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HAS THERE BEEN SCIENTIFIC MISCONDUCT REGARDING MYALGIC ENCEPHALOMYELITIS IN THE UK?

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This document raises questions and serious concerns expressed by members of the myalgic encephalomyelitis (ME) research and patient communities regarding the conduct, influence and publications of psychiatrist Professor Sir Simon Wessely and his colleagues in the "Wessely School" in relation to ME (to which he synonymously refers as "chronic fatigue syndrome" or "CFS"). It draws upon publicly available sources and does not allege illegal or criminal wrongdoing, but rather highlights the urgent need for thorough institutional and ethical review in light of potential patient harm and the continued misrepresentation of medical science.

Brief Background

From about 1988, Sir Simon began his campaign to re-categorise ME as a psychiatric disorder. Subsequently, psychiatrists in the Wessely School who worked for the health insurance industry decided that if the name "ME" was specific to a serious, chronic and untreatable neurological disorder, then health insurance companies such as UNUM could face meltdown. They believed that a generally-named illness without a specific cause was required. Subsuming ME into the non-specific term "chronic fatigue" would pose less of a threat to company profits. Moreover, an "illness" is not a disease, but a behavioural condition (the word "disease" is only applicable when there is objective, medically diagnosable pathology). Their published objective was that "ME" should disappear – it would be obliterated and eradicated. On the other hand, antidepressants were the boom industry of psychiatry, so Big Pharma also saw its chance.

There is a known culture of psychiatrists being well-rewarded financially by Big Pharma for promoting their drugs and some could receive up to $10,000 per talk for doing so – currently about £7,000 plus air fare and hotel costs (Skewed: Psychiatric Hegemony and the Manufacture of Mental Illness. Martin J. Walker. Slingshot Publications 2003 -- this book looks at how psychiatry came to re-define ME as a psychiatric disorder and created a vast pool of patients with a wide variety of fatigue-like symptoms for which antidepressants could be prescribed).

From the early 1990s, a powerful coalition between UK government policy-makers and the Wessely School came into existence and was actively involved in the re-categorisation of ME from a WHO-classified neurological disorder to a somatoform (ie. mental) disorder.

Also involved in the drive to change the status of ME was Dr Mansel Aylward, then Chief Medical Officer at the DSS, who was supported by Dr Adrian Furness. Their correspondence in 1992 and 1993 is unambiguous and leaves no doubt about their intention: ME was not to be considered as a separate disorder from chronic fatigue syndrome (CFS) and CFS is a somatoform disorder.

The Disability Living Allowance Advisory Board was preparing its revised Handbook when, on 10th January 1992, Sir Simon wrote to Dr Aylward about the draft entry for ME: *"I have been particularly concerned in the area of rehabilitation of CFS patients and was therefore most interested to read the proposed guidelines…I think they are based on a misinterpretation of some of the published research…I and my colleagues consider that anxiety about the consequences of activity is one factor perpetuating disability in CFS patients…I hope that the guidelines will not perpetuate the idea that CFS is both of poor prognosis and untreatable…I have advised that CFS should not be grounds for permanent disability".*

On 13th October 1993 Dr Aylward wrote to Sir Simon: "*The prognosis for those who acquire the label of 'ME' is at the moment poor…It is a treatable disorder but its management is deplorable at present, the worst thing to do is to tell them to rest. Rehabilitation is essential, exercise is good for these patients, prolonged inactivity* *causes adverse physical and psychological consequences…As regards benefits – it is important to avoid anything that suggests that disability is permanent, progressive or unchanging. Benefits can often make patients worse".*

In the Handbook, ME was then accepted as a separate disorder for which a consensus agreed that "*affected people remain disabled, make little or no progress, or even deteriorate over time".* However, on 10th November 1993 psychiatrist Dr Peter White from St Bartholomew's Hospital, London, wrote to Dr Aylward advising that separating the two conditions ME and CFS *"may enhance disability"* because "*those who believe in the separate existence of ME believe this is a totally physical condition, probably related to immune dysfunction or persistent viral infection (for) which no treatment is available. On the contrary…the present evidence suggests that…treatments and rehabilitation programmes are available which address both the physical and psychological factors that maintain this syndrome"*.

The outcome was that "ME" became "CFS" and CFS was to be categorised as a somatoform disorder.

Given the substantive published evidence of pathology already known to exist in ME when these somewhat protracted discussions took place, the fact that a somatoform disorder can only be so classified in the absence of an adequate physical explanation (WHO ICD10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines, Geneva, 1992) seems to have been overlooked.

Central to this transformation was the publicising of the psychiatrists' "biopsychosocial" (BPS) model. This appears to be based upon the 1977 model advocated by George Engle, which posits that: *"illness and health are the result of an interaction between biological, psychological and social factors".* Despite its promotion as a compassionate synthesis of biological, psychological and social elements of illness, the Wessely School's BPS model in reality was a blunt tool used to psychologise, de-legitimise and sideline the biomedical aspects of ME.

This transformation was strengthened when in 1994 Simon Wessely stated in his Eliot Slater Memorial Lecture: *"I will argue that ME is simply a belief, the belief that one has an illness called ME"*. This categorised patients with ME as psychologically compromised and as misattributing normal bodily sensations to symptoms of a non-existent illness. Sir Simon's views, widely disseminated through his publications, the media, policy briefings and medical education, fostered a growing atmosphere of suspicion around patients with ME – an atmosphere that resulted in their ridicule and abandonment by mainstream medicine.

Aylward and other BPS proponents produced a series of documents that embedded their BPS model into social and disability policy. Their 2005 report "The Scientific and Conceptual Basis of Incapacity Benefits" drew heavily on Sir Simon's psychogenic model of ME, which taught that long-term illness was often perpetuated by "*false illness beliefs"* and deconditioning as a result of inactivity. State benefit claimants with ME were specifically targeted and their benefits were denied or withdrawn (even from those whose award was "life-long").

By subsuming "ME" into the general term "chronic fatigue" (and calling it "CFS"), the Wessely School dispossessed a large number of people -- now thought to be about 400,00 in the UK – not only of their authentic organic disorder but also of benefits, specific investigations, symptomatic management and insurance cover. Anyone in the UK who developed a seriously disabling post-viral disorder would suffer from an invalidated illness.

