorable and may amount to actual iatrogenic abuse of extremely sick and defenceless patients because of the knock-on effect such disparaging views have not only medical and public perception of the disease but on policy-makers and providers of care, and particularly on companies such as Atos which has been contracted by the DWP to assess people for eligibility for State benefits, at whose hands people with ME/CFS face intense harassment and dismissal.

The SMC’s role in this saga is not insignificant. Wrongly attributing ME/CFS to a mental health category, the SMC’s report “Review of the first three years of the mental health research function at the Science Media Centre” boasts: *“The SMC’s work on mental health research has produced more awards than any other area of our work. The SMC ourselves won the European College of Neuropharmacology’s inaugural Media Award for science in the media for our championing of evidence-based science in the face of...public prejudice and our efforts to ensure that the most critical issues currently affecting science and public health are debated on the basis of accurate and objective scientific information.*

“ Tom Feilden, science correspondent for BBC Radio 4’s Today programme, won the UK Press Gazette’s first ever specialist science writing award for breaking the story the SMC gave him about the harassment and intimidation of researchers working on CFS/ME. The SMC had nominated him for the award”.

(For factual information about the Tom Feilden “expose” on 29th July 2011 that was orchestrated by the SMC, see: <http://www.meactionuk.org.uk/Wesselys-Words-Revisited.htm> 30th July 2011).

In the interests of common justice, Tom Feilden would have done better to investigate the reasons why people with ME are so angry with the Wessely School by checking the easily verifiable facts and then to redress the balance by reporting with equal enthusiasm the other side of the “battleground” because, compared with Wessely’s 25-year campaign of dismissal and denigration of extremely sick people that has resulted in no appropriate healthcare provision and in the relentless harassment by the DWP of people with ME, there are those who consider that, whilst abusive emails and death threats are never in any circumstances to be condoned, complaints to the GMC of a dangerous failure to keep up to date with medical science are entirely understandable and legitimate.

Following the SMC’s expose on the BBC’s Today programme that was put on the BBC’s website, the SMC ensured that the campaign accusing sick people of harassing those who wanted to help them went global via the News Feed Centre, being reported not only in UK nationals such as The Guardian and science journals including The Scientist and the Medical Express, but by AFP; The Straits Times – Singapore English Language Newspaper; SKN Vibes – St Kitts, Windward Islands; Arabs Today; in Pakistan; in India; in New Zealand; the USA; Bulgaria and in Nigeria Daily News, amongst many others.

Unaware at the time of the SMC’s role in that campaign, it was noted that there are many who hold that it is Wessely et al who are orchestrating a media campaign against patients with ME, not the other way round.

Disregarding the substantial evidence that Wessely is wrong about ME/CFS, the SMC’s Review of its first three years’ work on mental health continued: ***“The SMC jointly nominated Simon Wessely for the inaugural Sense***

about Science John Maddox Prize for Standing up for Science for his courage and bravery in speaking out on CFS in the face of intimidation, which Simon won.

The SMC said about the John Maddox prize: *"The prize rewards individuals who have promoted sound science and evidence on a matter of public interest, with an emphasis on those who have faced difficulty or opposition in doing so"*. Given that Wessely's belief that ME is a somatoform disorder has been comprehensively invalidated by the scientific evidence, for him to have received a prize for "standing up for science" for his work on ME/CFS has resulted in widespread dismay, not least because it does not accord with the Declaration of Helsinki: section B11 requires that *"Medical research involving human subjects must conform to generally accepted scientific principles (and) be based on a thorough knowledge of the scientific literature"*, but Wessely's work ignores the existing scientific literature. There is abundant evidence that Wessely's views and influence have necessitated extraordinary courage and determination, not by Wessely, but by ME patients in the face of his orchestrated opposition to the acceptance of their disease as a legitimate medical entity.

Given the abundance of the biomedical evidence-base that exists which proves beyond any doubt that Simon Wessely's beliefs about ME/CFS are wrong, it is incomprehensible how any scientist or scientific organisation could support the award of the John Maddox Prize to him, yet the accolades from these pillars of the Establishment garnered by the SMC are there for all to see:

In a press release about the John Maddox Prize issued by Sense about Science, Tracey Brown (one of the judges), said: *"The John Maddox Prize recognises the work of individuals who promote sound science and evidence on a matter of public interest, facing difficulty or hostility in doing so"* and she referred to *"the courage and responsibility that people are taking for communicating sound science and evidence"*.

