

Behind the scenes: Setting up the UK CFS/ME Research Collaborative (UK CMRC)

When the UK CFS/ME Research Collaborative (UK CMRC) was set up in 2013, the Young ME Sufferers Trust declined to attend the launch, due to concerns we expressed in a Statement, the text of which is here: <http://www.tymestrust.org/txt/alert201305meawarenessday.txt>

Our concerns continue. The following information is from 212 email chains and associated attachments received from an FOI request to the Medical Research Council (MRC).

We note:

In the run-up to the full formation and launch of the Collaborative, a meeting was recorded by the Science Media Centre (SMC)'s outgoing head of Mental Health (details below). In attendance were key persons now involved with the Collaborative. Under their heading 'Harassment' (of researchers) they list:

Freedom of Information Requests
Complaints to the GMC and various institutions
Parliamentary Questions

A series of Action Points include:

'Support4rs - Work with Peter White and Simon Wessely to develop resources for dealing with harassment'
'SMC – Run a press briefing on biosocial illness to improve public understanding.'

NB Two sets of written records are kept of Collaborative meetings; one for the Board, another for the public. This should be borne in mind when reading records that are placed online.

Timeline with numbered quotes for ease of use

The first section of emails below shows how **Professor Stephen Holgate**, Chair of what was initially called the **UK ME/CFS Research Collaborative**, initiated and facilitated discussions resulting in a change of terminology, **with 'CFS' now predominating**.

The charities' views were overridden; however, they accepted the situation and still took part.

- On 12th January 2013, **Professor Stephen Holgate**, Chair of **what was at that point called the UK ME/CFS Research Collaborative (UK MCRC)** sent an email to Collaborative group members stating: "As you will know, we have firmed up the date and place for the Inaugural Launch of the **UK ME/CFS Research Collaborative (UK MCRC)**. I attach a list of people that I intend to approach as researchers or those interested in supporting research in the field ..." (*quote 1*)
- **Professor Holgate** then emailed **Professor Simon Wessely** with importance marked as 'High' and **copied only to Dr Esther Crawley** of Bristol University and **Joe McNamara** of the MRC. It read "Dear Simon, If you feel there is anything you can do to help in identifying researchers or in other ways, I would be very grateful. Thank you so much. Kind regards, Stephen." (*quote 2*)
- **Simon Wessely** replied "First of all, it looks very good..... can't see many omissions (*sic*). I would probably sprinkle one or two scientists/researchers not particularly connected with

CFS into the mix myself. Experimental psychologist perhaps, joe, do you know one?....”

Simon Wessely’s suggested researchers were redacted. *(quote 3)*

- **Stephen Holgate** replied “Wow! This is terrific, Simon – thanks so much. I will add your suggested names. Kindest regards, Stephen” *(quote 4)*
 - NB At the end of January, **Stephen Holgate** sent an update on the issue of researchers to Collaborative group members (31st January 2013): “Please see attached list of research-interested people so far attending the launch... Could you see if there is anyone else we should include...?” *(quote 5)* The list of recipients included **Simon Wessely.**
- Again on Saturday 12th January, **Stephen Holgate** sent another email: “To all: One point that I would like a view on is the terminology: CFS/ME or ME/CFS, NHS, NICE and MRC use CFS/ME. I wish to be consistent so can I have a view from all please. **I will then make any changes (including the name of the collaborative!)**” *(quote 6)*
- **Simon Wessely** was on the list of recipients. He replied: “Thanks for asking. **I think we should stick with CFS/ME** frankly. Keeps it in line with MRC and NICE. Journals certainly only use CFS. USA doesn’t use ME at all. CFS/ME seems to be the best compromise. Nervous that ME/CFS would alienate one or two researchers not actively involved in area but who you would like to see involved.” *(quote 7)*
- **This view was endorsed by Peter White** “..... I agree with Simon that **CFS has to lead.** The hybrid CFS/ME allows the broad church that encourages generalizable research, while allowing stratification where necessary.” *(quote 8)*
- **Sonya Chowdhury**, CEO of Action for ME (AfME) replied “ ... my preference is that we use **ME/CFS** and I suspect if we were to ask members, there would be a preference for this form from them too. However, I am prepared to work with either as the importance here is consistency and collaboration and if the general view differs, **I will go with the majority.**” *(quote 9)*
- **The MEA** stated a preference for **ME/CFS** but that they also were “**happy to accept the majority view on this**”. *(quote 10)*
- **MERUK’s** preference was also for **ME/CFS**, they added “we use ME/CFS as do the patient-based campaigning charities.” *(quote 11)*
- On 21st January **Stephen Holgate** emailed the group, “After undertaking a poll for preferences of a title, the **CFS/ME terminology** seems to be the option most wish to go for. It seems that the NHS, Research Councils and NICE use this terminology as do the majority on Pubmed. I hope we can now accept this.” *(quote 12)*
- The Collaborative thus became the **UK CFS/ME Research Collaborative (UK CMRC).**

At the end of January a meeting was held at which 'harassment' of researchers was discussed.

