Invest in ME

Charity Nr: 1114035

PO Box 561, Eastleigh SO50 0GQ, Hampshire, UK

***Tel*: 02380 251719   07759 349743**

email: info@investinme.org   web: www.investinme.org

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Dear Mr Yip,

In response to our submission to the Press Complaints Commission (29th August 2011) you asked the charity to respond to the areas of the articles about which we were concerned.

Our complaint related to recent articles in the Times, Sunday Times, Observer, Spectator and Daily Telegraph during July and August, all purporting to examine issues surrounding Myalgic Encephalomyelitis (ME) - (also referred to as Chronic Fatigue Syndrome) and promoting the opinions and views of Professor Simon Wessely of King's College, London,

We have included more specifics in this letter, as you requested, and hope that you will now be able to take this complaint forward.

Our complaint covered these areas of the Editors' Code of Practice.

Accuracy

Opportunity to Reply

Harassment

This Editors' Code also states that –

> "All members of the press have a duty to maintain the highest professional standards".

We do not believe these professional standards have been maintained by these articles.

Here are some specific areas and statements in these articles which we believe contravene this code.

The Sunday Times

"Shoot the medical messenger – see if that'll cure you"

- Rod Liddle 31 July

Mr Liddle writes –

> "He (Professor Simon Wessely) believes the illness, which results in debilitating tiredness, aches and pains and so on, probably has a neurological basis."

However, this is not borne out by facts. Professor Simon Wessely is on record as stating the following [1] and [2] –

> ***"The description given at the Mayo Clinic remains accurate: 'The average doctor will see they are neurotic and he will often be disgusted with them' "*** -(In: Psychological Disorders in General Medical Settings, ed: Sartorius et al; Hogrefe & Huber, 1990)
>
> ***"There lies at the heart of CFS not a virus (or) immune disorder, but a distortion of the doctor-patient relationship"*** -(Chronic fatigue syndrome: an update. Anthony J Cleare, Simon C Wessely. Update (Recent Advances): 14th August 1996:61-69)
>
> ***"It seems that ME sufferers prefer to feel they have a 'real' disease – it is better for their self-esteem"*** -(Pfizer Invicta Pharmaceuticals 1992:4-5)
>
> ***"ME has never been fully accepted as a real condition, says Simon Wessely"*** -(The Guardian, 21st April 1998)
>
> Note that the World Health Organisation fully accepted ME as a real condition in 1969 and continues to do so.
>
> ***"Functional somatic syndromes include chronic fatigue syndrome"*** -(Rev Bras Psiquiatr 2005:27:3)
>
> **"I WILL ARGUE THAT ME IS SIMPLY A BELIEF, the belief that one has an illness called ME"** - Microbes, Mental Illness, The Media and ME: The Construction of Disease - 9th Eliot Slater Memorial Lecture, Institute of Psychiatry, London, 12 May 1994

These quotes seem to prove that Mr Liddle's statement is inaccurate and misleading to the public. He should have researched far more before writing the above statement.

Mr Liddle writes –

> "As a consequence, he (*Professor Wessely*) has received menacing phone calls and even death threats from "extremist" ME sufferers. So too has another researcher, Prof Myra McClure, who says she will now have nothing more to do with the whole business because she's fed up with being abused."

These threats are allegations. Mr Liddle offers no proof of the incidents and neither does he offer any evidence that these were "extremist" ME sufferers who allegedly made such threats. They could just as well have been made by freelance journalists looking for a story.

Mr Liddle writes –

> "It seems that those who suffer from ME, which used to be known as yuppie flu, do not wish to be stigmatised as malingering mentals, which is what they fear will happen if the illness turns out to have a psychiatric rather than biomedical basis."

Mr Liddle repeats the term "yuppie flu" – there is no reason to do so– it is merely an old-fashioned, inaccurate and disparaging term nowadays used to further enforce a discriminatory view against people suffering from this disease.

The rest of that statement is conjecture. How can one blame a whole community of patients (estimated to be up to 250,000 in UK) as not wishing to be stigmatised and what they fear will happen if the disease is psychiatric? There is no basis for this statement and it is wildly inaccurate from our own experiences as an ME charity. Mr Liddle offers no proof of this statement and misleads the public.