The journal Nature said it congratulated Simon Wessely: *"Simon Wessely is a psychiatrist at the Institute of Psychiatry, King's College, London, who has specialised in two areas above all – the mental health of military personnel and veterans, and chronic fatigue syndrome....He subsequently developed a treatment approach using cognitive behavioural therapy techniques...This treatment...can now be found in the guidelines of the United Kingdom's National Institute for Health and Clinical Excellence. 'All along the way', says the individual who nominated him (Wessely's fellow psychiatrist, Professor Anthony David) 'Wessely has had to suffer continued abuse and obstruction from a powerful minority of people who, under the guise of self-help organisations, have sought to promote an extreme and narrow version of the disorder....Hostile letters, emails and even death threats have been directed at Professor Wessely over two decades. Mischievous complaints have been made against him and his clinical team, and bogus questions raised in the Houses of Parliament'"* (that questions raised about Wessely in both Houses of Parliament were anything but "bogus" can readily be checked by consulting Hansard).

Writing in support of the award to Wessely, the Editor of Nature and one of the judges, Philip Campbell, said: *"We looked beyond communicating for a more unusual degree of courage. The winners of the prize demonstrated the kind of sustained resilience and determination to communicate good science that John Maddox personified"* and at the presentation he spoke of the *"acute hostility"* that Wessely had endured and said he was *"a very worthy winner"*.

Professor Colin Blakemore, one of the judges, said: *"...the two winners stood out....Simon Wessely and Fang Shimin have worked with courage and dignity to uphold the standards of science and evidence against the forces of prejudice and greed"*.

Professor Sir John Beddington, recently retired Government Chief Scientific Advisor, said: *"Given the importance of science...it is more important than ever for scientists to speak up and make their views heard. This always requires conviction but often requires real courage too, and I welcome the John Maddox Prize as recognition of that"*.

Sir Paul Nurse, President of The Royal Society, said: *"The John Maddox Prize is an exciting new initiative to recognise bold scientists who battle to ensure that sense, reason and evidence base play a role in the most contentious debates. The winners will be an inspiration to us all"*.

(For factual information about the award of the inaugural John Maddox prize to Professor Simon Wessely, see: http://www.meactionuk.org.uk/Wessely_John_Maddox_Award.htm 12th Nov 2012).

Pressing ahead with its campaign to support the allegedly beleaguered ME/CFS researchers, in its item "Supporting experts targeted by extremists" (part of its "Review of the first three years of the mental health research function at the Science Media Centre", which was supported by funding from the Maudsley Charity), the SMC was clear: *"We have also been involved in supporting experts who have found themselves being targeted"*

by individuals or groups who do not like their research. This has been particularly important in the case of psychiatrists and psychologists working on chronic fatigue syndrome/ME....The SMC ran a press briefing on the first findings from the PACE trial, and supported the researchers involved throughout this process, for example by organising media training in collaboration with the MRC. When we became aware of the level of intimidation researchers were experiencing we brought together key parties for a brainstorm to discuss what could be done to aid researchers. At this event it was agreed that these harassed experts should speak out publicly about the harassment they were experiencing. As a result the BBC Radio 4 Today programme ran an expose on the piece and a number of outlets followed the story including The Observer and the Daily Mail”.

In case people did not get their message, the SMC Report continued: *“One of the consultation findings was that psychiatry is particularly badly portrayed in the news media so the SMC has concentrated a lot of effort on getting to know academic psychiatrists. This has been a great success...Seizing the agenda: The SMC has also helped set the agenda and frame the narrative of reporting on a number of big issues...This kind of agenda setting was also on display in our work around the harassment and intimidation of researchers working on chronic fatigue syndrome/ME. The meeting organised by the SMC on this was the first of its kind and brought the beleaguered researchers together with representatives of funding agencies, the police, the GMC etc. One of the results of that meeting was the decision of a number of academics to go public on their situation with the support of the SMC and their respective press officers. The SMC engineered the coverage through working with the Today programme on an exclusive – a story that was planned over many weeks. The result was huge with Today making the very best of their exclusive...As expected, the follow up was huge with almost every newspaper, Sunday paper and influential magazine covering the subject in some way...Our proactive press work has been popular with journalists and experts have benefitted from our support to help them speak in the media”* (Review of the first three years of the mental health research function at the Science Media Centre; Dr Claire Bithell, Head of Mental Health, Science Media Centre: <http://bit.ly/12mL0LD>).

