

**From the Press Complaints Commission - Response to Complaints from  
Invest in ME**

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**Our references: 113837/114230/114231/114232**

Further to our previous correspondence, the Commission has now made its assessment of your complaints under the Editors' Code of Practice.

The Commission members have asked me to thank you for giving them the opportunity to consider the points you raise. However, their decision is that there has been no breach of the Code in these cases. A full explanation of the Commission's decisions are attached.

Although the Commissioners have come to this view, they have asked me to send a copy of your letter to the editors so that they are aware of your concerns.

If you are dissatisfied with the way in which your complaints have been handled - as opposed to the Commission's decision itself - you should write within one month to the Independent Reviewer, whose details can be found in our How to Complain leaflet or on the PCC website at the following link:

<http://www.pcc.org.uk/about/whoswho/independentreview.html>

Thank you for taking these matters up with us.

Yours sincerely

Elizabeth Cobbe

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### **Commission's decision in the case of**

#### **Invest In ME v**

#### **The Sunday Times/The Times/The Observer/The Daily Telegraph/ The Spectator**

The Commission received a complaint from Invest in ME about a number of articles covering the subject of ME/CFS and research into the condition. Two additional complaints were submitted about the article published in the Daily Telegraph.

The Commission made clear from the outset that the cause, and indeed treatment, of ME/CFS was a controversial subject on which there was no unanimous scientific position. A number of positions were held - including some researchers who believed that the cause was biomedical and others who believed that there was a psychological explanation. There was on-going, international debate on the subject. It was not for the Commission to make a ruling as to the correct explanation. Rather, the Commission was required to consider whether the manner in which newspapers reported or commented on the subject would mislead readers as to the situation. As such, the Commission first addressed the concern raised about the article "Shoot the medical messenger - see if that'll cure you" (The Sunday Times 30/08/2011).

Columnists are entitled to express their personal views on a subject – however controversial or robust their opinions might be – provided that they were clearly distinguished from fact. As such, Rod Liddle was entitled to express his opinions and speculate on ME/CFS, its causes and those who suffered from it. Readers would understand that the claim that some sufferers were "paranoid" and that they "do not wish to be stigmatised as malingering mentals" reflected his views on those who suffered from the condition. Indeed, the latter claim was clearly distinguished as conjecture from the beginning of the sentence, which stated "it seems that those who suffer from ME...".

Readers would be aware that the comments represented his opinions on the subject and did not amount to statements of fact about all those who were affected by ME/CFS. There was no breach of Clause 1 (Accuracy) of the Code.

The complainant had expressed further concern that the newspaper had published allegations that Professor Wessely and Professor McClure had received threats from "extremist" ME sufferers as fact. The Commission noted that both individuals had stated that they had received such threats from individuals suffering from ME and who disagreed with their research. This had been widely reported in the press and there was no suggestion that the claims were

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incorrect. Given that the complainant had not provided any grounds to suggest that the claims were inaccurate, other than speculation that they may have been sent by journalists creating a story, the Commission did not consider that it was inaccurate or misleading to report that the two professors had received abuse and threats from those suffering from ME. There was no breach of the Code on this point.

The Commission then considered the reference to the “non-existent biomedical explanation”. It recognised the debate in this area – that some researchers dismissed a purely biomedical explanation while others dismissed a purely neurological explanation. The article had already made clear that some parties held the position that a retrovirus was responsible for the condition, and readers would understand that the issue was highly contentious. Indeed, the focus of the article was the controversy attached to the debate. Given that a definitive biomedical explanation had not been universally, or indeed predominantly, accepted by the scientific community, the Commission considered that the columnist was entitled to claim that there was no biomedical explanation for the condition. It well understood that some readers would strongly disagree with the position taken by the columnist, however, it considered that he was entitled to take this position – which was held by a number of members of the scientific community researching the subject – in the debate and could not establish a breach of Clause 1 (Accuracy) of the Code.