In our experience this is not the fear of ME patients. Mr Liddle has not interviewed any ME patients to substantiate this comment. He offers no evidence to support this assertion. This type of loose comment is intimidatory and discriminatory. It maligns a whole section of the population, who already have much to cope with due to this disease, with no proof or scientific research provided.

Mr Liddle writes about "the foaming paranoia on this site (the MEA web site)" and "The truth about ME, they (*MEA*) assert, is that it is the consequence of some sort of weird retrovirus."

This is not what the MEA website states. The MEA are not known to be avid supporters of the Whittemore-Peterson Institute (who jointly discovered an association between the XMRV retrovirus and ME) or of the research which promotes the XMRV retrovirus as a cause of ME. The retroviral causality is only one possibility which has been discovered by biomedical research. Mr Liddle has not read the research or the other streams of possible viral, and immune dysfunction research.

Mr Liddle, in his inaccurate writing, continues this one-sided barrage of ill-considered and erroneous reporting –

> "Some sufferers cling with grim determination to a non-existent biomedical explanation"

Mr Liddle does not refer to the reams of biomedical research papers which prove the disease is of organic origin. Why not? How can he substantiate the claim of a "non-existent biomedical explanation"? Invest in ME have organised and hosted six international biomedical conferences in London which have provided a large amount of peer-reviewed biomedical research which has led to biomedical explanation for this disease. A review of papers in PubMed would also have corrected Mr Liddle's inaccurate statement.

Mr Liddle writes of patient "paranoia" yet offers nothing to substantiate this.

This is discriminatory, insulting and pejorative. Where is the proof of paranoia?

The Editors' Code of Practice states that -

> *iii) Preventing the public from being misled by an action or statement of an individual or organisation.*

This is obviously not the case with the above statements by Mr Liddle and those of Professor Wessely which Mr Liddle has dropped into in his article while denigrating sick and vulnerable people who suffer from a neurological disease as recognised by the WHO and the UK government.

We believe that Mr Liddle is not only feeding the public incorrect information and that the editor of the Times has failed to exercise due diligence in ensuring that this article was factual.

We therefore submit that this article was not only biased propaganda but that the Editors' Code of Practice was infringed.

The Editors' Code of Practice states that -

> *i) The Press must take care not to publish inaccurate, misleading or distorted information,*
> *ii) The Press, whilst free to be partisan, must distinguish clearly between comment, conjecture and fact.*

This was not done. Both of the above Code points were infringed by this article.

The Times

Interview with Professor Simon Wessely

-(Stefanie Marsh -6 August 2011 -)

Ms Stefanie Marsh states in her article -

> "He (Professor Wessely) is Britain's foremost authority on ME, or chronic fatigue syndrome (CFS) as it is also known"

This is incorrect and misinforms the public.

Professor Wessely is not Britain's foremost authority on ME. How can a psychiatrist be a foremost expert in a neurological illness?

Again Ms Marsh repeats the term "yuppie flu" in relation to this disease. There is no need or reason to do this other than to repeat the biased propaganda put out by the media to denigrate ME patients. Would Ms Marsh or Mr Liddle refer to MS patients as suffering from "women's hysteria" or HIV/AIDS patients as having "gay men's disease"? If they did the public outrage would be enormous as it indeed should be. The same should apply to ME.

Ms Marsh states that -

> "For it was his (*Professor Wessely's*) research that proved ME was not, as the general public, many doctors and certainly all employers once imagined, "yuppie flu"."

This is untrue. Professor Wessely has not done anything to allay the misperception that ME is an organic illness. We refer to the earlier quotes by Professor Wessely which were mentioned above and which corroborate this.

Ms Marsh states that

> "He (*Professor Wessely*) discovered that by combining cognitive behavioural therapy and light exercise a third of patients make a full recovery."

This is contentious, misleading and has not been researched properly.

There is no evidence to show that a third of patients make a full recovery.

The Belgian government evaluated the outcome of CBT (and Graded Exercise (GET)) at their CFS centres. Their conclusion was that rehabilitation with CBT/GET could not be considered curative [3]. Patients were working less not more after these therapies. The recent publicly funded PACE Trial study published by the Lancet claimed that a third of patients showed improvement. However the concept of "normal" used by this study does not mean good health or recovery. One also has to look at the diagnostic criteria used. Professor Wessely uses the Oxford criteria – which are criteria designed and implemented by psychiatrists and which exclude patients suffering from a neurological illness (remember the WHO and UK government position on this).