At the news briefing held on 22nd April 2013 at the SMC to launch the UK CFS/ME Research Collaborative funded by the MRC in which the PACE Principal Investigators are instrumental and where all members of that Collaborative (including those ME charities who agreed to be part of it) are required to sign a declaration supporting Dr Esther Crawley’s Collaborative Charter (ie. that they will not challenge the psychiatrists’ views about ME/CFS, which are that it is a behavioural disorder -- CFS/ME Research Collaborative Charter: “3.2.3 **Members will be required to sign a declaration that they will not take part in the harassment or abuse of researchers. Neither will they take part in orchestrated campaigns against those conducting peer-reviewed research**”), the SMC press release stated: *“Predisposing factors include female sex, functional somatic syndromes, and prior mood disorders. For treatment purposes, important maintaining factors include co-morbid mood disorders, beliefs about causation and either pervasive inactivity or swinging from inactivity to over-activity”*. That is entirely false information but it accords with the SMC’s policy of incorporating ME/CFS within its “mental health” category and is in accord with its support of mental health researchers as set out in its Review of its first three years research function.

As part of its aim to control the media and thus to influence public opinion, the SMC produced a leaflet (“Advice for Researchers Experiencing Harassment”) in which it states: *“Some researchers working on high-profile subjects that attract controversy, such as...chronic fatigue syndrome/ME have also found themselves targeted by people who have extreme views about their research. This harassment could include... malicious complaints to institutions or regulatory bodies, bombardment with Freedom of Information requests....There is a serious risk that researchers become focussed (sic) on answering those with extreme views rather than speaking to the media, wider public and policy makers....The Science Media Centre is an independent press office for science in the media...We see time and time again how engaging with the media can help ensure public opinion is on your side....If you can communicate your views effectively, it is likely most people would agree with you....Focus on ...the general public, news media, policy makers or a patient group...We can ...help you engage with the national news media to ensure your voice is heard....We can also alert stakeholders such as press officers in relevant organisations, funding organisations etc”* (<http://www.meactionuk.org.uk/SMC-Advice-for-Researchers.pdf>).

Further episodes of the campaign to discredit those with ME and the scientists and clinicians who support them were to follow: on 18th September 2012 Michael Hanlon, described as *“Britain’s sharpest and most well-read newspaper science journalist”* (but who was compelled to admit that he has no scientific training or experience) wrote a provocative article: *“ME is probably a mental illness after all – but that does not mean that it is not real”* in the Daily Mail online: *“Tin hats on. A story about myalgic encephalomyelitis has emerged and, save animal experimentation, I cannot think of another area of medicine that arouses such passion. Indeed ‘passion’ may not be the right word – ‘hysteria’ may be a better term....No-one really understands what ME is but what we do seem to have shown is that whatever the cause, it is not a virus....Doctors who have stated that ME is not caused by a virus but may instead be a psychiatric condition have been compared to Nazi war criminals....Last March, The Lancet published a study showing that a series of therapies, including exercise and cognitive behavioural therapy*

could be highly effective against ME – suggesting of course that this was primarily a mental problem not a physical disease. The doctor who performed the study, Simon Wessely, a professor psychiatry at King's College in London, was subjected to a hate campaign few scientists who do not perform vivisection on apes have ever had to endure”.

It should be noted that Hanlon got many of his “facts” wrong: The Lancet study referred to was published a full year earlier in March 2011, and Simon Wessely did not perform the study, although he did direct the management of it.

Hanlon continued: **“Quoted in the British Medical Journal last year, in an excellent piece on the ME hysteria written by Nigel Hawkes, Professor Wessely pointed out the sheer unpleasantness of these attacks. ‘These people are sulphurous, vicious; horrible.’What does it matter whether ME is caused by a virus, a faulty gene, a psychiatric issue or an errant immune system?....The problem seems to be the labelling of ME as a ‘psychiatric’ condition....Something about this disease seems to cause a suspension of reason....The trial reported in the Lancet suggesting that exercise and CBT were effective was subject to a vigorous campaign, and one doctor (not an ME sufferer) wrote a 442-page rebuttal to the Lancet, which was full of accusations of bias. When this was given to the Medical Research Council for a response, another flood of accusations followed. There was a campaign to prevent NICE, the value-for-money watchdog, not to approve ‘psychiatric’ treatments such as CBT. There was even a petition sent to Downing Street. This does not happen in other areas of medicine....Perhaps now the final nail in the coffin of the virus theory appears to have been driven home, we will find out once and for all the true story behind the ME fanatics”.**