The health authorities were duly advised by the Wessely School that there was no need for any specialist facilities for "CFS", so the NHS has no specialist referral clinics other than to a psychiatrist.

For ME patients, this convergence of ideology and policy had devastating consequences. Biomedical research into ME was deprioritised, dismissed and prevented, with funding bodies rejecting grant applications from scientists wishing to study the pathophysiology of ME. Instead, funding focused on psychosocial interventions, including Sir Simon's own version of cognitive behavioural therapy (CBT) and graded exercise therapy (GET). These interventions were strongly promoted despite mounting evidence – including patient testimony – that exertion exacerbated their symptoms, sometimes irreversibly. Those who challenged the psychiatrists' model of ME were vociferously branded as "*militants"* or accused of sabotaging research, and those who sought more scientific rigour were denounced as threats to clinical orthodoxy.

This institutional contempt filtered down into everyday clinical practice, with ME patients being accused of malingering; they were denied laboratory investigations and many were left housebound or bedridden, struggling not only with their life-wrecking illness, but also because of dismissal and neglect from the very system whose role was to support them but which disbelieved them.

A reversal of this damaging legacy is long over-due. It must begin with the re-instatement of ME by UK Departments of State as a serious, complex, chronic, organic disorder deserving of appropriate medical support and humane treatment of sufferers.

The lack of such provision in the UK is attracting international opprobrium, for example, from Professor Carmen Scheibenbogen, Professor of Immunology and Deputy Chair, Institute of Medical Immunology, at the University Hospital Charité in Berlin, who has published her concern about the Wessely School's decades-long control over all aspects of ME ("Why the Psychosomatic View of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is Inconsistent with Current Evidence and Harmful to Patients": 31st December 2023 (Journal of Clinical Medicine 2023:12(24)8345 https://doi.org/10.3390/jcm122483345).

"A vocal minority of researchers remains convinced of a psychosomatic…causation of ME/CFS despite the frequently demonstrated organic abnormalities and the simultaneous lack of evidence for relevant psychosomatic factors. The striking discrepancy between the strong conviction among proponents of a psychosomatic aetiology of ME/CFS and the simultaneous lack of evidence for this view has also been observed in other scientific fields. Research shows that…individuals who strongly disagree with the scientific consensus are, on average, less knowledgeable about the topics than others but are more convinced of their knowledge.

"Contrary to psychosomatic hypotheses, replicable organic abnormalities are evident in ME/CFS. The most important replicated abnormalities include a significant reduction in cerebral blood flow, endothelial dysfunction, a reduction in systemic oxygen supply, a reduced peak oxygen consumption, an increase in ventricular lactate levels, hypometabolism and increased levels of autoantibodies against G-protein-coupled receptors. Many organic abnormalities found in ME/CFS correlate with symptom severity, indicating a relevant role in the disease process.

"In addition to ME/CFS itself, the lack of medical care and social support is particularly burdensome for those affected. In the health care system, patients with ME/CFS have to reckon with medical gaslighting and sometimes severe maltreatment – physicians convince patients…that they are psychosomatically ill. When admitted to hospital or rehabilitation programmes, patients with ME/CFS who are wrongly classified as having a psychosomatic illness are threatened with mistreatment, including activity-increasing therapies like GET that can seriously harm them".

Professor Scheibenbogen emphasises the importance of educating physicians and the public about the incorrect and harmful psychosomatic model, as this misdiagnosis can lead to mistreatment, stigmatisation and difficulty in receiving appropriate care and benefits. She is clear: healthcare professionals in the UK must stop such misdiagnosis and mistreatment and provide adequate research funding and medical care for ME patients.

Has there been scientific misconduct regarding ME in the UK?

What comprises scientific misconduct? The UK Research Integrity Office (UKRIO), the Medical Research Council (MRC) and the National Institute for Health and Care Research (NIHR) define it to include:

- fabrication (making up data)
- falsification (manipulating research processes or omitting data so that the research is not accurately represented)
- deviation from accepted practices: the MRC specifically includes "*deliberate, dangerous or negligent deviations from accepted practice*" and "*failure to follow established protocols where failure results in unreasonable risk or harm*".

If a group of registered medical practitioners persists in disregarding or failing to engage with a substantial and growing body of peer-reviewed biomedical research into a WHO-classified neurological disorder and instead continues to promote an unevidenced hypothesis that the disorder is psychogenic, such actions, if substantiated, could raise concerns that may be interpreted as approaching scientific misconduct, especially when evaluated against definitions provided by UK authorities. The consequences of such a stance might include:

- Misrepresentation of current biomedical knowledge
- Distortion of the scientific literature
- Potential patient harm
- Misdirection of public funds
- Influence on public policy to the detriment of legitimate claimants of State benefits
- Breaches of obligation to obtain informed consent required in clinical care, raising serious concerns regarding compliance with UK legal statutes.

Brief Overview

Myalgic encephalomyelitis (ME) has been classified by the World Health Organisation as a neurological disorder since 1969 (ICD10:G93.3).

A significant number of clinicians, researchers, patients and advocacy organisations have expressed concern that Sir Simon, a leading figure in the field of psychiatry, does not accept the WHO classification of ME as a neurological disorder and for over 30 years has promoted his unproven psychogenic model of the disorder. It is indisputable that he has exerted disproportionate influence over UK research funding, medical education, the peer review process, public policy, and the NHS management of people with ME, resulting in the failure to provide appropriate medical care.

International research, including neuroimaging studies demonstrating neuroinflammation and reduced cerebral blood flow in ME/CFS, immune dysfunction including abnormal T-cell subsets, cytokine patterns and the presence of autoantibodies, and evidence of mitochondrial dysfunction, impaired energy metabolism and post-exertional molecular abnormalities, all confirm ME as a complex multisystem organic disorder.

Critics are concerned that the continued dismissal of such findings by members of the Wessely School constitutes serious deviation from current scientific understanding and contributes to a culture of disbelief in the organic nature of the disorder which, in turn, contributes to inappropriate patient care and to medical dismissal of patients' symptomatology.

Sir Simon has repeatedly dismissed world-renowned biomedical researchers and clinicians as engaging in *"obsessional science"* and rejects their biomedical research findings as *"not replicated"* or *"unconvincing"*, despite it being the highest calibre of research.

It is held by many that this over-riding of the scientific evidence leads to iatrogenic harm and that repeatedly to do so without robust counter-evidence may be considered not only a lack of professional accountability and a failure of duty of care, but might be approaching scientific misconduct.

To date, there appears to be no public acknowledgment by Sir Simon of the documented harms patients have experienced under the now-discarded psychosocial treatment regime which he formulated.

In particular, the Wessely School's public rejection of the 2021 revised NICE Guidelines NG206 – which withdrew Sir Simon's own form of CBT and GET due to the quality of the studies which underpinned them (11% were found to be of "*low*" quality and 89% were found to be of "*very low*" quality) and in particular because of the lack of evidence of benefit and the documented evidence of harm -- has prompted renewed debate over the appropriateness of Sir Simon's psychosocial model of ME.

Sir Simon has long advocated for the integration of psychiatry into general medicine. Of concern is that such integration may overstep necessary boundaries, to the detriment of patients with physical, not mental, illness.

That Sir Simon asserts that ME is a somatoform disorder is a matter of public record. However, this requires consideration, because he appears to be inconsistent. He has publicly denied that he believes ME to be a somatoform disorder, but for decades he has published his belief that he does believe it to be a somatoform disorder. His published work on ME over many years uses terminology indicative of mental illness, such as "somatoform", "somatisation" and "functional somatic syndrome", thus placing ME within a psychosomatic paradigm, which may have contributed to inappropriate and harmful psychosocial interventions being imposed upon patients with ME in whom there is no evidence of mental illness.

For example, he has stated on written record: *"I don't classify CFS as a somatoform disorder"* ("Wessely answers some questions", 10th April 2002; CAME). As Sir Simon asserts that the titles "CFS" and "ME" are synonymous, this appears to confirm that he does not classify ME as a somatoform disorder, when his prolific published output proves that he does classify ME as such.

Sir Simon is on record stating: *"I have never said that CFS is all in the mind. I do not believe that, and have never written that"* ("ME: bitterest row yet in long saga": Independent on Sunday, 25th November 2012) but it is notable that his colleagues are on record stating that he regards ME/CFS as "*somatisation par excellence"* (J Psychosom Res 1994:38:2:89-98).

It is also a matter of record that Sir Simon gave the keynote lecture at The International Congress on Somatisation Disorders held at Marburg, Germany, on 23rd February 2002 and that his lecture was entitled "*The chronic fatigue syndrome and the " 'S' word"*.

Whilst a somatoform disorder, somatisation and functional somatic syndromes are related but distinct concepts, Sir Simon is well-known for using specific terms interchangeably, eg: ME, CFS, CFS/ME, and "chronic fatigue", all of which come under his spectrum of mental disorder:

- again referring to ME as "*a belief"*, Sir Simon then stated: *"Somatisation sufferers consume vast amounts of health resources for little benefit"* (Clin Exp Allergy 1995:25:503-514)

- in 1996, the Joint Royal Colleges' Report on CFS (CR54), with which Sir Simon was closely involved, stated: *"CFS is frequently associated with somatisation symptoms"*

- in 1999 he was unequivocal in asserting that CFS/ME is a somatisation disorder (Somatoform Disorders: (in) Current Opinion in Psychiatry: 1999:12:163-168)

- also in 1999, in his lecture on 29th October at the Royal Society of Medicine, he said: *"The core reason people somatise (is) the stigma of psychiatric disorders. I'm going to use – to make this point – Chronic Fatigue Syndrome… Somatisation is a common way for people to present with psychological problems".*

- in 2004, following on from his 1999 article in The Lancet ("Functional somatic syndromes – one or many?" Lancet 1999:354:936-939) in which he included "CFS/ME", Sir Simon was adamant that syndromes like ME should be viewed as one part of a single functional somatic syndrome, stating that there is only one functional somatic syndrome and it includes chronic fatigue syndrome, and that: "*Five years later, Sharpe and I stand by our thesis"* (referring to his co-author, psychiatrist Professor Michael Sharpe). They wrote: *"Functional somatic syndromes…are associated with unnecessary expenditure of medical resources. Chronic fatigue syndrome is associated with worse disability than conditions such as heart failure. Many of these syndromes* (in which the authors include irritable bowel syndrome, fibromyalgia and multiple chemical sensitivity) *are dignified by their own formal case definition and body of research…We have put forward the hypothesis that the acceptance of distinct syndromes as defined in the medical literature should be challenged. We propose an end to the belief that each different syndrome requires its own particular sub-specialist"*).

- *"Functional somatic syndromes…include chronic fatigue syndrome"* (Rev Bras Psiquiatr 2005:27:3)

- Sir Simon includes chronic fatigue syndrome in his chapter "Functional Somatic Syndromes" in "Handbook of Liaison Psychiatry" (Ed: Geoffrey Lloyd & Elspeth Guthrie; chapter 7, pp 125-136: OUP 2007).

There are many more such examples in Sir Simon's copious publications, as he has consistently maintained his position, despite widespread disagreement from many international biomedical researchers.

As long ago as 19th December 2002, one internationally esteemed US psychiatrist wrote about Sir Simon's discrepant statements on the same issue: "*Considering the thrust of his views there seems to me to be deception hiding behind semantics*" (personal communication). This reflects wider concerns about the clarity of communications from influential figures in the field.

As Philip Steer, Professor Emeritus, Imperial College, London, noted: *" 'Conviction politicians' may be popular, but conviction doctors are potentially dangerous"* (BMJ 2008:336:673). This quotation has been widely cited in critiques of strongly held ideological stances in medicine that may conflict with emerging scientific evidence.

Illustrations of Concerns

It is indisputable that for over 30 years Sir Simon has produced no evidence to substantiate his belief that ME is a mental disorder, yet his teachings and influence remain unchallenged by the relevant UK authorities. This ensures that the continued propagation of a false narrative and harmful interventions prevail, despite the international scientific evidence that disproves his own model of ME.

It is alleged by many people that Sir Simon and his Wessely School colleagues have:

- intentionally acted counter to the WHO's taxonomic principles by changing the classification of ME in the UK from neurological to behavioural without the WHO's knowledge and without the approval and permission of the World Health Assembly, and have disseminated this unauthorised change throughout the UK Department of Health and the NHS as being the accepted and required policy

- intentionally misrepresented a WHO-confirmed organic illness as psychiatric in alignment with (i) the UK government's policy of reducing benefit expenditure; (ii) the financial aims of Big Pharma and (iii) the permanent health insurance industry, for whom they worked as consultants (psychiatric disorders being excluded from cover), thereby subjecting people with ME to harm, denial of care, financial destitution, and wrongful sectioning of sufferers under the Mental Health Act

- breached the GMC's Good Medical Practice Code (see below).

It is believed by many people that such actions may have resulted in:

- misfeasance in public office (inappropriate influence over public policy to deprive eligible sick people of State benefits and medical care)

- medical negligence (promoting and implementing interventions known not to be effective and disregarding evidence that the interventions are harmful to people with ME (see below)

- failure to declare conflicts of interest (see below)

- systemic abuse of sick people (patients in NHS hospitals with severe ME left to starve and die because their physical illness was misclassified as psychogenic and ill-informed doctors did not want to "*medicalise"* what they believed to be the sufferers' psychiatric illness, a belief which prevails throughout the NHS, necessitating the serving by a Devon Coroner on 7th October 2024 of a Regulation 28 "Prevention of Future Deaths" Notice).

It is believed by many people that Sir Simon himself may have violated the GMC Good Medical Practice Code in the following domains:

Domain 1: Knowledge, skills and performance: *"You must recognise and work within the limits of your competence".* This includes awareness of evolving medical knowledge by continuing professional education (CPE). It is undeniable that for many years Sir Simon has failed to acknowledge or understand the advances demonstrated in the biomedical pathophysiology of ME that are beyond his domain of psychiatry.

He continues to disregard decades of biomedical research identifying immune, cardiovascular, endocrine/metabolic, musculoskeletal, gastrointestinal and neurological abnormalities in patients with ME and therefore treats patients with ME inappropriately.

In ME patients it has been conclusively shown that the immune system is dysfunctional, but Sir Simon's public statement that: *"A man has got to know his limitations and my limitations are immunology"* (his evidence given on 10th August 2004 to the Lord Lloyd of Berwick Inquiry) appears to acknowledge, but then disregard, his lack of expertise in immunology, while continuing to promote contra-indicated psychiatric interventions.

His continued influence on medical guidance and training of medical students risks teaching future doctors to misdiagnose ME patients based on an outdated and disproven model, thus contributing to inappropriate – or lack of – due care.

Domain 2: Safety and quality:

Doctors are obliged to make the care of their patients their first concern and duty. Despite widespread patient testimony, evidence of clinical deterioration and published evidence of harm, Sir Simon has persisted in defending the interventions which he formulated (a particular kind of CBT and GET).

In 2019, in Forward-ME's survey of 2,274 participants' experience of Sir Simon's recommended interventions, Professor Helen Dawes and her team at Oxford Brookes University found that 80.1% reported physical deterioration as a result of GET.

A 200-page file submitted to NICE during the revision of its Guidelines provides case histories of about 170 ME patients harmed by GET. Some of those patients deteriorated irreversibly and died from ME. The document was requested by NICE, giving it official status.

Sir Simon is known to favour prescribing tricyclic antidepressants for people with ME; he also particularly recommends lithium if patients with ME do not respond to tricyclics. Despite being informed of the dangers of these drugs for people with ME, it has been reported by patients that he continues to prescribe them.

This raises the question about his judgment and whether other motives – such as financial ties to pharmaceutical companies – might conflict with patient safety.

It is known that world-renowned immunologist Professor Nancy Klimas from the University of Miami contacted Sir Simon expressing a warning about using tricyclic antidepressants and lithium in patients with ME because those drugs are known to be damaging to ME patients' already-damaged immune system, as further confirmed by her own studies, but her advice was rejected. Does such behaviour show contempt for the values of partnership, teamwork and empathy which underpin medical ethics?

Domain 3: Communication, partnership and teamwork:

Medical professionals must communicate with patients and work in partnership with them and with other doctors. Sir Simon has often appeared to reject input of both patients and medical experts in ME, as confirmed by patients' testimonies, case histories and articles posted by medical practitioners.

This does not accord with Sir Simon's first blog as President of the Royal College of Psychiatrists, in which he stated: *"We are the most democratic of colleges. We welcome the views of patients and carers"* (24th May 2014).

Domain 4: Maintaining trust:

It is known throughout the ME community that Sir Simon has severely damaged ME patients' trust in most NHS doctors by his frequent mocking and deriding of people with ME and that his behaviour fuels similar behaviour throughout the NHS, for example, in his Eliot Slater Memorial Lecture on 12th May 1994, he said: *"How do you prove that you are not hysterical? You must convince the doctor that you really are ill – organically ill – so…the arm becomes more floppy – the leg weaker – the sensory changes more bizarre, yet what is the result of this…the neurologist, who is not a fool, is now more convinced that the problem is functional. How…can you prove the doctor wrong? Well, the one thing you might not do is get better, since that might be interpreted…as proof that it was all in the mind after all".*

Other illustrations of his derisory attitude towards people with ME include: *"The average doctor will see they are neurotic and he will be disgusted with them"; "It seems that ME sufferers prefer to feel that they have a 'real' disease – it is better for their self-esteem"; "Patients (with ME) are generally viewed as an unavoidable, untreatable and unattractive burden"; "The term ME may mislead patients into believing they have a serious and specific pathological process"; "Patients' beliefs are probable illness-maintaining factors"; "To the majority of observers, including most professionals, these symptoms are indeed all in the mind"* (for individual references, see "Quotable Quotes about ME/CFS" available online at https://margaretwilliams.me/).

