

## DRAFT Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 6 February 2018

### Present:

Stephen Holgate (SH)  
Esther Crawley (EC)  
Charles Shepherd (CS)  
Gabrielle Murphy (GM)

Sonya Chowdhury (SC)  
Ana Atunes-Martin (AAM)  
Mark Jones - (MJ)  
Opal Webster-Philips (OWP)

Ed Sykes (ES)  
Craig Bullock (CB)  
Colin Smith (CS)

### Joined via phone:

Chris Ponting (CPP)

Glen Plant (GP)

Mark Edwards (ME)

### In attendance for part of the discussion:

Patrick Chinnery (PC)

Claire Kidgell (CK)

### Apologies:

Paul Little (PL)

James Brodie (JB)

Carmine Pariante (CP)

Mike Dalrymple (MD)

Jo Elson (JE)

Neha Issar-Brown (NIB)

Lars Erwig (LE)

	Agenda Item	Action
1	<p><b>Welcome &amp; Introductions</b></p> <p>SH opened the meeting and welcomed members including new members including two members from the Patient Advisory Group (PAG), OPW and GP. SH also noted that JB has recently left GWPharma but wishes to stay in contact with the CMRC Board and will continue to act as liaison point with GWPharma as he maintains a formal relationship with them.</p>	
2	<p><b>Away Day</b></p> <p>SH highlighted some key points from the day:</p> <ul style="list-style-type: none"> <li>• There was a unanimous decision that the CMRC continues.</li> <li>• We need to take a forward-looking focus and to embed the Patient Advisory Group (PAG) within the Board.</li> <li>• While we want to support research across the piece, however, we need to focus on causal pathways and adopt a more biological approach to our prioritisation exercise to identify disease mechanisms.</li> <li>• The MRC Highlight Notice has been of great help and we would adopt that as a proportion of the biological research journey going forward but there is more to do.</li> <li>• The NIH funding of the centres of excellence are a fantastic step for the field and opportunities need to be explored to build on this.</li> <li>• Prof John Gallacher provided great insight and guidance based on his experience of the Dementias Platform and offered support.</li> <li>• In the next phase, we need to ensure collaboration and effective linkage with what exists already as well as build on this.</li> <li>• PSM Board (discussed later) and a potential partnership grant will</li> </ul>	

	<p>provide grounding to explore, more formally, any opportunities for linking with NIH.</p> <ul style="list-style-type: none"> <li>• A multi-omics, phenotyping platform which would start with set-up a bioresource.</li> <li>• We discussed engaging with other organisations beyond the NIH. SH received a letter from senior decision-makers/politicians which provides a significant opportunity to influence at a high level.</li> <li>• SH and a few others have had contact with an individual who is meeting with a high-level research funder decision-maker and there is alignment in the narrative being put forward.</li> <li>• The platform should also have an applied science aspect and there was discussion about a James Lind Alliance Priority Setting Partnership. CK offered to connect SH/SC with the department.</li> <li>• There was discussion about securing a high level report (as previously discussed at a Board meeting). SH has been in contact with a number of individuals to progress this. The PAG statement was a powerful engagement tool to open discussion.</li> <li>• There were a number of working areas that were identified in the agenda for the meeting: industry, communication, research comment, CYP, prioritisation of research and funding of research.</li> <li>• We now need to identify what we take forward and how. The PAG should lead this with their views.</li> <li>• The last aspect was to seek partners that are not currently engaged that might want to come on board. A list of ideas will be developed and contact will be made with them – send to SC/SH.</li> </ul> <p>SH invited reflections from other participants:</p> <ul style="list-style-type: none"> <li>• Contribution of the Dementias Platform (DP) and learning from this was an excellent contribution.</li> <li>• Discussions about the values used by the DP and agreed this provides the foundation for the CMRC moving forward. The Charter will no longer exist and a restructure of membership will ensue with circulation to the Board for approval.</li> <li>• Importance of developing a coherent narrative in communicating with high-level decision-makers including a list of asks to be developed.</li> </ul> <p>PC provided an example of infrastructure funding by NIHR that could be leveraged. There is a call open at the moment that could be considered. PC will liaise with SH to provide further information. Need to explore linkage between health and social care.</p> <p>CP stated his view that the process of prioritising what the CMRC does should be led by the PAG. SC added that there is need for a mechanism to ensure wider patient involvement/voice to shape the work and would welcome thoughts from the PAG. OWP agreed to send SC list and for the PAG to identify five or six key issues that they would like to see addressed as a priority while wider consultation is undertaken.</p>	<p>CK/SC/SH</p> <p>All</p> <p>SC</p> <p>PC/SH</p> <p>OWP/SC</p>
--	---	---

	All participants to send thoughts through to SC/SH over the next 48 hours re priorities, statistics, solutions and other thoughts to prepare for forthcoming meetings.	All
3	<p><b>MRC Population &amp; Systems Medicine Board</b></p> <p>The presentation to the Board will take place in March with SH/CP attending and SC (subject to jury service/availability). A brief will be required in advance for the Board and the information and thoughts invited above will inform this.</p> <p>SH anticipates ten minutes of presentation with slides and the paper to go to the Board in advance. SH set up his initial thoughts for the briefing. A small group will work together to pull together the document.</p>	
4	<p><b>Conference</b></p> <p>SC reported that work is progressing on plans for the conference with some invites to speakers made but others still need to be made. There is a limited budget for overseas travel expenses. SC requested that members send through ideas and suggestions.</p> <p>GM stated that BACME has a conference on 14-15 March and there will be a vote at the conference about joining forces with the CMRC for a joint conference. Should this be positive, discussion would be needed with the CMRC membership.</p>	
5	<p><b>Minutes &amp; Matters Arising</b></p> <p>The minutes of the last meeting (10 October 2017) were approved as an accurate record of the last meeting.</p> <p><b>Matters Arising</b></p> <p>All actions have been completed or will be discussed as part of the main agenda. CP asked regarding the follow up from the funders' meeting; this has informed discussion during the away day and future plans.</p>	
6	<p><b>AOB</b></p>	
6.1	<p><b>Membership of the CMRC Board</b></p> <ul style="list-style-type: none"> <li>• At the Away Day, it was agreed that SH would continue as Chair</li> <li>• The Deputy role was established for a term of 5 years. EC's term concludes in April. SH thanked EC for the significant contribution she has made to the CMRC.</li> <li>• A new Deputy is required and, at SH's invite, CP agreed to take on the role from April.</li> </ul>	

Minutes typed by SC: 6.2.17

Approved by Chair: