

## DRAFT Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 24 April 2018

### Present:

Sonya Chowdhury (SC)	Mark Jones (MJ)	Christine Laennac (CL)
Charles Shepherd (CS)	Gabrielle Murphy (GM)	Jane Whittaker (JW)
Carmine Pariante (CP) – left at 2pm		

### Joined via phone:

Chris Ponting (CPP)	Colin Smith (CSm)	Glen Plant (GP)
Mark Edwards (ME)		

### Apologies:

Stephen Holgate (SH)	James Brodie – (JB)	Ana Antunes-Martin (AAM)
Craig Bullock (CB)	Mike Dalrymple (MD)	Jo Elson (JE)
Lars Erwig (LE)	Claire Kidgell (CK)	Paul Little (PL)

	Agenda Item	Action
1	<p><b>Welcome &amp; Introductions</b></p> <p>CPP opened the meeting and passed on his apologies for not being physically present due to a faulty plane and for SH who has norovirus. CPP stated he will co-chair meeting with SC.</p>	
2	<p><b>Population &amp; Systems Medicine Board (PSMB), MRC</b></p> <p>SC fed back that she, CPP and SH attended a meeting of the MRC PSMB at the beginning of March. From a lay person perspective, SC felt that there was a high level of interest and there were lots of questions from members at the meeting. CPP and SH provided a presentation which built on a paper that had been submitted in advance of the meeting (contained within Board papers). There was an issue with opening some of the embedded documents; these will be shared individually and a google drive established to ease access in the future. It was agreed to make these publicly available with the minutes. CPP stated that these two documents can be amended for use with other funders and invited feedback/amendments.</p> <p>CPP added that there has not yet been a formal response from PSMB following the meeting except to confirm that they will be considering further activities in the field at their next meeting in June. A request was made to the PSMB to establish a cross-MRC committee that might help drive forward the priorities identified by the CMRC.</p> <p>CL reported that the PAG has read through both the documents and were</p>	<p>SC All/ CPP</p>

	<p>very supportive of the content and reflective of the PAG views and experiences from a patient perspective.</p> <p>CPP stated that the next steps are not clear until we hear back formally from the PSMB on their views. Further work is being undertaken to engage other funders, seek support and pull together the different strands of the CMRC strategy.</p>	
3	<p><b>Conference Planning</b></p> <p>SC introduced the report she had submitted and the Board noted the progress made. There will be plenary sessions on collaboration/learning from other fields; immunology, metabolomics and updates from some of the MRC-funded researchers.</p> <p>The Board:</p> <ul style="list-style-type: none"> <li>• Provided further suggestions for invited speakers with follow-up actions identified to help take forward ideas/introductions</li> <li>• Agreed a further suggestion for a potential sponsor to approach</li> <li>• Identified workshop suggestions were put forward which now need to be progressed</li> <li>• Approved the projected budget</li> <li>• Agreed the peer review panel for abstracts</li> <li>• Agreed to establish an advisor to those wishing to submit abstracts to help improve quality – non-CMRC person to be identified</li> <li>• Approved the fee structure – conference sales will commence early May</li> <li>• Agreed that the full conference should be open, including the dinner (which was the only closed section last year) so as to reflect the spirit and the ethos of the CMRC to partnership working with all stakeholders.</li> <li>• Agreed that ad hoc bursaries could be offered to Associate Members, as budget allows and to be allocated by SC/ CPP/SH</li> </ul>	<p>CPP, GM, CL, SC GM/SC  SC  CSm/CP/GM  GM/SC   SC/ CPP/SH</p>
4	<p><b>International Advocacy, Action for M.E.</b></p> <p>SC introduced the paper she provided for the Board which sets out the vision for the programme of work which is funded by Action for M.E. The objectives are:</p> <ul style="list-style-type: none"> <li>• To facilitate an international advocacy movement, focused specifically on soliciting political leadership from the World Health Organisation (WHO) and its member states (countries)</li> <li>• To get M.E. on the international policy agenda by raising awareness at the highest political level - the United Nations</li> <li>• Develop and initiate an international public health policy response for M.E. by leveraging political leadership from the WHO and its</li> </ul>	