Another illustration reported by a medical practitioner exactly captures Sir Simon's derision about ME sufferers: *"Several years ago I was lecturing in British Columbia. Dr Wessely was speaking and he had the hundreds of staff physicians laughing themselves silly over the invented griefs of the ME and CFS patients who, according to Dr Wessely, had no physical illness whatsoever but a lot of misguided imagination… His message was very clear and very simple. If I can paraphrase him: "ME and CFS are non-existent illnesses with no pathology whatsoever. There is no reason why they all cannot return to work tomorrow* (*"*Hysteria and Myalgic Encephalomyelitis": Byron Hyde MD 13th September 2011. The Nightingale Research Foundation).

One illustration in particular reveals Sir Simon's true beliefs about people with ME: in late October 2003, he said that those who believe that ME is an organic disorder – to whom he referred as "***the radicals"*** -- are (quote): ***"crazy"*** and that they are "***engaged in fantasies, lies and gross distortions"***, that the ***"radicals"*** are left ***"fighting yesterday's battles"*** because he believes he has established that ME does not exist except as a false illness belief. He said that they need a *"**reality check"*** and that "***their behaviour is outrageous"*** (personal communication). Such expressed views do not accord with Sir Simon's claim to be a caring and compassionate doctor.

Sir Simon has caused distress to parents of severely affected children and to severely affected adults by publicly stating about bed-bound ME patients: *"Psychological factors are important and I don't care how unpopular that statement makes me"* (Interview with Simon Wessely by Clare Wilson. New Scientist 11th March 2009)

He makes dismissive comments about people with ME, for example, he is on record saying: *"We're not going to go doing more and more tests… even if we found (evidence of viral activity), there's nothing we're going to do about it. We're in the business of rehabilitation".*
BMJ podcast: http://podcasts.bmj.com/2010/03/05/chronic-fatigue-syndrome 5th March 2010

Sir Simon's public attitude toward people with ME is reflected in the abhorrent way in which they are treated by NHS doctors, for example: "*I'm not prepared to do any tests*"; *"Hypochondriac, menopausal, you have the audacity to come here and demand treatment for this self-diagnosed illness which does not exist"*; *"ME is a malingerer's meal ticket"*; *"You are a menace to society – a pest"*; *"Stop feeling sorry for yourself – I have patients with real illnesses"*; *"I'm not going to further your career of twenty years of being ill". "He said the illness was a load of trollop"; "I was called 'stupid' and shouted at on more occasions than I care to mention …one neurologist said he 'couldn't care less' whether I ever got better"; "I was told I was a disgrace"; "the doctor said it was 'attention seeking'"; "I was told that I was selfish and introverted and it was nothing but hysteria"; "the doctor said my symptoms/signs 'didn't exist' "; "if you go on like this you will be struck off* *the register "* (from the results of 1500 professionally conducted questionnaires conducted by the charity Action for ME).

On 17th November 2012 in an online group "ME/CFS: Harassment of Researchers / Stuff And Nonsense", RJC wrote: *"(Wessely's) constant rhetoric for 25 years has seen patients dismissed and ridiculed by their own doctors and have struggled to get benefits and appropriate care and treatment…Children with ME today are still being threatened with forceable removal from their parents and indeed some children are actually removed. Their crime? Being ill and struggling to go to school regularly. That is Wessely's legacy".*

The same person posted again the same day: *"We know what (Wessely) said and did because we lived and live through the consequences. I was sent for CBT and had to sit through ten hour-long sessions where I was told again and again and again that my illness did not exist and that I merely had a false illness belief. I was told by a doctor that ME is an illness of 'eloquent introspectives', another that I was 'running away from challenges in my life'. I have been accused of attention-seeking. What actually happened was that I was living a happy, successful and not remotely stressful life and I got ill. I have fought to retain a normal life for 15 years but my body will not let me and I have spent at least half of that time in a bedroom, on my own. Some way to get attention….Those attitudes towards our illness didn't come from nowhere. Those quotes have been…repeatedly published by… doctors highlighting Wessely's influence. His merry band of disciples including Peter White…continue to claim that ME is not an illness, but simply a behaviour…We have a right to be angry…There are nearly 250,000 of us who…want to be treated with respect by the medical profession and who want proper NHS services…We want some help to get better and I don't think that's too much to ask".*

Quite recently, one person who has had severe ME for over 30 years was told by her local doctor: *"My colleagues regard ME patients with contempt".*

In reaction to the latest award given to Sir Simon in the King's Birthday Honours in June 2025, Andy Christophi wrote on a Facebook group: "*How can one person get away with doing so much harm to so many for so long?"*

On the same group, Nic McPaul wrote: *"A man who has caused suffering to millions and stunted scientific research for decades…. His work has been discredited widely world wide and proven to be wrong. In fact, his work is used as an example of 'how not to' do scientific research in prominent Universities".*

Another person in the group, Helen Ashby, wrote: "*This man has damaged the course of research, the training of professionals and the hope of understanding an illness which he has spent a career determined to present as psychiatric for his own career, reputation and financial gain....It boggles my mind that one man can insert himself and be accepted into so many powerful roles and not be challenged or revealed for the incorrect dogma he peddles".*

Later, Helen Ashby posted the letter she sent for the attention of the Honours Forfeiture Committee: "*As the Mother of an almost 21 year old daughter who has suffered with Myalgic Encephalomyelitis since she was 14 years, I am horrified, mortified and downright disgusted that this man, who has done so much damage in the ME/CFS/Long Covid community, in a self-serving attempt to keep his reputation, recognition, importance, financial security and hero-worshipped status is being honoured yet again, this time with a GBE. How are we supposed to believe the Honours system is built on integrity?...There is strong evidence in post-mortem results of this being a very physical illness (but) Professor Wessely has consistently stuck to his guns in saying this illness is a false belief of the mind. I can assure you…that this illness is devastating and is very physical and I can testify that my daughter does not want to be ill, does not want to spend up to 18 hours a day asleep and the other 6 in pain, discomfort and struggling to function…I have watched my daughter be robbed of her teenage years and be devastated when medical professionals suggest this is a mental health illness and we find the only knowledge they have of the illness is the disinformation spread from Professor Sir Simon Wessely's own school of teaching…This man's position on ME is allowing people at worst to lose their lives unnecessarily, and at best lose any quality of life".*

Also in the same group, Karen van Dyck wrote that Sir Simon: *"Caused and continues to cause gross suffering and fear and sheer threat of being made worse by all NHS workers…Simon Wessely failed to put the Patient Voice above his own…he took away all knowledge that was there…he made an entire generation…of ME* *sufferers more ill. He is responsible for failure to listen and just being focused on his own career. That is not someone who has done society any good at all".*

This evidence – of which there is much more – confirms that Sir Simon's characterisation of ME patients contributes to the widespread clinical invalidation and resultant psychological harm so often experienced by people with ME.