The Medical Research Council (MRC) and the **Science Media Centre (SMC)** are two of the UK CMRC Observers. **Ed Sykes, SMC Head of Mental Health**, attends the meetings of the Executive Board on behalf of the SMC, while **Joe McNamara & Neha Issar-Brown** attend on behalf of the MRC. The MRC contributed nearly £5000 to the launch of the Collaborative and have stated their willingness to be involved in and contribute further both directly and in kind.

- On the 1st February 2013, an email was sent from the **out-going Head of Mental Health at the SMC.** It was a “write up of the **main points** to come out of” **the ‘CFS’ meeting** held at the Wellcome Trust the day before. *(quote 13)*
- “All the best with this for the future, I hope the launch of the research collaboration goes well and that it gets easier to do research in this field.” *(quote 14)*
- Those in attendance at this meeting had included **UK CMRC members Peter White** of

QMUL, **Joe McNamara** and **Carmel Turner** of the MRC and **Esther Crawley** of Bristol University. **Simon Wessely** & **Trudie Chalder** of IOP, King's College London were also in attendance.

- Quotes 15-18 are taken directly from this meeting's records in the email of 1st February.
- *(quote 15)*

Current situation:

- 'Coming out' about the harassment has led to increased support for CFS/ME researchers, for example, from colleagues who were not aware of the situation.

- *(quote 16)*

Harassment

- Harassment is most damaging in the form of vexatious FOIs.
- Complaints are also causing problems. Researchers are still dealing with complaints about them to the GMC.
- House of Lords Debates on CFS/ME can result in Parliamentary Questions which often require detailed responses
- *(quote 17)* researchers are using strategies to reduce the impact of harassment and put the case for research into CFS/ME including:
 - Learning about the FOI Act and using strategies to reduce time spent responding, eg putting minutes of meetings online
 - Coming together as a research community to respond to criticisms eg the joint letter in response to criticisms of **Simon Wessely** receiving the John Maddox prize.
 - Working with trusted journalists to cover the problems associated with CFS/ME research
 - **Esther Crawley** and **Stephen Holgate** are establishing a research collaborative including researchers, charities and other interested parties. There will be a launch event on 22nd April.
- *(quote 18)* from **Action Points**
 - **SMC** – run FOI Act brainstorm
 - **ALL** – look for opportunities to publicise CFS/ME research and give background information about the condition
 - **Support4rs** – work with **Peter White** and **Simon Wessely** to develop resources for dealing with harassment
 - **SMC** – run a press briefing on biosocial illness to improve public understanding. **Fiona Fox** to get information from **Trudie Chalder** and **Rona Ross-Morris**.

Subsequent action by the UK CMRC can be seen in the context of these Action Points (above).

- **One SMC 'strategy' to reduce 'harassment'** was to "put minutes of meetings online." Following the 22nd May 2013 meeting of the Executive Board of the UK CMRC **Sonya Chowdhury** emailed "Hi all – **please find attached the minutes of our meeting and a summary for public consumption. I have deliberately made the summary detailed so that people don't feel we're only providing limited information...**In the future, I would suggest that the summary is approved by the Chair and Vice Chair so that they can go up immediately after the meeting." *(quote 19)*
 - 3rd June, **Sonya Chowdhury** to group "As agreed we can now share the above summary ["CFSMERC minutes 23.5.13"] on websites etc. and **the minutes are for the Board only.** *(quote 20)*
 - 11th October, **Sonya Chowdhury** to group "Hi All – please find attached: Chair-approved minutes of our meeting on Monday; Chair-approved summary notes of the meeting

which will go on our website, as previously agreed.” (quote 21)