The statement by Ms Marsh is totally misleading for the public and is erroneous. Professor Wessely has also stated elsewhere that his therapies are not curative.

Ms Marsh states

> "Before his work, the standard treatment for ME was rest, with the result that many patients were left incapacitated. Many health professionals agree that he has done more for the sufferers of ME than any other individual, not just in Britain but worldwide."

There are many other patients, patient groups, researchers and clinicians and healthcare experts who would also agree that the views about ME which have been expressed by the "Wessely School" of psychiatrists have done untold damage in promoting ME as a somatoform illness, thus influencing healthcare services, research institutes, research funding and the media. The statement by Ms Marsh is, we feel, misleading. Patients have been left incapacitated by the enforcement of graded exercise treatment which is part of the legacy of this psychiatric approach to treating ME. In our opinion many healthcare professionals could also be said to agree that Professor Wessely has done more damage to ME sufferers than any other individual.

Ms Marsh allows this conjecture to continue as though they were facts. She writes –

> "Such was the vitriol and the constant ratcheting up of the threats emanating from the fringes that, ten years ago, Professor Wessely chose to give up his research.

Why does the journalist not research properly and state that Professor Wessely is still involved in CFS and ME research – something Professor Wessely has stated is not the case? The reporter and editor have allowed misinformation to be published. This would have easily been avoided if the reporter had performed even a cursory glance at PubMed and research into ME. She would have seen Professor Wessely's name associated with recent research into ME.

Ms Marsh allows Professor Wessely to comment -

> "They're (ME activists) not as bad as the animal liberation people," Professor Wessely tells me. "But they're just as fanatical. It's constant stalking, harassment, attempts at intimidation."

This is extreme language by Professor Wessely which is allowed to go unchallenged by the reporter, the editor and the newspaper. This shows a lapse in editorial integrity.

It is Professor Wessely's views on ME and ME patients that seem to be fanatical and Ms Marsh has not been impartial enough to present this – unless the readers were all assumed to be able to read some subliminal message which Ms Marsh was attempting to impart by repeating Professor Wessely's opinions.

Ms Marsh allows further distortion by Professor Wessely when she quotes him as saying –

> "So there is no threat to their status or self-esteem. But CFS sufferers are in a different place."

These are just Professor Wessely's opinion and allegations. No proof is offered. Yet these unchallenged remarks further denigrate sick and vulnerable people.

Ms Marsh writes -

> "And the problem for some is that Professor Wessely is a psychiatrist at all. "I think finally, fundamentally, it is that they cannot stomach the thought that this might be a, quote, 'psychiatric disorder'. By which they mean — not what I mean — 'it's imaginary', 'it doesn't exist', they are 'malingerers'."

This is Professor Wessely's view and the editor has not given an opportunity for an ME organisation to receive equal space to provide the correct view.

The fact is that ME is a neurological illness and is recognised as such by the Department of Health.

There is a legal obligation for the Department of Health to provide ICD data to the WHO for international comparison.

What classification does Professor Wessely use for ME and how does this affect the NHS Data Dictionary?

Why does Ms Marsh not state this in order to redress the balance between fact and opinion?

Ms Marsh writes

> "There was a theory that ME was a retrovirus but it fell apart when tested."

This is misinformation and incorrect.

The research is still ongoing involving the National Institute of Health in USA.

Ms Marsh allows Professor Wessely to comment -

> "Like it or not, CFS is not simply an illness, but a cultural phenomenon and metaphor for our times."

This is an outrageous statement to leave unchallenged and shows Professor Wessely's true beliefs. But the reporter and the editor do not provide references to research which have dismantled Professor Wessely's theories. Why?

Ms Marsh allows Professor Wessely to further distort the public perception of ME -

> "A metaphor that does not apparently translate into non-English speaking countries. "ME is virtually unknown in France, Italy and Spain. Only a small number of doctors will make this diagnosis. So most doctors will not call it this. They will call it neurasthenia, they might call it depression, they might call it stress. …….When we gave them descriptions of our typical clinical cases here in Britain, they didn't recognise them. They said, 'Nah, we haven't seen that'."