Hanlon’s media campaign against people with ME did not stop: he published his next attack on ME patients in The Sunday Times on 5th May 2013. It was entitled “This man (with a picture of Simon Wessely) faced death threats and abuse. His crime? He suggested ME was a mental illness”. The sub-heading read: **“Leading scientists such as Sir Simon Wessely are facing a sustained terror campaign – just for researching the causes of ME”.**

Once again, much of Hanlon’s article was misleading and factually wrong and was another inflammatory piece portraying those with ME as dangerous fanatics: **“Professor Wessely’s misfortune is to have entered the bewildering world of myalgic encephalomyelitis, or ME – initials that strike fear into the hearts of doctors. The story of ME activism is probably not one you will have heard much about, even though it is just as controversial as vivisection. Because not only do doctors who work in the field get a lot of grief, so does any journalist who covers the story. I was told by more than one colleague that I was mad to even think about writing about it. The story of ME is in fact a story of a war...On the one side in the ME war are the doctors and scientists...(who) believe that ME...is often associated with psychological problems....Most doctors who treat ME ...believe that certain treatments, notably cognitive behavioural therapy and exercise therapies, provide the best hope for sufferers to get better....On the other side are the activists. These people say that any attempt to label ME as ‘psychiatric’ illness is to denigrate the suffering....Fiona Fox, head of the Science Media Centre, believes that the extremism of some ME activists is skewing a whole branch of medicine. ‘We were deeply shocked to discover a few years ago that many scientists doing research on ME/CFS were too afraid to speak out in the media about their work, because of a campaign of harassment and intimidation’, she says.**

Hanlon’s article continued: **“Few people will speak on the record about the extent of the threat to the ME researchers. There is, I am told, a specialised unit at the Metropolitan Police dedicated to monitoring the threat, but no-one at Scotland Yard will speak publicly about this....The most high-profile combatant of the ME war in Britain is Wessely....Wessely has been accused of just about every transgression going”.**

Referring to the finding that a retrovirus known as XMRV was not, after all, the cause of ME, Hanlon wrote: **“The extremists erupted in fury.....As for the XMRV paper, Wessely snorts with derision”.**

As Professor Hooper noted: **perhaps the most telling sentence in Hanlon’s article is this: ‘As for the 2009 XMRV paper, Wessely snorts with derision’: it is this derision and absolute triumphalism over the XMRV debacle that personifies the scornful way people with ME have been – and still are – treated.**

Hanlon’s article went on to quote from Tracey Brown, Director of Sense about Science: **“ ‘It’s quite cultish’, says Tracey Brown...She lists the defining characteristics of the extremist: ‘Predominantly female, intelligent, in her forties. Brighter than their jobs and education suggest they are’....As Fiona Fox says: ‘The terrible irony is that the very scientists who treat CFS patients, who understand how debilitating this condition can be and who are dedicated to finding effective treatments, have been silenced’ ”.**

Perhaps the one redeeming point made by Hanlon is a quote from sociology lecturer Angela Kennedy: **“ ‘Raising reasonable objections to something through legitimate means – such as FoI requests or official complaints – is not**

harassment or abuse'. Indeed, she claims, the abuse is often in the other direction: 'Hate speech is being waged against people with ME'".

What Hanlon might equally have pointed out is what seems to have escaped the behavioural lobbyists, namely that no biomedical scientist working in the field of ME has ever been subjected to FoI requests or reported to the GMC, which ought to tell the industry lobbyists who so vociferously support the Wessely School something very important.

(A reply to Hanlon's email and Professor Hooper's full comments on Hanlon's article can be read at <http://www.meactionuk.org.uk/Sensationalism-versus-Science.htm>).

The behavioural lobbyists' campaign against ME and the clinicians and scientists who support them took another disturbing turn at the end of 2012. To its credit, on 25th November 2012 the Independent on Sunday (IoS) published a short article entitled "ME: bitterest row yet in a long saga" by Sanchez Manning in which three well-known opponents of the Wessely School commented on the award of the John Maddox Prize to Simon Wessely:

"A British psychiatrist should be stripped of an award, fellow scientists said last night....Critics... said the professor's work perpetuates the idea that myalgic encephalomyelitis, also known as chronic fatigue syndrome (CFS), is a mental health problem....Malcolm Hooper, emeritus professor of medicinal chemistry at Sunderland University, said: 'He's responsible for trying to make ME into a psychiatric condition when it's not. He has done very poor science'. Another opponent, the Countess of Mar, said: 'I was absolutely horrified when I read he'd won the award and I would like to see it retracted'. Dr William Weir...who says ME is caused by a chronic viral infection, called the decision 'almost satirical. If the scientific data is properly examined it will be seen that Professor Wessely's doctrine is wrong and it will be proved to be wrong'".

