

## Paper 1: *DRAFT* Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 16 October 2019

### Present:

Stephen Holgate (SH) – Chair  
Deb Brown (DB)

Charles Shepherd (CS)  
Anna Gregorowski (AG)

Gabrielle Murphy (GM)  
Sonya Chowdhury (SC)

### Observing

Denise Ribaroff (DR)  
Alex Ribaroff (AR)

### Attended by phone

Opal Webster-Philp (OWP)  
Chris Ponting (CP)  
Carmine Pariante (CPa)

Sam Bromiley (SB)  
Neil Harrison (NH)  
Jim Wilson (JW)

Craig Bullock (CB)  
Colin Smith (CS)

### Apologies

Neha Issar-Brown (NIB)  
Margaret Mar (MM)

Stephen Meader (SM)

Jo Elson (JE)

	Agenda Item	Action
	<p><b>Welcome &amp; Introductions</b> SH opened the meeting and introductions made.</p>	
1	<p><b>Minutes and Matters Arising</b> Slight amendments made to the minutes for accuracy</p> <p><b>Decision</b> The Board approved the minutes of the last meeting as an accurate record of the meeting subject to the above amendments.</p>	SB
2	<p><b>MRC progress</b> SH updated the group on the application to the MRC. They had a strategy board meeting in July. (8<sup>th</sup> and 9<sup>th</sup>). The discussions held with the MRC highlighted how it would be good to bring together those interested in the field, those from outside the field and take account of the wide views within the community.</p> <p>A meeting was held in September with the MRC/NIHR and PAG with a workshop planned for November with a view to get an application off before the end of the year. CP said he hoped to have an outline of the application ready for November meeting. It was agreed that communication with the patient and carers' population would be essential during this process, especially if the recruitment of the large number of people needed if to be successful.</p> <p>The MRC will be communicating about the workshop via its website in due course.</p>	SH/CP

	<p>JW said they have been pushing hard to get early information from MRC. They don't know who on the day will be able to attend yet.</p> <p>SC suggested short films with SH and CP to give as much information in a bright and informative way.</p>	
3	<p><b>CMRC Working Groups</b></p> <ul style="list-style-type: none"> <li>• <b>Medical Education Group:</b> SB updated on the work NM has been engaging with health professionals from different fields and assisting SB with the preparation for RCGP conference. GM gave an update on producing learning modules. DB looking to coordinate activity with NM to assist. Physios 4 ME were invited to join the group.</li> <li>• <b>Priority setting partnership (PSP):</b> SC updated on the work with the PSP and referred to a paper she had prepared with the working group.</li> <li>• <b>Omics and Big Data:</b> A meeting was held earlier in the month. CSM spoke about a health case management system called Patients Know Best. It also allows you to communicate directly to physicians and access help online.</li> <li>• <b>Mitochondrial biology:</b> JE was unable to attend the meeting so there was no update.</li> <li>• <b>Immunology:</b> CP wishes to step down as leader of this group due to work commitments so we will need to identify a new chair.</li> <li>• <b>PR:</b> OWP talked about her paper and the PR working group. A meeting was held in September to discuss driving group forward and being more inclusive.</li> </ul> <p><b>Decision</b> The Board agreed that the PSP Working Group should progress with the readiness questionnaire process phase.</p>	SC/Group
4	<p><b>Conference</b></p> <p>SC stated that there are 12 speakers confirmed with a high number of overseas speakers due to the quality of work being done in other countries. This will have consequences for the budget. SC detailed the draft programme for the two days and the procedure for posters and abstracts. SC invited Board members to contact her with further ideas.</p> <p>SC outlined the budget for the conference highlighting that there is still money to be raised to fund the speakers. Registration will open 21<sup>st</sup> October with an Early Bird rate. Abstract invites will be launched at the same time. Anyone interested in peer reviewing abstracts should contact SC. GM offered.</p> <p>Once registration opens we will send details and ask that everyone markets the conference. SC proposed the fees are kept the same as last year.</p> <p><b>Decision</b> The Board approved the fees for the conference to remain as the last conference.</p>	All

5	<p><b>Cochrane</b>  SC introduced Karla Soares-Weiser to the meeting from Cochrane. She gave an update on the Cochrane review and said she is aware of controversies around this. Karla acknowledged there is a need for full and meaningful involvement of people with ME at the outset of any protocol review and she will be working with her team to ensure this.</p>	
6	<p><b>International updates</b>  SC confirmed this is an opportunity to update on international work. SC gave updates on the restructure of the International Alliance. There were no other updates provided.</p>	
7	<p><b>AOB</b>  SH said there is a fatigue workshop at the Kennedy trust and Versus Arthritis to understand mechanisms of fatigue.</p>	

*Minutes taken by SB 16.10.19*

*Approved by SH 04.11.19*