And again –

> "Certainly we know that in Italy we do know only a small number of doctors will make this diagnosis."

These statements are totally incorrect and could have been refuted with some cursory research by the journalist. We direct you to the letter to the Times by the European ME Alliance (EMEA) [4] which shows that ME is known and accepted in these countries. The reporter should have verified this instead of passing on misinformation. The editor of the Times did not allow the EMEA letter to be printed. This is gross negligence by the editor and the reporter. It allows the public to be misinformed.

European governments, as with the UK, must adhere to the WHO classification of ME as a neurological illness.

Observer

> **"Chronic fatigue syndrome researchers face death threats from militants**"
> **-** Robin McKie, 21 August 2011)

Mr McKie continues the media panoply of pro-Wessely publicity with this article and repeats much of the distortion which the previous articles have created.

He writes -

> "It is the latter group (*psychiatrists who state that ME is a psychological illness*) that has become the subject of extremists' attacks. The antagonists hate any suggestion of a psychological component and insist it is due to external causes, in particular viruses. In the case of McClure,

> her "crime" was to publish a paper indicating that early studies linking the syndrome to the virus XMRV were wrong and the result of laboratory contamination. So furious was the reaction that she had to withdraw from a US collaboration because she was warned she might be shot.”

No comment is made on the number of alleged activists or extremists in relation to the number of ME patients. Was it one or two or three or more? The journalist does not know because the journalist has not researched this – merely taken Professor Wessely’s viewpoint. Yet the statements make it seem as though there was a huge number. This is pejorative. There is no proof provided - only allegations.

Mr McKie continues-

> “A similar hate campaign was triggered by a study published in the LANCET earlier this year. It suggested that a psychological technique known as cognitive behavioural therapy could help some sufferers. This produced furious attacks on the scientists involved, including Michael Sharpe, professor of psychological medicine at Oxford University. He had already been stalked by one woman who was subsequently found to be carrying a knife at one of his lectures.”

Why has the legitimate critique of the Lancet publication not been reported? Why has the reporter not quoted the extensive number of patient organisations who have rejected the Lancet paper? Why does the reporter only concentrate on anecdotal evidence from vested interests? Was the alleged knife-carrying woman reported to police? What evidence is there of a “hate campaign”.

Mr McKie writes -

> "The tragedy is that this tiny group of activists are driving young scientists from working in the field," said Sharpe. "In the end, these campaigns are only going to harm patients."

There is no proof of this statement. Just Michael Sharpe’s allegation. The journalist hasn’t explored the number of biomedical research applications rejected by the Medical Research Council. This is the real reason for lack of biomedical research into ME. All the public funding has gone to psychiatrists. Why does Mr McKie not examine this evidence? Why has Mr McKie not looked at threats to Professor Malcolm Hooper who has consistently and thoroughly criticised the role of Professor Wessely, Sharpe and their colleagues in denying the existence of ME as an organic illness?

Mr McKie quotes a director at the Science Media Centre stating that these alleged threats are damaging to society. The hypocrisy of this statement being allowed in print is not lost on ME patients.

The Science Media Centre’s Science Advisory Panel includes Professor Simon Wessely [5]. This shows biased reporting.

Mr McKie writes -

> "He (Professor Wessely) gave up his research on chronic fatigue syndrome several years ago"

As stated earlier Professor Wessely has still been involved in research – including a paper authored by Professor McClure on 2010 which was quoted. The reporter should have researched that fact. Just a cursory look on PubMed brings Wesseley's name up in several papers from 2011.

Spectator
"Mind The Gap"
– Professor Wessely -26 August

The Spectator merely allows Professor Wessely to write what he wishes and continue the publicity wave of pro-Wessely propaganda in the media. One could be forgiven for thinking that Professor Wessely had a book which was imminently to be published!!

Where is the opportunity for an ME organisation to respond?

The Spectator allows Professor Wessely to write –

> "But there was. The more I saw, the more convinced I became that the condition was a genuine, serious, debilitating illness."