Wessely was yet again quoted as saying how he had been harassed, stalked and intimidated by fanatical ME/CFS lobby groups that dispute his views.

Not unexpectedly, the following Sunday the IoS published a letter signed by 26 supporters of Wessely and his views about ME/CFS, foremost signatories being the three PACE trial Principal investigators (Professors Peter White, Michael Sharpe and Trudie Chalder, all of whom work for the insurance industry), together with others known for their same beliefs about ME/CFS. That letter accused Lady Mar, Professor Hooper and Dr Weir of making "allegations" against Simon Wessely. The signatories claimed that "Such harassment risks undermining research...and discouraging specialist clinicians from entering the field".

This was a serious development, because it was manifestly untrue that any of the three people quoted in the article had ever engaged in – nor would they ever engage in – harassment of Simon Wessely or anyone else, but it showed the depths to which the behavioural lobbyists were prepared to stoop to accuse those who disagree with them of "harassment".

To cast doubt – and so publicly -- on the judgment of another registered medical practitioner who does not subscribe to their own view is in breach of the GMC Fitness to Practice Guidelines.

In a surprising about-turn, possibly because of the seriousness of the public accusations against the Countess of Mar, Professor Hooper and Dr Weir, on 4th December 2012 Professor Peter White wrote individually to all three, saying the same thing:

"Unfortunately, the final version of the letter which was published was revised by the IoS, without our prior knowledge or agreement, such as to change its meaning, so as to imply that we were accusing you and others mentioned of personally being responsible for harassing Professor Wessely....I regret that this has occurred and hope that you will accept my apology for any harm or upset this may have caused you".

Because of the seriousness of this situation, the Deputy Editor of The Independent on Sunday was contacted and was asked if the paper had indeed "revised" Professor White's letter. He replied:

"Avoiding the charge that we have misrepresented someone's views is just the sort of thing that makes this job so stressful, and we work very hard to make sure no-one has grounds for claiming such a thing. So I'd be grateful if Peter White could tell me in what way we have substantially altered what he wrote...My colleague (the sub-editor in charge of that page) asked for a minor clarification for legal reasons, so that the reader would not infer that it was the paper that was making the allegations".

The Deputy Editor kindly provided the original letter submitted by Professor White and it was placed on the paper's website; the version that Professor White had intended to be published was in fact more defamatory and inflammatory than the version that had been published in the hard copy issue.

This whole matter gave rise to a series of correspondence between Lady Mar and Professor White; on 24th December 2012 the latter wrote to Lady Mar explaining that the Science Media Centre had been involved with mediation on his behalf:

"The IoS were unwilling to publish a correction or clarification in the hard copy newspaper. This was in spite of mediation by the Science Media Centre on our behalf".

However, on 13th January 2013 the IoS published a letter in its hard copy paper from the Countess of Mar, Professor Hooper and Dr Weir, which said:

"Scientific understanding always depends upon sound evidence...For scientific understanding to prevail, the extensive biomedical evidence-base of ME/CFS must now be recognised by all researchers in the field. The idea that ME/CFS is due to a dysfunctional psyche is a hypothesis without an evidence-base. The Maddox Prize was therefore awarded to the defender of an hypothesis with no evidence-base rather than to someone who was upholding true scientific inquiry. Personal attacks against Professor Sir Simon Wessely do not advance the cause, but it is scientifically legitimate to direct criticism at the hypothesis both he and Professor White continue to espouse".

People are justifiably angry that a small group of psychiatrists who have consumed such a large share of research funding for over 20 years have acted in a way that is wholly unscientific, ie. when the evidence from their own studies shows their ideas to be wrong, they either ignore their own evidence or appear to misrepresent it and, in the case of ME, the system which is meant to protect against this (academic peer review) has completely failed to prevent such misrepresentation; furthermore, the SMC has been actively involved in such misrepresentation to the media.

