

## DRAFT Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 10 July 2018

### Present:

Stephen Holgate (SH) – Chair	Sonya Chowdhury (SC)	Mark Jones (MJ)
Chris Ponting (CPP)	Countess of Mar (MM)	Lars Erwig (LE)
Charles Shepherd (CS)	Gabrielle Murphy (GM)	Craig Bullock (CB)
Jane Whittaker (JW)	Caroline Secake (CS)	Neil Harrison (NH)
Gabrielle Murphy (GM)		

### Observers

Libus Ratcliffe (LR), BACME Chair	Luis Nacul (LN), CURE-ME/LSHTM
Ana Antunes-Martin (AAM)	

### Joined via phone:

Colin Smith (CSm)	Christine Laennac (CL; note-taker for PAG)
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### Apologies:

James Brodie – (JB)	Carmine Pariante (CP)	Patrick Chinnery (PC)
Mike Dalrymple (MD)	Jo Elson (JE)	Claire Kidgell (CK)
Paul Little (PL)	Mark Edwards (ME)	

	Agenda Item	Action
	<p><b>Welcome &amp; Introductions</b></p> <p>SH opened the meeting and welcomed MM who has joined, representing Forward M.E. as a new member; LN who is interested in finding out more about the CMRC; PAG members; and LR who has taken over from GM as Chair of BACME. GM will remain as a Board member but will no longer represent BACME.</p>	
1	<p><b>Updates</b></p> <p>CPP and SH met with Prof Whitty (DoH) a couple of weeks ago. There was expressed commitment to seeing developments in the field and agreement that the strategic priorities seemed an appropriate way forward.</p>	
2	<p><b>Strategic Priorities</b></p> <p>2.1 <b>High level report on ME in the UK</b></p> <p>SH reminded members of the impact of the Institutes of Medicine (2015) inter-disciplinary report that generated traction in the US. However, in the UK, there has not been anything significant. The Academy of Medical Sciences (AMS) expressed an interest in producing something in the field of pain and fatigue but were not minded to focus on a specific disease area. Through discussion with Prof Whitty, there was an expressed view</p>	

<p>2.2</p> <p>2.3</p>	<p>that this would be of benefit to the field.</p> <p>SH shared a couple of ideas for consideration by members: request meeting with CEO of AMS to put forward a case for support for their support. Another option is to consider an approach from fellows to support the request. CS proposed consideration of a symposium. MM suggested writing directly to the PM. It is essential that we ensure a clear ask to ensure that the output is fit for purpose.</p> <p>SC raised questions about what value would be created in pursuing this and would further delay be caused if there is political momentum currently?. It was decided to review again in due course.</p> <p><b>James Lind Alliance Priority Setting Partnership (PSP)</b> SH introduced the PSP which is focused on treatment and interventions and not research. There is a set of processes that are worked through in all disease areas and applied rigidly to arrive at a set of agreed priorities between patients and clinicians which are then published. Research funders would then use the priorities to determine the use of research funding. There is a lot of work involved in this process as well as cost. However, arriving at joint priorities to shape future research could be helpful with patient voice at the heart of this.</p> <p>The Board agreed that this should continue to be a priority. A working group will be established to look at how to progress this. The working group will identify an action plan.</p> <p><b>ME Platform</b> CPP/SC visited Dementias UK Platform (DPUK) lead, Prof John Gallacher, last month to understand how the Platform functions and what an ME Platform might look like. The DPUK model enables:</p> <ol style="list-style-type: none"> <li>1. Data Access (rapid).</li> <li>2. Recruitment to clinical studies.</li> <li>3. Experimental medicine incubator. Industry and academics. Precompetitive space.</li> </ol> <p>There is a lot of learning and a blueprint from the DPUK which would be beneficial to the ME field. The expertise would be developed in the field across the UK as a collaboration and not as a centre of excellence.</p> <p>Scale is an issue given the lack of research/numbers of participants in comparison to dementia and there are a whole range of other issues that need to be considered. Need to explore with PC, the options for collaboration with the work he is leading on with the NIHR BioResource for Translational Research in Common and Rare Diseases. SH stated the need to understand causal pathways at this stage through discovery science. LE reiterated the need for stratification in this illness field and its</p>	<p>SC, PAG, GM, MJ, NH CB</p>
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	<p>importance.</p> <p>It was agreed that this remains a core priority and an Advisory Board now needs to be developed with strategic investment identified by the research councils. This will be discussed this afternoon with MRC as a first step but there will need discussion at UKRI level.</p>	<p>SC/ CPP/SH /AAM</p>
3	<p><b>IAFME (International Alliance for ME) Consensus Document</b></p> <p>SC referred members to the email and the document that was previously circulated. She highlighted that the purpose of the document is to provide an agreed statement to WHO on ME to seek a global health response from them to the illness. It was developed following advice from the WHO representative met with in April. The document has been developed with input from researchers/academics in the UK and US, including Lily Chu and is intended to be reflective of published research and not opinion.</p> <p>SC has received some feedback which she will incorporate into a final draft. NH offered to send some small suggested amendments.</p> <p>SH highlighted that there was a need for agreement on principles not details. Members were encouraged to review the final draft when sent and to let SC know if willing to support. If there is agreement across the CMRC Board members then CMRC will endorse. CS stated MEA has already agreed to sign.</p>	<p>SC/NH</p> <p>All</p>
4	<p><b>Conference Planning</b></p> <p>SC reported that the programme is now live and has been circulated to all past attendees and members. The abstract submission date has been extended by two weeks and the process is in place for peer review. To date, there have been five submissions which is low although there is a week left before the call closes. All to promote along with registration.</p> <p>CS reminded members that student bursaries are available via the MEA.</p>	<p>All</p>
5	<p><b>PAG Terms of Reference</b></p> <p>SH highlighted that there has been considerable work and effort from the PAG to develop their terms of reference. JW highlighted that the group has worked through a consultative process with six drafts and a number of phone calls. JW identified that seven out of nine have approved the document with two members who have identified they are too unwell to input at this stage. It is an evolving document that can be changed as necessary and is a model that has been set up to respond to the needs of members given the impact of the illness which make a traditional committee model challenging and unworkable.</p> <p>CPP suggested some areas that could be included to further increase the transparency. The PAG would like some assistance with recruiting new</p>	

	<p>members and requested some input from CMRC members. Agreed support and process to be established.</p> <p>CS stated that MEA has agreed to provide funding for PAG expenses to equivalent of £200 per meeting. SC will provide the budget available to PAG for their decision on how to use funding, including conference fees.</p>	<p>JM/CS</p> <p>SC</p>
6	<p><b>Minutes &amp; Matters Arising</b></p> <p>The minutes of the last meeting were approved as an accurate record of the meeting.</p> <p>All actions have been completed or addressed through the main agenda with the exception of the action in relation to BACME and the conference. There will not be a joint conference at this stage.</p> <p>It was also noted that there has not been an update from David Nutt's study at the CMRC conference. SC is pursuing with AAM.</p>	<p>SC/AAM</p>
7	<p><b>AOB</b></p> <p>None.</p>	

*Minutes taken by SC*

*Approved by SH/CP 11.7.18*