

DRAFT Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 16 January 2019

Present:

Stephen Holgate (SH) – Chair	Chris Ponting (CPP)	Charles Shepherd (CS)
Sonya Chowdhury (SC)	Jim Wilson (JW – new PAG member)	
Deb Brown (DB – new member)	Charles Shepherd (C)	Colin Smith (CSm)

Attended by phone

Carmine Pariente (CPa)	Phil Murray (PM)	Craig Bullock CB)
Opal Webster-Philp (OWP)	Neil Harrison (NH)	Jo Elson (JE)

Observers in attendance

Luis Nacul (LN – ME Biobank)	Ana Antunes-Martin (AAM)	Neha Issar-Brown (NIB)
Steve Smith (SS – Action for M.E.)		

Apologies

Countess of Mar (MM)	Mark Jones (MJ)	Claire Kidgell (CK)
Patrick Chinnery (PC)	Michael Dalrymple (MD)	Gabrielle Murphy (GM)
James Brodie – (JB)	Paul Little (PL)	Lars Erwig (LE)

	Agenda Item	Action
	<p>Welcome & Introductions SH opened the meeting and formally thanked Anna (Action for M.E.) for all her secretariat support.</p>	
1	<p>Minutes and Matters Arising All actions have been completed or addressed through the main agenda except for the following:</p> <ul style="list-style-type: none"> • James Lind Alliance – Priority Setting Partnership: SC reported that the first group call was held. To ensure a shared understanding of the process and whether we should pursue this, a call has been convened with the Alliance. • PAG: recruitment has been successful with JW in attendance today. There are now 15 members. Induction has been undertaken. • IAFME (International Alliance for ME) Consensus Document: SC reported that the consensus document has been submitted and updated on progress. The Alliance has now been formally constituted and there are 12 members. The strategic plan is being finalised. SH requested that updates are added as a standing agenda item for future meeting. • David Nutt study: there has been no update on progress. The final report has not yet been submitted. • Conference – accounts to be submitted to the next Board meeting. SC hasn't had a chance to finalise as she has only come back to work this week from sick leave. • Conference report – to be submitted to MRC. 	<p>SC/SH/ CPP</p> <p>SC</p> <p>SC</p>

	<p>Decision The Board approved the minutes of the last meeting as an accurate record of the meeting with the exception of one amendment – LN to be added to the minutes as in attendance</p>	
2	<p>MRC Strategy Board SH introduced the paper that has been produced as a vision for the field for the February meeting which has been submitted with letters of support including NIH, CIHR and the PAG. This has been a very collaborative process - engaging a wide number of individuals/organisations and the PAG has been central to this.</p> <p>NIB outlined the potential outcomes from the submission and potential timescales. She also highlighted the level of confidence that the amount of collaboration achieved should instil.</p>	
3	<p>CMRC Working Groups</p> <ul style="list-style-type: none"> • Medical Education Group: draft terms of reference have been established and a meeting is in the diary. JW spoke to Nina Muirhead last night and excellent progress is being made with contacts with medical schools. Work is also progressing through Forward ME. LN outlined that the Canadians are also keen to collaborate. • Omics and big data: has fed into the submission to the MRC. CSm is leading this group. • Mitochondrial biology: Karl Morten and JE are jointly leading the group. • Immunology: CPa agreed to establish the first group meeting where a lead will be identified. SC to connect CPa with the group. <p>SH added that OPW has provided a suggestion via her local group that there is an imaging group. NH and OPW have been exploring this. PAG is keen to input to each of the groups. Terms of reference for each group need to come back to the next Board meeting. SC will re-circulate the draft.</p> <p>Decision The Board approved a fifth group on imaging to be led by NH.</p>	PAG Group Leads / SC
4	<p>CMRC Membership CS/DB has offered to act as a science liaison/rep with the PAG and assist with engagement and communication for the CMRC.</p> <p>Discussion regarding other potential charity members to ensure inclusivity. SH to progress. Agreed, with MM permission, to add Forward ME logo to the CMRC one.</p>	CSm/PAG SH SC/MM
5	<p>AOB CB highlighted discussions that are taking place between Versus Arthritis and the Kennedy Trust to identify synergies and potential partnerships. SH has been engaged in the discussions as Chair of the Kennedy Trust. Fatigue is a patient priority across musculoskeletal and non-musculoskeletal illnesses. Plan to work together to develop sandpit workshops to focus on systems and biology to fatigue. CB will keep CMRC updated on progress and any opportunities for input.</p>	

Minutes taken by SC
Approved by SH/ CPP