This, we feel, is disingenuous and not supported by Professor Wessely's recorded comments. We repeat the earlier quotes which were mentioned and made by Professor Wessely –

> ***"The description given at the Mayo Clinic remains accurate: 'The average doctor will see they are neurotic and he will often be disgusted with them' "*** (In: Psychological Disorders in General Medical Settings, ed: Sartorius et al; Hogrefe & Huber, 1990)
>
> ***"It seems that ME sufferers prefer to feel they have a 'real' disease – it is better for their self-esteem"*** (Pfizer Invicta Pharmaceuticals 1992:4-5)
>
> ***"ME has never been fully accepted as a real condition, says Simon Wessely"*** (The Guardian, 21st April 1998)

> **"I WILL ARGUE THAT ME IS SIMPLY A BELIEF, the belief that one has an illness called ME" - Microbes, Mental Illness, The Media and ME:"** The Construction of Disease - 9th Eliot Slater Memorial Lecture, Institute of Psychiatry, London, 12 May 1994

The editor allows Professor Wessely to continue –

> "In 2007, some 20 years after we started, the National Institute for Health and Clinical Excellence approved both treatments as safe and effective."

Professor Wessely does not state, and neither does the editor, that practically every ME patient organisation (except those accepting money to toe the line with government policy) objected to and rejected these NICE guidelines. Professor Wessely does not mention that NICE were taken to a judicial review by ME patients objecting to the NICE guidelines. Professor Wessely does not mention that NICE ignored all biomedical research into ME. This is fact.

We believe this article misleads the public.

The editor allows Professor Wessely to continue –

> "The evidence is that, like most illnesses, CFS is a mixture of the physical and the psychological."

Where is the evidence? It is here that we need to have the views of patients represented and of other scientists and researchers who disagree with Professor Wessely's views.

Also this goes against Professor Wessely's stated comments which were mentioned earlier.

The editor allows Professor Wessely to continue –

> "For the outraged minority, however, being referred to a psychiatrist or psychologist is tantamount to being told that the symptoms are imaginary."

This is disingenuous as Professor Wessely has stated that "**ME IS SIMPLY A BELIEF**".

Patients object to being referred to a psychiatrist when they have a neurological illness that needs to be examined and treated accordingly. MS patients, for example, are not primarily referred to psychiatrists.

The editor allows Professor Wessely to continue –

> "At present, the treatments pioneered at Queen's Square are the best we have."

This is just opinion – not borne out by facts. It misleads the public.

The editor allows Professor Wessely to continue –

> "And last, the malign tactics of the minority have helped to delay scientific progress: numerous scientists in other fields, including neurology, immunology and virology, have dipped their toes in the water of CFS, been scalded and given up."

It is also true to point out that many scientists would be willing to perform ME research had the "Wessely School" of influence not stopped funding by MRC into biomedical research. Why in all of these articles have the editors not sought quotes from these immunologists, neurologists and virologists to find out the real reason of them leaving the field?

Professor Wessely is allowed to write -

> "The worst is the deliberate falsification of what we have said or written: quotes are circulated with the essential word 'not' deleted, for instance. And transcripts of our speeches are sometimes altered so that 'yes' becomes 'no'.

Professor Wessely's views and comments about ME are on public record.

Asking questions from ethics committees is a legitimate avenue for patients to express their concerns and seek clarification on matters that affect them.

Professor Wessely writes -

> "The World Health Organisation, which runs something known as the International Classification of Diseases, a Sisyphean attempt to bring order to diagnostic chaos, is now working on yet another revision. They should think seriously about following the MRC lead and merging psychiatry and neurology into one category. This would rid us of the 'all in the mind' slur, and let us get on with our jobs — improving the treatment of patients and their illnesses."

Why is Professor Wessely allowed his view without proper reply from patient groups? If Professor Wesley's views are accepted then why aren't MS or epilepsy patients seen primarily by psychiatrists?
In a BMJ podcast of 5th March 2010 Professor Wessely stated (in relation to the retroviral association with ME as determined from the research by the Whittemore-Peterson Institute, Cleveland Clinic and the National Cancer Institute) -

> "We're not going to go on doing more and more tests to find what was the virus, because frankly even if we found it there's nothing we're going to do about it, we're in the business of rehabilitation." [6]

It would seem that Professor Wessely would not change his methods of "improving the treatment of (ME) patients" no matter if neurology were to be merged with psychiatry. Professor Wessely rejects objective neurological testing for ME patients.