- 14th January 2014, **Sonya Chowdhury** to group “Attached are the chair-approved minutes (for the Board only) and the summary notes (for public consumption).” (quote 22)
- **Re the SMC Action Point** regarding “opportunities to publicise CFS/ME research and give background information about the condition” (reference quote 18); on 17th April **Esther Crawley informed the Collaborative** that the **press release regarding the launch had been rewritten** and “hopefully incorporates most of your comments. I hope this is now the final version.” (quote 23)
- She clarified that this press release concerned the launch of the Collaborative, and not the press conference, which was to take place separately. Journalists were sent a separate invitation to the press conference. She explained: “**journalists will already have received this invitation from the SMC about the press conference (pasted below).**” (quote 24)
- **The press conference invitation ‘pasted below’ began – “Science Media Centre News Briefing – What? Chronic Fatigue Syndrome – unravelling the controversy”** (quote 25)
 - **It stated “Chronic Fatigue Syndrome (CFS; also known as ME) is an incredibly controversial field,** not just in terms of public perception, diagnosis and treatment but even **for the very researchers trying to help who have experienced campaigns of harassment from some patients.”** (quote 26)
 - It went on to state that “The disease affects over 600,000 people in the UK” inviting journalists to come along to find out amongst other things “What imaging studies are showing us about overactive brains”. (quote 27)
 - **For further information journalists were asked to contact Dr Edward Sykes, Head of Mental Health at the Science Media Centre.** (quote 28)
- **Dr Charles Shepherd** of the MEA objected in an email of the 17th April:
 - 1. **I still don’t believe it is sensible to drag the harassment campaign into the press reporting of the launch of the collaborative ...I just don’t see what is going to be achieved by encouraging journalists to include this aspect in their reporting of the event.** (quote 29)
 - 2. **Could we also include myalgic encephalomyelitis (or encephalopathy) in the title and CFS/ME elsewhere.** (quote 30)
 - 3. **I don’t know what ‘overactive brains’ are in relation to ME/CFS. Sounds a bit like anxiety I don’t think this is a good term to be feeding to the press.** (quote 31)
- The response from **Esther Crawley** was “**Just to clarify – the SMC invitation** was included [in her previous email] just to explain why we have done the press release as we have. It is **not for public consumption. It has already gone out.**” (quote 32)
- **Further to the SMC Action Point** regarding “opportunities to publicise CFS/ME research and give background information about the condition” (reference quote 18): on 12th March 2014, **Esther Crawley** emailed to the group: “**There is a competition to present research to Parliament.** The aim is to provide information about research to try and ensure funding is secure for next year. If successful the winners will have posters about projects with demonstrable benefits in parliament at a reception on June 3rd this year.” (quote 33)
 - “I have prepared an application (attached) with help from both **Stephen** and **Peter** for the CMRC. We have only 300 words to describe a “project” which has already had health benefits. Looking at previous successful applications, they expect very lay friendly descriptions of projects that tell a story. As it is only 300 words, I have included snippets about research that I am familiar with that has already had health benefits (the category I think we should submit under).” (quote 34)
 - “**Stephen** has obviously helped me a lot with this. Although **we have mentioned the**

harassment, this is part of the previous story and is to help identify what is new and different at the moment....." (*quote 35*)

- "The deadline is Friday but **I will need to submit it tonight** So if you have any comments, can you let me know as soon as possible? Can you please copy **Stephen** in please?" (*quote 36*)
- The original draft of the 300 word description by **Esther Crawley, Stephen Holgate & Peter White** included "**In the past, the CFS/ME researchers and charities have been divided, with researchers leaving the field because of personal attacks and funding difficulties.**" (*quote 37*)
- The final submission included: "...Research has been a powerful tool for change in the UK with a small amount of funding producing significant health benefits. For example, in children and teenagers, we have shown that it is common, occurs in primary school children; is more common in those from socially disadvantaged families and is very treatable with excellent outcomes. In adults we have shown it is more common in UK ethnic minorities, described inequalities to accessing health care and shown which treatments are safe and effective. This research evidence-based approach has encouraged more commissioners to provide services and helped clinicians to improve services, increasing the numbers of children and adults offered treatment." (*quote 38*)
- **After Esther Crawley sent the draft version out to the Collaborative for comment she sent another email to Stephen Holgate and Peter White: "As you can see – I have sent the form to the executive. I mentioned the harassment bit in the email because early feedback suggested this might be a problem with the charities (sigh)."** (*quote 39*)

The launch of the UK CFS/ME Research Collaborative (UK CMRC) took place on April 22nd 2013.

The Young ME Sufferers Trust (Tymes Trust)
August 2014