The latest accusation of a campaign of harassment by people with ME/CFS against the behavioural researchers is to be found in the Decision Notice of 22nd August 2013 by Judge Christopher Hughes at a UK Information Rights Tribunal, who found against the Appellant, Mr John Mitchell, and ruled that both the Information Commissioner and Queen Mary University of London were correct not to accede to a FOIA request for release of documents relating to the PACE trial. The Tribunal Judge ruled that academic freedom overrides public interest; indeed, he went further by stating that the FOIA request was: *"part of a campaign which has now extended to the use of FOIA"*. He even went so far as to state: *"The tribunal has no doubt that properly viewed in its context, this request should have been seen as vexatious – it was not a true request for information – (and)...might have been more efficiently and effectively handled if treated as vexatious"*.

Unsurprisingly in the light of its invited Feature by Nigel Hawkes on the alleged harassment of researchers by ME/CFS activists published in June 2011, the BMJ carried a resume of the judgment by its legal correspondent Clare Dyer (BMJ:2013:347:f5355).

That the entire UK ME/CFS community has been subjected to disparagement and vilification by the behavioural researchers is a matter of record.

It is also a matter of record that in 2002, the BMJ ran a ballot asking doctors to vote on what they considered to be "non-diseases" that are best left medically untreated and Wessely is believed to have proposed ME. Along with freckles and big ears, ME was voted a "non-disease" and in April 2002 both broadsheet and tabloid newspapers ran banner headlines proclaiming that ME is a non-disease. As a direct result, patients with ME/CFS were removed from GPs' lists on the basis that *"This practice does not treat non-diseases"*.

To dismiss a serious neuro-immune disease from which patients die – as confirmed by UK Coroners' reports -- with such ridicule is shocking.

For the SMC to support and actively promote those involved with the PACE trial who continue to maintain that for people with ME/CFS, **"medical intervention is no longer appropriate"** and that the aim of therapy is to **"reduce healthcare usage"** (http://www.meactionuk.org.uk/Problems_and_Solutions.htm) is equally shocking.

Section 5: evidence of the SMC's misrepresentation of the PACE trial results to the media.

The emanations from the Science Media Centre may be accepted by informed observers to be suspect because it represents only one narrow section of the scientific community (<http://ngin.tripod.com/020602c.htm>) but its wildly exaggerated press briefing for the PACE trial on 17th February 2011 was a travesty *par excellence*.

There is irrefutable evidence that the Principal Investigators (and others involved in the trial):

1. failed to fully declare their competing interests, thus informed consent may not have been obtained
2. failed to comply with essential ethical guidance and Codes of Practice in many crucial domains
3. chose (their own) entry criteria that did not define the population purportedly being studied
4. failed to subgroup the cohort according to the presence of neurological signs and symptoms, without which CFS/ME cannot be diagnosed
5. failed to adhere to the published protocol (Dr Ben Goldacre of "Bad Science" says of such practice: "*in a trial... you have to say which is the 'primary outcome' before you start: you can't change your mind about what you're counting as your main outcome.... It's not just dodgy, it also messes with the statisticsYou cannot change the rules after the game has started. You cannot even be seen to do that*" (The Guardian: 5th January 2008). The fact is that the PACE Investigators did change the rules after the game had started and they have been seen to do that
6. changed the required entry score on the SF-36 physical function scale after the trial had started
7. changed their scoring methods and thresholds once they had obtained their data
8. carried out the one objective test (6 MWT) in a meaningless way in the context of CFS/ME (after one year of therapy, PACE participants – average age 38 years -- did not achieve a one-off result achievable by healthy people aged 85)
9. admitted they were not studying "CFS/ME" after all (merely chronic "fatigue")
10. reported that there was no reduction in State or insurance benefits claimed by participants (in fact there was an increase in benefit uptake)
11. refused to supply the return-to-work figures despite FOIA requests
12. reported that at the end of the trial, the Clinical Global Impression results showed that 60% of participants in the GET group and 58% of participants in the CBT group reported negative or minimal change in overall health
13. proclaimed the trial as successful, whilst ignoring the fact that 70-72% were not helped.

Most importantly, the PIs used an inappropriate comparator to define their own "normal range", which enhanced the claimed efficacy of the interventions; furthermore, **their *post-hoc* changes, revisions and recalculations resulted in the illogical situation whereby participants could score worse on completion than on entry but still be classed as being "within the normal range" due to the (alleged) success of the interventions** (NB. The "normal range" is a statistical term and does not equate to "normal" health, and certainly not to "recovery").