We submit that by allowing Professor Wessely to publicise his views in this article, without allowing the ME community to respond, that the Spectator has contravened the Editors' Code of Practice on a number of points. This article has allowed the public to be misled and risked denigrating further a section of the public who suffer from a neurological illness as categorised by the WHO and officially accepted as such by the UK government. The Spectator has allowed prejudiced views on ME to be publicised without proper attention to detail. The public have not been served by this article. A section of the community has been discriminated against without an opportunity being given to respond.

Daily Telegraph
-'Protestors have got it all wrong on ME' 27 August 2011
-Max Pemberton

Mr Pemberton writes -

> "That people feel threatened by the idea that ME has a psychological component says a lot about the stigma of mental illness."

There is no evidence to support this statement. Where has this been proven that ME patients feel threatened?

Mr Pemberton writes -

> "The reason for their behaviour is that research is focusing on the psychological basis of the condition; as a result of the findings, ME is now

> considered to have a significant psychiatric component. While the protesters represent only a tiny fraction of those with ME, it is true to say that many others feel strongly about the suggestion that it has any basis in psychology at all.

This is totally incorrect. There is no scientific evidence for this statement. If Mr Pemberton had researched and reported the evidence he would have seen that objections to Professor Wessely are due to the statements and actions of Professor Wessely over the years – where he consistently denies that ME exists. Professor Wessely studies the so called Oxford Criteria defined CFS (not used outside UK) which has nothing to do with the Department of Health and NHS endorsed ME as classified in ICD10-G93.3

Mr Pemberton writes -

> "Many claim that their condition is the result of a viral infection or exposure to environmental toxins. Research to date has failed to support conclusively this hypothesis, much to the chagrin of sufferers, who feel frustrated and angry that doctors remain sceptical that this is the actual cause."

This is untrue. Much biomedical research does support this and many researchers believe the cause of ME is of a virological origin.

Mr Pemberton writes -

> "In addition, years of research have already been undertaken, which has produced underwhelming, inconclusive results to support a biomedical cause. It wasn't until psychiatrists such as Prof Wessely started treating the condition psychologically that real progress was made."

This misses the point completely that the evidence is not underwhelming – the funding for biomedical research is underwhelming. The psychiatrists who share Professor Wessely's views have taken the lion's share of the funding on ME research – totally for their psychiatric theories which remain unproven.

Mr Pemberton writes -

> "The current gold standard for treatment, as supported by the National Institute for Health and Clinical Excellence (Nice), is a combination of supervised exercise and talking therapies. "

This is untrue. Practically all ME patient organisations rejected the NICE guidelines. They cannot be said to be a gold standard, or current.

Mr Pemberton writes -

> "A major British trial published in The Lancet found that at least one in three patients with ME improved or recovered using this approach. The biggest hurdle faced by doctors is persuading people to actually attend and engage with treatment. They resist because they refuse to be seen as mentally unwell. It does seem bizarre that those with such a debilitating disease would refuse treatment because it was given by a psychiatrist.

Mr Pemberton omits the fact that the Lancet publication is based on flawed research which moved the goalposts for the research criteria midway through the trial. One only needs to compare the trial registration documents and the final published research to see the flaws in this expensive publicly-funded study and the claims they make.

Mr Pemberton writes -

> "Microbiologists and immunologists have been unable to help ME patients, and so psychiatrists have become involved. But that is considered outrageous. People refuse to go to outpatient appointments and refuse treatment, despite evidence that it works. Accusations are thrown around that the medical profession is not taking them seriously. But, just because doctors frame a condition in terms the sufferer does not like, does not mean doctors are not taking it seriously. That people feel threatened by the idea that ME has a psychological component says a lot about the stigma of mental illness."

This is just misinformation based on ignorance, poor research for the article or manipulation/cooperation to promote a view of ME which is incorrectly supported by research. ME patients are not threatened by the idea that ME has a psychological component. ME patients just do not want their health treated with misinformation and obfuscation of the truth.

Mr Pemberton writes -

> "It's an attitude that dogs the lives of many people living with mental health problems. Yet, for me, a psychological explanation is a very real one. It doesn't mean someone is faking it; it doesn't mean the illness

> doesn't exist. It also doesn't mean that people should be able simply to pull their socks up and get better, or that it's under conscious control. However, it is testament to the complexity of the brain that the mind is capable of such stark physical symptoms. As a model for understanding a condition, it's as valid as any other."