Indeed, it is proven that physically sick people whose symptoms are dismissed by healthcare providers experience serious psychological harm, and that medical invalidation triggers a cascade of harmful consequences, leaving patients damaged and desperate (Allyson C Bontempo et al: Psychological Bulletin 2025: 151:4:399-427).

Sir Simon has been uninhibited in his criticism of people with ME, including claiming that ME activists are dangerous: *"For some years now all my mail has been X-rayed. I have speed dial phones and panic buttons at police request and receive regular briefing on my safety… (People with ME are) damaged and disturbed, with an obsession about psychiatry. 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….I now go to Iraq and Afghanistan, where I feel a lot safer"* ("Dangers of research into chronic fatigue syndrome" BMJ 2011:342:d3780).

Possible Violation of UK Law: Duty of Candour and Informed Consent

Doctors must provide evidence-based treatment and be aware of and comply with relevant Guidance, but the Wessely School psychiatrists publicly refuse to accept the revised NICE Guidelines published in October 2021 which are clear that ME/CFS is not a psychogenic disorder. The refusal of the Wessely School to adhere to the revised NICE Guidelines is set out in their lengthy article "Anomalies in the review process and interpretation of the evidence in the NICE guideline for chronic fatigue syndrome and myalgic encephalomyelitis" by Peter White, Michael Sharpe, Simon Wessely et al. (JNNP 2023:0:1-8: doi:10.1136/jnnp2022-330463. This unambiguously undermines the NICE Guidelines, which all registered UK doctors are expected to respect as the national standard of care. The Wessely School's refusal to do so, especially while continuing to promote disproven interventions, also undermines medical integrity and compliance with professional duties of care.

All medical practitioners registered with the GMC are required by law to inform all patients of all known risks before patients consent to any medical intervention (the Bolam principle was replaced by the Montgomery case law in March 2015). Failure to disclose such risks arguably contravenes standards of safety.

Although the Montgomery case law post-dated the PACE Trial and the Bolam principle was extant during the trial period (2004 – 2011), participants in the PACE Trial were not informed of the known risks of GET, nor were they informed of the proven biomedical abnormalities found in ME which explain why patients are adversely affected by exercise.

Systemic harms caused by the Wessely School include:

(i) Suppression of biomedical research: Sir Simon's position on three MRC Boards and within the NHS funding bodies is widely believed to have suppressed UK biomedical research on ME for over two decades, delaying the development of potentially effective treatment and stunting scientific advancement.

(ii) Economic damage: promotion of ineffective interventions has reduced workforce productivity, increased disability claims and inflated public expenditure. Following the PACE Trial, the statistics show that participants' benefit claims increased, not decreased.

Rebuttal of the Wessely School's beliefs about ME

The Wessely School's beliefs and assertions about ME have been rebutted not only by the substantive evidence-base that disproves them and by irrefutable evidence from autopsies confirming neuroinflammation and cardiac fibrosis, but also are rejected by global authorities:

- The UK National Institute for Health and Care Excellence (NICE 2021 and NICE 2024)
- The US National Academy of Medicine (2015)
- The International Consensus Criteria (2011)

Further information

Documentary evidence shows that the Wessely School's advice to Government specifically includes withholding medical care for ME patients. The Joint Royal Colleges' Report on CFS in which Sir Simon was instrumental (CR54, October 1996) was categoric: *"…abnormalities of immune function…should not deflect from the (psychiatric) approach and should not focus attention towards a search for an 'organic' cure…No investigations should be performed to confirm the diagnosis".*

Could this be construed as encouragement to withhold necessary medical care for people suffering from a WHO-classified serious neurological disease and which therefore might be considered professional misconduct?

It is a matter of increasing concern that there is a rising number of Long Covid (LC) patients who fulfil the strict International Consensus Criteria for ME and that LC sufferers are facing the same dismissal and disbelief as ME sufferers, with LC being categorised as a psychosocial disorder. Of note is that Long Covid was seen to be listed as a top priority for research funding in the UK, but very soon after Sir Simon was appointed to NHS England Board of Directors (who control funding) in January 2023, Long Covid no longer appeared on that list.

Use of Authority to Silence Critics

Sir Simon does not hesitate to threaten injunctions and legal action through the Medical Defence Union against those who quote his own published views critically and who disagree with him. His unrestricted use of legal threats to suppress legitimate opposition raises grave ethical concerns about academic freedom and patient advocacy.

Without doubt, Sir Simon is now widely respected specifically for his leadership role in "behavioural science" and he exerts a dominant influence in many areas of UK government. This makes him impregnable, while patients with ME continue to be harmed, neglected, misdiagnosed or left to die as a result of the policies and cultural attitudes promoted and instituted by his Wessely School.

The unquestioning reverence with which Sir Simon is regarded reflects a profound failure of medical and political accountability in the UK – a situation that patients with ME and their advocates continue to challenge, but one over which Sir Simon maintains a strong media presence, positioning himself as a rational scientist combatting "*militant*" or "*delusional*" patients and portraying them as "*anti-science*" even though he has not produced any evidence to support his own beliefs about ME and even though his beliefs have been comprehensively rejected by NICE.

Sir Simon's *modus operandi*

It is worthwhile to reflect on Sir Simon's pattern of behaviour.

1. In a BBC radio discussion (http://www.bbc.co.uk/programmes/b047zk6q) Sir Simon complained that antidepressants are under-prescribed and he was adamant that depression is under-diagnosed. James Davies (Senior Lecturer in Psychology) responded: "*We need greater transparency (about) the financial ties between the pharmaceutical industry and psychiatry".*

Sir Simon replied: "*I've never worked for Pharma*".