Significantly, between 2002 and 2011-2013, the PIs' definition of recovery fell from an SF-36 physical function score of 85 or above to a score of only 60 or above. **The Investigators' new threshold of 60 is noteworthy because it is lower than the score of 65 required for entry to the trial, so a participant could deteriorate or stay the same but still be counted as recovered in the published results.**

This has resulted in an explicit contradiction by the Investigators because, having set the lower bound for recovery at 60, they also state in the same paper that any SF-36 score of less than or equal to 65 represents abnormal physical function, therefore, in the same paper, scores of 60 and 65 represent both abnormal physical function and recovery (Psychological Medicine 2013;43(10):2227-35).

Common sense would suggest that a mathematically-derived recovery threshold which allows a participant to deteriorate and still be described as recovered must contain a mistake, yet common sense has not prevailed in the case of an MRC-funded trial of psychological interventions for ME/CFS.

It is important to be aware that the figure of 60 for "recovery" was used by the Investigators specifically for the PACE trial and it contradicts how they themselves previously defined markers of recovery in the same disorder using the same measure: in 2007 they stated: "*A patient had to score 80 or higher to be considered as recovered*" (Psychother Psychosom 2007;76:171-176) and in 2009 their Dutch colleagues asserted: "*A cut-off of less than or equal to 65 was considered to reflect severe problems with physical functioning*" (European Journal of Public Health 2009;20:3:251-257).

All this evidence was known about by the PIs and others involved with the PACE trial at the time of the SMC press briefing.

In total disregard of the evidence, the SMC produced and publicised the opinions of clinicians known for their adherence to the behavioural model, including some physicians – such as Dr Alastair Miller and Dr Brian John Angus – who were involved in the PACE trial itself. For example, the Science Media Centre Press Release included the following:

- Dr Alastair Miller from Liverpool: ***“This trial represents the highest grade of clinical evidence – a large randomised clinical trial, carefully designed, rigorously conducted and scrupulously analysed and reported. It provides convincing evidence that GET and CBT are safe and effective and should be widely available for our patients with CFS/ME”.***

It should be noted that Dr Miller was one of the three “independent” assessors of trial safety data for the PACE Trial.

As the PACE Trial was not a controlled trial, Dr Miller was in error to refer to it as: ***“the highest grade of clinical evidence”***, and it cannot be described in such terms.

- Dr Brian John Angus: ***“The study should reassure patients that there is an evidence based treatment that can help them to get better.... It was extremely rigorous... (and) was carefully conducted....As a trial this involved a huge amount of checking and cross checking....This should mean that GET and CBT should be widely available throughout the country....The trial was conducted to a high ethical standard... .It was rigorously performed”.***

Dr Angus was Centre Lead for the PACE Trial in Oxford.

- Professor Derick Wade from Oxford: ***“The trial design of this study was very good, and means the conclusions drawn can be drawn with confidence. This is a very significant finding. It identifies that one commonly used intervention (by which he meant pacing) is not effective (and therefore should not be used), and it confirms the effectiveness of two treatments, and their safety. The study suggests that everyone with the condition should be offered the treatment, and every patient who wishes to be helped should be willing to try one or both of the treatments”.***

The implication of this is that if people refuse to take part in these “rehabilitation” programmes, they do not wish to get better, so they can expect their State benefits to be withdrawn. Professor Wade has notably written to the DWP advising that, despite the WHO classification, ME/CFS is not a neurological disorder but a ***“non-medical illness”*** (letter dated 22nd August 2005 to Dr Roger Thomas, Senior Medical Policy Advisor in the Benefit Strategy Directorate at the DWP). He has also written to an ME/CFS patient: ***“it is wrong to fit ME/CFS into a biomedical model of illness”*** (letter dated 7th July 2006).

- Dr (now Professor) Willie Hamilton: ***“This study matters. It matters a lot...It sends a powerful message to PCTs – and the soon-to-be-formed GP consortia – that they must fund CBT or GET. NICE proposed this before the study came out – the evidence is stronger now”.***

Dr Hamilton is Chief Medical Officer for three permanent health insurance companies -- Exeter Friendly Society, Liverpool Victoria and Friends Provident – and he categorises ME/CFS as a functional disorder. (People diagnosed as having this disorder will thus be excluded from payments under a permanent health insurance policy with these companies, since psychiatric disorders are not covered). He was a member of the NICE CG53 Guideline Development Group which recommended CBT/GET as the only intervention for people with ME/CFS.