The implication in this article is that ME patients object to a psychological explanation because they are threatened by some stigma toward mental illness. The WHO and the UK government officially classify ME as a neurological illness. Why would ME patients fear any stigma to a disease classification unconnected to their own disease?
This is just misinformation and biased reporting and does not serve the public interest. It misleads the public and no chance is offered by the editor to redress this imbalance between fact and opinion.

Why do we feel it is so important that the PCC investigate these complaints?
It is because those who suffer from ME have to endure enormous pain and illness caused by the disease. They suffer enormous hardship as do their families and carers. They do not need to be denigrated even further by misinformation and shoddy journalism.

The disease is officially recognised by the WHO as a neurological illness. The UK government accept this also. Yet the views propagated by Professor Wessely and his colleagues have helped distort this classification and affected perception of the illness by media, academia, researchers, politicians and the public. By allowing these one-sided views to be repeated and embellished by poor reporting the editors of these newspapers have misled the public.

The lack of any real research in these articles is staggering bearing in mind the effect these articles will have on sick and vulnerable patients who have been left with little proper healthcare due to the policies of and beliefs of people like Professor Wessely, which have been the only views published in this coordinated series of articles.
We would ask for similar coverage to be given to the patients' stories.

We would also like to ask the PCC to investigate the possible collusion by the editors of these newspapers in producing essentially the same propaganda by promoting the views of mainly one person in such a short space of time.

The Editors' Code of Practice states -

Accuracy

iii) The Press must take care not to publish inaccurate, misleading or distorted information,

We believe the editorial procedures in these newspapers have not been rigorous enough. The views of Professor Wessely with regard to ME are, we feel, extremist and largely inaccurate and the public will have been given a completely distorted view of this disease by reading these articles.

ii) The Press, whilst free to be partisan, must distinguish clearly between comment, conjecture and fact.

The editors and journalists participating in the production of these articles have not been careful enough to distinguish between fact and conjecture. In fact some of the journalists have contributed to this lack of distinction.

All of the articles allow sycophantic homages to Professor Wessely and his views, whilst painting Professor Wessely as a victim and denigrating ME patients as extremists. Yet they avoid mentioning the damage being done by psychiatrists who enforce their doctrine and theories on sick and vulnerable patients suffering from an organic illness which is officially recognised by the WHO and the UK government as a neurological illness [8].

The repetition of the alleged death threats to Professor Wessely has had no research to corroborate the fact that multiple researchers have received death threats – as has been stated in The Telegraph. We only have Professor Wessely's allegation.

The Editors' Code of Practice states -

Opportunity to Reply

> *A fair opportunity for reply to inaccuracies must be given when reasonably called for.*

These newspapers have not allowed any fair opportunity for replies or requested any opportunity to reply. They have not provided a similar amount of space for anyone to refute Professor Wessely's claims or those comments of the journalists.

The Times ignored the letter by the European ME Alliance which disproved some of Professor Wessely's remarks.

The Editors' Code of Practice states -

Harassment

i) Journalists must not engage in intimidation, harassment or persistent pursuit.

One could argue that these seemingly coordinated efforts to provide biased articles in support of one person's viewpoint, are harassing and intimidating to ME patients.

These articles have caused great distress for many sick and vulnerable patients who do not have the means or the health to reply. As such the patients are cheap targets for these editors who have allowed poorly researched, biased and superficial articles to be published instead of factual content.

The Editors' Code of Practice states -

Discrimination

i) The press must avoid prejudicial or pejorative reference to an individual's race, colour, religion, gender, sexual orientation or to any physical or mental illness or disability

The tone of the articles is completely biased and denigrates ME patients and trivialises the disease itself as not of organic origin – remember the WHO and UK government classification and position on this.

The Editors' Code of Practice states -

Discrimination

3. Whenever the public interest is invoked, the PCC will require editors to demonstrate fully that they reasonably believed that publication, or journalistic activity undertaken with a view to publication, would be in the public interest.

Your Code of Conduct states that the Public interest includes

ii) Protecting public health and safety.
iii) Preventing the public from being misled by an action or statement of an individual or organisation.