James Davies challenged this: "*Why does Simon Wessely say that he has never worked for Pharma when according to this 2004 article (detailing a study of SSRIs from JAMA and an editorial from Wessely): 'Dr Wessely has received funding from Pierre Fabry Pharmaceuticals and from Eli Lilly and Co. to attend academic meetings and for speaking engagements'. Why did Simon Wessely – on BBC radio – say that he has never worked for Pharma when he has received funding from Fabry Pharmaceuticals and Eli Lilly for academic meetings and speaking engagements? How much 'funding' did he receive… Why did he not disclose this?".*

This was not the only time that Sir Simon appeared to be electively forgetful: on 26th August 1998 he stated in a Channel 4 television programme about the forcible removal of children with ME from their parents: "*I think it's so rare. I mean, it's never happened to me*", yet his involvement in the wardship of 12 year-old Ean Proctor is a matter of public record. The Channel 4 programme was recorded, providing evidence that Sir Simon is not always truthful. Unfortunately, the forcible removal of sick children from their parents continues and is far from rare.

2. On 26th June 2014, Philip Hickey PhD discussed on his website an item entitled "Lingering Doubts About Psychiatry's Scientific Status" in which he quoted from Sir Simon's first Blog of 24th May 2014 as President of the Royal College of Psychiatrists, where Sir Simon stated about the College's Congress at the Barbican Centre in London that month: "*Any lingering doubts that psychiatry is not scientific will hopefully be dispelled, since the science of psychiatry is on constant display*".

Hickey's response was: *"Psychiatry has <u>never</u> established the truth of its core assumption (that psychiatry is scientific)…They have simply <u>assumed it to be true</u> and have steadily promoted its acceptance through endless repetition, manipulation of the media, and vigorous condemnation of critics. Then, to create the <u>impression</u> of science, they have conducted vast numbers of studies…all depending for their validity on the core assumption. This isn't science. It is nonsense, dressed up as science".*

Hickey continues: *"(This) is not science, but a travesty…Psychiatry, despite decades of failed attempts at validation, continues to cling to its core assumption… In fact, it would have collapsed long ago but for the massive, ongoing financial support that it receives directly and indirectly from its symbiotic, and incidentally corrupt, relationship with Pharma"* ("Spotlight on Sir Simon Wessely": Philip Hickey's website: Behaviorism and Mental Health).

This brings to mind the question of conflicts of interest from the perspective of people with ME.

On 21st June 2013 Philip Hickey had noted that: "*The concept of mental illness is just another spurious <u>assumption</u> which would have been scrapped long ago but for the fact that it serves the interests of psychiatrists and their pharmaceutical allies".*

Hickey went on to refer to Sir Simon's paper published on 10th June 2013 ("DSM-5 at the IoP") in which Sir Simon stated: "*For most psychiatrists, claims that we are embarked on…seeking to extend our boundaries, populations and wallets further and further sounds hollow*".

This caused Hickey to note: "*This requires some scrutiny (because) psychiatrists have been, are, and apparently plan to continue extending their boundaries, populations and wallets…In fact, the psychiatry-pharma alliance has been consistently and successfully pursuing an expansionist agenda for the past 40 years".* ("Spotlight on Sir Simon Wessely". Philip Hickey's website Behaviorism and Mental Health).

Is it conceivable that such an "*expansionist agenda*" might be relevant to the Wessely School's indisputable extension of psychiatry's professional boundaries by claiming the long-classified neurological disorder ME as a psychiatric disorder for which antidepressants are recommended by Sir Simon?

Has there been any ethical violation by members of the Wessely School?

The PACE Trial, in the planning of which Sir Simon was involved and for which he was Director of the Clinical Trials Unit was beset with methodological flaws including coercion of participants to enter the trial (including the threat of withdrawal of access to state benefits if they did not do so); the deliberate inclusion of participants known to be diagnosed with disorders other than the disorder allegedly being studied; financial incentives to GPs to refer any patient with a diagnosis of fibromyalgia or "fatigue"; alteration without permission of outcome domains once the trial had begun, and falsification of outcome scores so that the trial appeared successful, all of which violated international standards for clinical trials, as well as being misuse of public funds. Despite this, Sir Simon published his view that the PACE Trial was "*a thing of beauty*" (Health in mind and body. Simon Wessely. The Journal of the Foundation for Science and Technology December 2011:20:7:9-11).

Has there been advocacy of harmful management Interventions?

The PACE Trial Manuals indicated that CBT and GET could be curative, but Sir Simon had previously published his assertion that these interventions are "*not remotely curative*", conceding that many patients do not benefit from them (Editorial: JAMA 19th September 2001:286:11). It is known that financial considerations played a major role in the joint funding of the PACE Trial by the DWP, and that the reason the DWP agreed to fund it (it was the only clinical trial ever funded by the DWP) was because of the expectation of a "cure" for patients with ME given by the Wessely School. Given his published statement that the same interventions are "*not remotely curative*", what changed Sir Simon's mind between 2001 and 2004, when the PACE Trial commenced, given that it was already known that the interventions it was using were "*not remotely curative*"?

It is indisputable that Sir Simon knew from a study which he co-authored (High levels of type 2 cytokine-producing cells in chronic fatigue syndrome; Clinical & Experimental Immunology: February 2004:135:2L294-302) that GET in particular was likely to be harmful because people with ME/CFS have significant immune dysfunction, leading to exercise intolerance.

Furthermore, the Chief Principal Investigator, Professor Peter White, also knew of the dangers of incremental exercise as used in the PACE Trial because he co-authored a different paper demonstrating immune dysfunction in people with ME/CFS, in which **the TGF-β median values were proved to be approximately 18.1 times as high in patients versus controls (**JCFS 2004:12: (2): 51-66), yet the PACE Trial still went ahead with an intervention which compulsorily increased aerobic exercise in one arm of the trial.