	<p>member states through the adoption of a World Health Assembly (WHA) resolution.</p> <p>SC stated that significant progress has been made with the workplan:</p> <ul style="list-style-type: none"> <li>• Meetings with the patient organisations of the informal International Alliance of M.E. (IAME) have taken place and it has grown in numbers with extended reach in Pakistan, South Africa and Japan; support is being established for the programme of advocacy work</li> <li>• There have been several meetings with member state health attachés and while it is early days, there has been considerable interest in the burden caused by the disease and the aspirations of the project</li> <li>• A meeting with WHO has been held and the objective to raise awareness and solicit advice was achieved</li> <li>• A #MillionsMissing event is being held in Geneva as an IAME event with an international focus. The aim is to represent the global public health issue of M.E. with shoes being placed under the ‘broken chair’ representing disability outside The Palais des Nations (UN offices) on M.E. Awareness Day, 12 May</li> <li>• A side event during WHA on 22 May, sponsored by IAME, with a 20 minute showing of Unrest clip and a panel debate which includes CPP and SC to raise awareness and understanding of M.E.</li> </ul> <p>As the paper outlines, SC reported that there are synergies with CMRC work and a wider issue in relation to the ICD-11 developments. SC stated that the field would significantly benefit from establishing a cross-country consensus or position statement on M.E.. She suggested that this could be based on the significant national reports from IOM and The Netherlands Health Council while incorporating statistics from the scoping report commissioned by the CMRC.</p> <p>The requirement would be, SC stated, to establish a synthesised statement that outlines: what the evidence does and doesn’t indicate in respect of what the disease is and isn’t, what the disease burden is, barriers to driving the field forward and recommendations for action. SC presented some statements (from the IOM report and others) that could be used. SC has spoken with a number of countries and networks and there is ‘in principle’ support for a consensus, subject to its content. Further work will be required on the areas that are not agreed on and sponsorship needs to be sought for a cross-country meeting for scientists/academics to take this forward.</p> <p>The Board considered the position and request and agreed that, in principle, this would be something the CMRC could consider supporting once a draft is shared.</p>	
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5	<p><b>CMRC Action Planning</b></p> <p>Slides were presented by SC/ CPP on the three strategic priorities identified by the CMRC starting with a SWOT analysis that while developed in relation to the Platform priority, is applicable across all three. There was discussion about aspects of the analysis and CPP invited all to send further thoughts to him.</p> <ul style="list-style-type: none"> <li>• SH has been leading on the high level report and will update at the next meeting</li> <li>• James Lind Alliance – SC has spoken with the priority setting partnership team and circulated information with papers including a readiness questionnaire and a draft budget. Action planning is now required to take this forward at the next meeting. CL/JW shared that the PAG are concerned that there are no effective treatments and no universally agreed diagnostic tool. Alongside this, there remains concerns about defining ME and CFS and that all this issues need to be scoped, discussed and agreed as part of this activity.</li> <li>• Platform – CPP shared suggested overview for critique and comment. SC/ CPP/SH will be visiting John Gallacher at Oxford for an in-depth discussion about Dementias UK Platform and how it operates in order to provide a presentation for discussion and action planning at the next meeting. The output is to include establishing a working group to take this forward. CPP highlighted that this priority should provide added value to go beyond the current small scale and underpowered science prevalent in CFS/ME research.</li> </ul>	All/ CPP
6	<p><b>Minutes &amp; Matters Arising</b></p> <p>The minutes of the last meeting (6 February 2018) were approved as an accurate record of the last meeting.</p> <p><b>Matters Arising</b></p> <p>All actions have been completed or are outlined below/discussed in main body of meeting:</p> <ul style="list-style-type: none"> <li>• BACME: GM reported that the vote for BACME members to consider whether joining conferences should be explored was withdrawn at conference. It will be reissued next week. SC/ CPP reminded members that should this be positive, there will still need to be a discussion and decision for CMRC about whether this is something they feel should be pursued.</li> </ul>	

6	<b>AOB</b>	
6.1	It was formally noted that given the change in terms of reference of the CMRC, it will now manage its own communications and retain independence. Therefore, SH wrote to the Science Media Centre thanking them for their contribution and acknowledging the end of role for them on the Board.	

Minutes typed by SC: 24.4.18

Approved by Chair: CPP 25.4.18