It can only be in the public interest to publish stories eulogising Professor Wessely if the victims at the receiving end of his particular doctrine are allowed a similar opportunity to present their views.

In our opinion these articles, by their content and their contiguity, being published consecutively in one newspaper after another during a relatively short period of time, are misleading the public due to their extremely poor research, lack of scientific rigour and due to the total absence of any reasonable editorial process. There seems to be no editorial discipline at all invoked.

The articles are conspicuous mainly because they all provide Professor Wessely with a platform to publicise his views on ME whilst at the same time repeating Professor Wessely's alleged death threats against him from ME patients – without providing any proof of the veracity of these allegations.

That these articles all seem to follow on one from another in different newspapers during a very short period of time would indicate to us a level of collusion and a coordinated attempt by the editors of these newspapers to distort the facts around this disease.

ME is a serious, disabling and chronic organic (i.e. physical not mental) disorder. ME has been classified by the World Health Organisation (ICD 10 G 93.3) as a neurological illness affecting up to 250,000 individuals within the UK. It is also accepted by the UK government as a neurological illness of severe disability.

ME patients have been banned from donating blood for life and are not allowed to donate live or deceased tissue, bone marrow or cord blood unless the condition has resolved according to the UK donor selection guidelines.

Yet all of the articles repeat, or allow to be repeated, the same inaccuracies embedded in Professor Wessely's opinion that ME is a somatoform illness.

This clearly goes against the WHO classification, the UK government policy, the Blood Transfusion Service and Tissue Transplantaion Services and an enormous body of evidence from biomedical research.

There is little impartiality in these stories.

The editors of these newspapers have not allowed an opportunity to be provided for any ME organisation or people with ME, or even the so called 'militant activists' (who remain unidentified), to respond with a similar article. They routinely ignore letters in reply and are not serving the public interest with the distortions in their biased articles.

We contend that these newspapers have misled the public.

As none of these editors have allowed patients or patient groups to respond with similar media space then we provide an example here by repeating the words of one ME patient.

In a presentation by Catriona Courtier at the Royal Society of Medicine meeting in the "Medicine and ME" series on 11th July 2009 she emphasised the scandalous situation faced by ME patients in the UK:

> *"Over the twenty years I have had this illness, what has really bedevilled the situation of patients with ME has been the belief, which has been persistently promulgated, that we are suffering, not from a physical illness but from an illness belief. This is at the root of all the problems we experience: the lack of resources, the hostility and disbelief from some doctors, the ignorance and disinterest in our symptoms, the ineffective treatments, the harmful treatments and in the very worst cases, the imposition of psychiatric treatment against the patient's wishes.*
>
> *"Those who promulgate the view that ME is an illness belief have undermined the mutual trust and respect that should exist between doctor and patient. They have done a great disservice to both patients and to the medical profession.*
>
> *"I began by describing the severely affected as the weakest among us. In some ways they are the strongest… to live for many years with an illness like ME is a huge feat of human endurance and courage but is seldom recognised as such. People with ME at all levels deserve to be respected. They deserve to be listened to".*

We would also like to repeat the words of Dr Harvey Alter – (chief of the infectious disease section and associate director for research of the Department of Transfusion Medicine, Warren Grant Magnuson Clinical Center at the National Institutes of Health in Bethesda, Maryland).

> "I'm absolutely convinced that when you define this disease by proper criteria, this is a very serious and significant medical disease, and not a psychological disease. It has the characteristics of a viral disease. It usually starts with a viral-like illness. If XMRV is not the causative agent -- and it may well not be -- there is still need by other groups to look for the next agent which may be the case." [8]

We hope that the Press Complaints Commission will investigate this breach of ethics and procedures by investigating this spate of coordinated attacks and propaganda against ME patients and their families.

The Editors' Code of Practice states that "All members of the press have a duty to maintain the highest professional standards".

We believe that these articles have instead lowered the professional standards to an unacceptable degree and the editors have therefore failed in their duty.

Thank you for allowing us to provide this information and for considering our complaints,

Yours Sincerely,

The Trustees and Supporters of Invest in ME

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8] Dr Harvey Alter's Closing Remarks at the Blood Products Advisory Committee Meeting - December 2010 http://www.investinme.org/InfoCentre%20Topics%20Dr%20Harvey%20Alter%20BPACM.htm