Immune dysfunction can lead to exercise intolerance, which is characterised by symptoms such as brain fog, extreme fatigue, prolonged recovery, and flare-ups of autoimmunity (as documented to occur in ME), where the immune system is constantly fluctuating. Over-exertion can raise inflammation and worsen autoimmune conditions, making it difficult for people with ME to engage in physical activity without experiencing adverse effects. Additionally, mitochondrial dysfunction (shown to be present in ME) is highly sensitive to inflammation, and this can contribute to exercise intolerance.

Given what Professors Wessely and White had just published in 2004 about immune dysfunction in their patients, it defies credibility that the PACE Trial went ahead in 2004. How could this be allowed to happen?

TWO ILLUSTRATIVE CASE HISTORIES

The two following case histories out of many similar case histories convey the reality: the first was read out by Carol Monaghan MP in Parliament on February 20th 2018 during the debate on the PACE Trial (recorded in Hansard):

"One mother contacted me, saying *'Our 12-year-old son was seen at a specialist ME centre by a consultant who prescribed GET. In one year, this 'programme' caused our youngster's body to develop higher and higher levels of inflammation, he began limping, was in continual pain from not only the ME headaches but joint and foot pain. The comments were 'well, he managed to limp into my office', 'you were very active, now since the virus* *you are very inactive, so you will have this pain due to lack of exercise'. GET caused his body's immune system to go into overdrive. My son developed Juvenile Idiopathic Arthritis. This was treated by a paediatric Rheumatology Consultant who was shocked it had been left so long'".*

Another case history is recorded in Hansard on 24th January 2019 in the debate on ME in children. Carol Monaghan MP opened the debate with the following speech:

"I want to describe one such case, which is really quite harrowing. It involves a girl, B, whose name cannot be disclosed. B became ill at the age of eight. A diagnosis of probable ME was made, but it was suggested that the underlying issues were psychological. To show willing, her parents took her to a child psychiatrist, who then involved social services. B's parents were warned that if they did not fully comply, child protection proceedings would be initiated. Social services specified graded exercise despite being warned of the dangers.

"As a result, B deteriorated rapidly until she became wheelchair-bound. Under threat of court action, B's parents were then forced to take her to a children's hospital, having been warned that they were "not under arrest just yet." B's parents found what they presumed to be a safer option in an ME unit run by a consultant who appeared to view ME as an organic illness, but this was disastrous. B arrived wheelchair-bound but still able to sit upright and read and write, but under the activity programme, she deteriorated. Her mother was banned from visiting, but other parents in the unit observed B unattended in the wheelchair, in constant pain, unable to sit upright, with her head hanging down the side and crying in distress.

"This treatment continued for five months. Her parents were threatened that if B did not progress, she would be transferred to a psychiatric unit or placed in foster care. Desperate, they turned to Dr Nigel Speight and the Young ME Sufferers Trust. B was finally allowed home, and her name was eventually removed from the at-risk register. However, by the age of 15, she was bedridden, paralysed, unable to feed or wash herself and utterly dependent on carers. Doctors, psychiatrists and social services all failed her when she was eight. As the Hon. Member for Hendon (Dr Offord) suggested, this is the case for one in five families living with a child with ME.

"This leaves the child open to social service intervention. Often, paediatricians phone a so-called expert on ME, who immediately prescribes graded exercise, without even seeing the child in person. I say to the Minister that this is a national disgrace and it needs urgent action. Children who are already blighted by ME must not be subjected to this trauma. I ask him to consider this issue with the utmost seriousness, and to give the House an assurance that parents will not be prosecuted simply for caring for a sick child. ME has been disregarded for far too long, and it can be fatal.

"In the UK, there have been two patients, Sophia Mirza and Merryn Crofts, whose deaths have been attributed by coroners to ME. However, the actual number of deaths due to ME may be much higher, and we cannot wait for more. The ME community has waited decades for their voices to be not only heard but believed. The Government has the power to make radical changes, and I invite the Minister to meet groups of patients who would welcome the opportunity to describe their experience. Little progress has been made in the 20 years since the 1999 debate. Surely, Minister, in the 21st century, we can do better for those suffering from this devastating illness".

Summary of consequences resulting from The Wessely School's insistence that ME is not an organic disorder:

- Suffering, deterioration and death of ME patients denied appropriate medical care
- No NHS provision for people with authentic, severe ME, leading to the necessity to serve a Coroner's Regulation 28 PFD Notice (Prevention of Future Deaths Notice) on 7th October 2024
- Children with ME forcibly removed from their parents under false accusations of FII (Fabricated or Induced illness, a form of child abuse)
- Adults with severe ME wrongfully sectioned under the Mental health Act

- Doctors punished (suspended or even struck off the Medical Register) for offering medical as opposed to psychosocial interventions to patients with ME

- Control of the media (especially the Science Media Centre, of which Sir Simon is a founding member and to which he is listed as advisor)

- False information being provided to the Palace of Westminster, to formal legal Inquiries and to UK Departments of State.

Total lack of accountability

Sir Simon's association with powerful institutions and top rank decision-makers in the NHS, the judiciary, and in the Cabinet Office appear to insulate him from any accountability. People with ME have published their belief that Sir Simon's pervasive influence and control contribute to their continued suffering -- people whose lives are wrecked and who live in pain, suffering, isolation and poverty, without recognition or support, wrongly diagnosed with a psychiatric disorder, and derided and dismissed by doctors who have been taught and who have absorbed Sir Simon's disproven dictum.

Despite overwhelming biomedical evidence contradicting his dogma, it is known that Sir Simon has accrued considerable personal and professional benefit. Although his work has been widely discredited in scientific circles, he continues to receive accolades and honours. Whilst thousands of sick and disabled people with ME continue to be adversely affected by his theories that are rooted in flawed and discredited non-science, he is increasingly lauded with paeans of praise and endless eulogies and honoured by His Majesty the King.

For such people, for Sir Simon to receive the UK's highest level of civil honour -- Knight Grand Cross of the Order of the British Empire (GBE) **--** in the King's Birthday Honours in June 2025 represents a public endorsement of policies that have resulted in preventable harm and sends a clear message of contempt towards sick and disabled people with ME; it not only compounds, but condones, their suffering. A newly grieving mother regards it as an insult to her dead child (who died from ME).

Who is responsible?

Note: *Although all references have not been included for reasons of space, all exist and most are available online.*