The complainant had objected to the reference to Yuppie Flu. While it acknowledged the derogatory nature of the term, the Commission considered that the columnist – and the authors of other articles under complaint – was fully entitled to reference it as a former colloquial name for the ME/CFS. It was not a statement that this was an accurate reflection of the condition, but merely a reference to a previous term of reference. Readers would not be misled and it was not inaccurate to claim that the term had been used in the past.

In regard to the concern raised by the complainant that the columnist had misrepresented the views both of ME Association and Simon Wessely in the course of the article, the Commission made clear that it would require a complaint from, respectively, the organisation and the professor, in order to establish whether they considered that their positions had been misrepresented. The ME Association was aware of the services offered by the PCC and that a complaint could be made over the accuracy of the portrayal of the organisation in the press. However, the Commission had not received a complaint from the ME Association, Professor Simon Wessely or his representative about the article. As such, it could not make a ruling on this aspect of the complaint.

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The Commission then turned to the second article under complaint: "Doctor who is loathed by the very people he wants to cure" (The Times 06/08/2011). The article was an interview with Professor Simon Wessely. Given the controversy surrounding his research and the strong objections many held to his views, it was inevitable that some readers would object to the publication of an interview with him. However, the Commission made clear that the newspaper was entitled to publish his opinions and comments, provided that they were clearly distinguished as such. The complainant had expressed concern over the publication of a number of direct quotes attributed to him – that he had been stalked and harassed by ME activists; that "CFS sufferers are in a different place" to cancer sufferers; that the condition was a "psychiatric disorder"; that CFS was "not simply an illness"; and that ME/CFS was not widely diagnosed in European countries – which it considered to be inaccurate. The Commission noted that in each case the comments had been clearly presented as representing the view, experience and position of Professor Wessely and that readers would recognise this. Interviews necessarily reflected the position of the interviewee – the very purpose was to ascertain their views on subjects. Readers would understand that the expression of such views did not necessarily represent statements of fact. As such, the Commission concluded that the newspaper was entitled to publish the comments of Professor Wessely and was satisfied that readers would recognise them as such. There was no breach of the Code on these aspects of the complaint.

The complainant considered the statement that Simon Wessely was the foremost authority on ME in Britain was inaccurate on the grounds he was a psychiatrist. The Commission acknowledged that the complainant, and undoubtedly other readers, would object to this description on the basis that they strongly disagreed with his research and position on the condition. However, given that he had been a prevalent researcher on the illness, the Commission did not consider that readers would be misled by the distinction. It was ultimately a judgement call which would not be significantly misleading. In addition, the newspaper was entitled to report that many health professionals considered that he had done more for the sufferers of ME than any other individual. There was no suggestion that no health professionals held this position – rather the complainant pointed that this opinion was rejected by many affected by the illness. Readers would not be left with the impression that his position on the condition was unchallenged or universally accepted and, as such, there was no breach of the Code on this point.

The Commission then addressed the claim that Simon Wessely had found that with a combination of cognitive behavioural therapy and light exercise a third of patients would make a full recovery. The Commission acknowledged the complainant's position that this related to a contentious PACE trial. However, it appeared to the Commission that the reference was to a study, published by Professor Wessely and others, named "*Cognitive Behavior Therapy for Chronic Fatigue Syndrome: A randomized Controlled Trial*". In this trial, of 53 patients who completed the treatment, 15 patients who received cognitive behaviour

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therapy (graded activity and cognitive restructuring) no longer fulfilled the diagnostic criteria for chronic fatigue syndrome. As such, while it acknowledged that there might be some dispute over the set of criteria used in the study, the Commission did not agree that the claim in the article was a significant misrepresentation of the study. There was no breach of the Code on this point.

The complainant was concerned by the claim that the theory that ME was a retrovirus had fallen apart. The Commission acknowledged that research was on-going into the connection between ME/CFS and retroviruses. However, given that no former study had conclusively demonstrated and been accepted as verifying that ME/CFS was caused by a retrovirus, the Commission did not consider that the journalist's comment was significantly misleading as to the situation. There was no breach of Clause 1 (Accuracy) of the Code on this point.

The final point raised by the complainant over this article was the claim that Professor Wessely had given up his research ten years ago. This was repeated in other articles under complaint. The complainant stated that this was incorrect as his name was still attached to various papers on the subject. Again, the Commission would require a complaint from Professor Wessely or his official representative in order to establish whether he considered that he had been misrepresented in the article. In the absence of such a complaint, it could not make a ruling on this point of the complaint.

The third article in contention was: "Scientists face stream of ME death threats" (The Observer 13/09/2011). The Commission repeated its position that newspapers are entitled to publish the comments and opinions of individuals and organisations. As such, the publication of Michael Sharpe's comment that such behaviour was driving young scientists from working in the field and the Science Media Centre's view on the threats did not raise a breach of the Code. They were both presented as direct quotes and readers would understand that they reflected their respective positions on the attacks.

The complainant repeated the concern that the newspaper failed to provide evidence to support the existence of the threats directed at researchers in the subject. As before, there was no dispute that the researchers in question had reported receiving such threats and the complainant had not provided any grounds that demonstrated the claims were inaccurate. Indeed, the police had stated that the ME/CFS "activists" were dangerous and uncompromising. The Commission did not consider that it was misleading to report that such threats and abuse had been issued. There was no implication that a large proportion of ME/CFS sufferers carried out such threats – it repeatedly referred to "extremists" and "activists" who attacked researchers, and Michael Sharpe referred to "a tiny group of activists". There was no breach of the Editors' Code on this point.

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The Commission then turned to the absence of reference to the legitimate critique of the Lancet study. It noted that the focus of the article was on "extremist" attacks provoked by research into ME/CFS. The Commission considered that the newspaper was entitled to report on the more extreme reaction to the study and did not consider that readers would understand this to mean that there had not been more levelled or legitimate criticism of the study. As before, there did not appear to be any grounds to suggest that the scientists had not received the threats, and the Commission considered that naming the more extreme reactions a "hate campaign" was not misleading. There was no breach of Clause 1 (Accuracy) of the Code.

The Commission then considered the article "Mind the gap" (The Spectator 26/08/11). The Commission understood that the complainant strongly disagreed with the position of Professor Wessely. However, he was entitled to express his view publicly and the newspaper was not obliged to include views that opposed his in the article. The article was very clearly an opinion piece and readers would understand that it reflected his position on ME/CFS, its cause and its treatment. All the points raised by the complainant – the acceptability of the NICE guidelines; the treatments pioneered at Queen's Square; the nature of CFS; and the reason other scientists did not enter the field – demonstrated that it disagreed with Professor Wessely's views and experiences. While it was certainly entitled to do so, this did not render the article a breach of Clause 1 (Accuracy) of the Code. Readers would be fully aware that article reflected the opinions of the professor and that other views on the subject existed. Given that the Commission had not established a significant inaccuracy, the Commission did not consider that the terms of Clause 2 (Opportunity to reply) were engaged.

The final article complained of was the piece which appeared in the Daily Telegraph headlined "Protesters have got it all wrong on ME". This had attracted two additional complaints. The article was again a comment piece in which Max Pemberton, a doctor, expressed his view of ME. The Commission understood that many of those affected by ME/CFS would strongly disagree with his position – namely that it had a psychological basis. While it acknowledged that the complainants did not necessarily accept the research on this subject, he was entitled to express his adherence to this view point and make reference to the existence of research that suggested there was a psychiatric component and that progress had been made since it had been treated psychologically. The Commission acknowledged that it was not universally accepted that ME had a psychiatric component – however the position did represent one side of the debate and was held by a number of parties. That the complainants rejected the veracity of the research did not mean that the journalist was incorrect to accept it. Ultimately it was a difference of opinion. Similarly, he was entitled to (a) reject research into a biomedical cause as inconclusive – a definitive biomedical basis had not yet been widely acknowledged; (b) to claim that the NICE guidelines were "gold standard"; and (c) to express his view that ME sufferers

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were threatened by the suggestion that the condition had a psychological basis. These were all differences in opinion on the illness, it causes, research into it and its treatment and did not render the article inaccurate or misleading. The article was clearly a comment piece and therefore evidently reflected Max Pemberton's views on the subject. There was no breach of the Code on these points.

The Commission acknowledged the position of the two complainants that the columnist conflated CFS and ME when they were two distinct conditions. The Commission noted that there was some dispute between researchers as to whether CFS and ME were the same disorder and that there was a lack of consensus on a universally acceptable name for ME/CFS. However, it appeared that CFS was also called by the NHS in England and Wales ME – suggesting it viewed the terms as broadly interchangeable. While it acknowledged their point, it did not consider that readers would be significantly misled by the use of the term ME in the article in contention. In regard to the reference to the study published in the Lancet, the Commission would require a complaint from those responsible for the study in order to establish whether they considered that its results had been misrepresented in the article.

The complainants objected to the suggestion that those affected by ME/CFS resisted treatment. The Commission considered that readers would understand that this reflected the actions of those who did not consider that the treatment on offer was appropriate for treating a biomedical condition. While there was obviously dispute over the validity of the reasons for rejecting the treatment according to NICE guidelines, the Commission considered that the columnist was entitled to express his opinions on this issue. There was no breach of the Code on this point.

One complainant stated that there was no evidence to support the claim that doctors had been subjected to "harassment, bullying and death threats". As the Commission had previously stated in the decision, it had been widely reported that the researchers had received this abuse and the complainant had not presented any grounds which suggested that the claims were inaccurate. It could not establish that the reference was inaccurate or misleading.

Invest in ME had expressed concern that the coverage discriminated against ME patients as had the two further complainants about The Daily Telegraph article. The Commission understood their position; however, the terms of Clause 12 (Discrimination) do not cover references to groups or categories of people – such as those with ME/CFS – but rather references to particular individuals. Given that the complainants considered that the article discriminated against ME/CFS patients in general, rather than a particular individual with the illness, the Commission could not establish a breach of the Code on these grounds.

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Some concerns had been raised that the newspapers routinely failed to publish the views of ME patients or patient groups. Clause 2 (Opportunity) did not amount to a requirement that balancing or opposing views must be published by newspapers in a comment piece or in response to an article. Rather, it stipulated that individuals must be afforded the opportunity to respond to published inaccuracies when appropriate. While it understood the frustration of the complainant that alternative viewpoints on ME/CFS were often not published, the Commission had not established any significant inaccuracies and as such did not consider that the terms of Clause 2 were engaged.

The purpose of Clause 4 (Harassment) is to prevent journalists from engaging in intimidation, harassment or persistent pursuit in the newsgathering process. As such, it related to the actual conduct of the journalist rather than the newspaper's choice of issues to cover or the editorial position it might take on a subject. While it noted that one complainant felt that the wide coverage of the threats to ME researchers and Simon Wessely's position on the illness showed a level of collusion among editors, it made clear that the choice of material for publication was a matter for the discretion of the individual editor. The Code does not seek to dictate what news is covered and whose opinions were reported – which would equate to censorship – but rather to ensure that newspapers maintain the professional and ethical standards defined by the Code. Given that the Commission had not found the articles under complaint inaccurate or discriminatory, it could not establish that the newspaper's decision to cover this subject raised a breach of the Code.

Finally, one complainant had cited the public interest aspect of the Code. This section explained that in circumstances of demonstrable public interest, editors could make exceptions to some of the clauses of the Code. As such, it could not be engaged by readers as a separate clause but rather could be invoked by editors as justification for publishing material which, in the absence of demonstrable public interest, might raise a breach of the Editors' Code. As such, it was not relevant to the complaints.

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The PCC is an independent body which administers the system of self-regulation for the press. We do this primarily by dealing with complaints, framed within the terms of the [Editors' Code of Practice](#), about the editorial content of newspapers and magazines (and their websites). We keep industry standards high by training journalists and editors, and work proactively behind the scenes to prevent harassment and media intrusion. We can also provide pre-publication advice to journalists and the public.

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