At the PACE trial press briefing, a number of grossly inflated and quite unjustified claims were made that are not supported by evidence – for example, one of the PIs, Professor Trudie Chalder, said: ***“Twice as many people on graded exercise therapy and cognitive behaviour therapy got back to normal”.*** Another PI, Professor Michael Sharpe was present but made no attempt to correct her, nor did the Chief PI, Professor Peter White (who was not present at the SMC press briefing) make any subsequent attempt to correct such blatant misrepresentation of the facts.

The Science Media Centre supplied and publicised quotations only from people with known and indisputable biases and with vested interests in maintaining the misperception of ME/CFS as a functional (behavioural) disorder, which does not accord with their claim of reporting science in a ***“balanced, accurate and rational”*** way.

Consideration of the PACE trial data dispels the assertions quoted above so it was essential for the protection of vulnerable patients that a more balanced interpretation of the PACE trial findings was supplied to the media and thus entered the public domain, but the Science Media Centre did not ensure any such dissemination.

Following publication of selective results of the PACE trial in The Lancet, Swiss Re's UK Life & Health Claims team arranged a web-based training session with Professor Peter White; it was called "Managing claims for fatigue the active way" and it was explicit: *"It will likely take time before the general public and some medical professionals accept the findings of this research....Key takeaways for claims management....It is likely that input will be required to change a claimant's beliefs about his or her condition and the effectiveness of active rehabilitation"*, hence the PACE trial Investigators' deceptions about ME/CFS are not merely an academic matter: they have led to sentiments such as these, where it becomes acceptable practice for insurers to coerce sick people into believing things that are demonstrably untrue.

Another key takeaway for claims managers said: *"A final point specific to claims assessors, and a question we're often asked, is whether CFS would fall within a mental health exclusion, if one applies to the policy. The answer to this lies within the precise exclusion wording. If the policy refers to functional somatic syndromes in addition to mental health, then CFS may fall within the exclusion....The point made is that a diagnosis of ME is considered a neurological condition according to the arrangement of the ICD...whereas CFS can alternatively be defined as neurasthenia which is in the mental health chapter of ICD-10"*.

These psychiatrists who work for the insurance industry have been notified more than once that their assertion that ME/CFS has dual classification in the WHO International Classification of Diseases (once in the Neurological Section at G93.3 and also in the Mental (Behavioural) Section at F48.0) is incorrect. Their false assertions have been repudiated by the WHO, who on 23rd January 2004 confirmed in writing: ***"According to the taxonomic principles governing ICD-10, it is not permitted for the same condition to be classified to more than one rubric"***. The WHO further confirmed that this means that ME/CFS **cannot** be known as or included with neurasthenia or any other mental or behavioural disorder, as ME/CFS is a distinct nosological disorder.

The readily-provable facts are that the PACE Investigators who work for the insurance industry pay no heed to the WHO classification, to scientific exactitude, to an international biomedical evidence-base on ME/CFS, nor to patients with ME/CFS because, it appears, profits must take precedence over patients, and the Science Media Centre fully supports them.

Conclusion

Fiona Fox proudly claims that the SMC: *"has pioneered the need for more scientists to engage with the really messy, contentious and politicised science stories"* in which one cannot but surmise that she includes ME/CFS (Fiona Fox's SMC blog: Why I accepted an OBE: 17th June 2013).

It is regrettable that when the SMC "speaks out" on ME/CFS, it fails to report on biomedical science and focuses only on the ideology and propaganda of the powerful vested interest groups on its own agenda.

Given the SMC's claim of *"balanced, accurate and rational coverage"* of scientific and medical issues, its disregard to the point of virtual suppression in the UK media of so much important biomedical research about ME/CFS that vitiates the psychiatrists' behavioural model but which supports the insurance industry shows the SMC in its true colours.

People want to know the truth. Unsuspecting journalists and the public generally believe that the information on ME/CFS that emanates from the SMC must be scientifically accurate but in the case of ME/CFS, it is anything but accurate or balanced.

The danger is that if a lie is repeated often enough by enough people, it becomes the truth, and that is what has happened in relation to ME/CFS.

The SMC has for years actively promoted the psychiatrists' behavioural model whilst ignoring the wealth of biomedical evidence that invalidates the psychiatrists' theory.

An organisation which behaves in such a blatantly unscientific way can have no legitimate claim to represent science.

