

DRAFT Minutes of CMRC Meeting 15 January 2016

Present:

Stephen Holgate (SH)

Esther Crawley (EC)

Mary Jane Willow (MJW)

Chris Ponting (CP)

Sonya Chowdhury (SC)

Ed Sykes (ES)

Carmine Pariente (CP)

Charles Shepherd (CS)

Paul Little (PL)

Neha Issar-Brown (NIB)

Apologies:

Zoe Gotts (ZG)

Hugh Perry (HP)

Mark Edwards (ME)

Alastair Miller (AM)

Jan McKendrick (JM)

Allison Wallace (AW)

Julia Newton (JN)

Steph Garfield (SG)

Des Walsh (DW)

	Agenda Item	Action
	Welcome & Introductions SH opened the meeting and welcomed new member, Chris Ponting. No additional conflicts of interest were recorded.	
1	Minutes & Matters Arising All actions completed or addressed below in main agenda. Decision The Board approved the minutes of the last meeting. All actions have been undertaken/are addressed in the main agenda.	
2	Conference 2016 SC is undertaking a site visit for a hotel in Southampton but cost is much higher than previous years. It may be that an alternative needs to be identified. Possible plenary sessions: <ul style="list-style-type: none">• Omics/big data• Systems approach• Name/criteria• Phenotyping• Treatment• Functional neuro-imaging• Microbiome• Children and young people• UK Grand Challenge	

	<p>Possible speakers to approach: Francis Collins (NIH), Leonard Jason, Mark Van Ness, Alan Light, Jason Ellis, Susan Vernon. Consideration to be given to expert panels to stimulate scientific debate at the end of each plenary bringing in all different angles and perspectives, including patient voice.</p> <p>All suggestions to be sent to SC by Friday 22 January 2016 for a list to be pulled together for Board members to vote on to enable invites to go out ASAP.</p>	All
3.	<p>Grand Challenge</p> <p>The meeting will take place on 13-14 April in Bristol, There is an exciting list of experts, many from outside the ME/CFS field, attending the meeting, to design the grant. Preliminary thoughts are that the study will recruit > 10,000 participants for detailed phenotyping and genetic analyses whilst collecting samples for future omic studies. An outline grant will be submitted in September 2016. Once confirmations have been received, a list will be shared on the Action for M.E. website. EC will follow up confirmations.</p> <p>Meetings with Wellcome Trust MRC to be held to discuss a potential application. Then meeting with MRC to discuss additional opportunities for funding</p>	<p>EC/SC</p> <p>SH/EC/NIB</p>
4	<p>Arthritis Research UK Funding</p> <p>Four grants have recently been funding on quality of life and they have demonstrated an ongoing interest in the overlaps with this illness field.</p> <p>SH will approach them formally to see if they would be interested in joining the Board.</p>	SH
5	<p>AGM</p> <p>This will take place in April, potentially at the SMC.</p> <p>The Charter requires some revision and all members were asked to suggest possible amendments.</p>	<p>ES</p> <p>SC</p>
6	<p>Code of Conduct for Communications</p> <p>There have been a number of iterations of this and a further revision was considered. It is a really important document and we need to ensure that we are clear about how the CMRC supports scientific debate and does not stifle individual members' perspective and positions.</p> <p>CS will circulate a further revision for consideration with the last version reviewed at the last CMRC executive. All executive members have agreed</p>	CS

	to contribute to improving the code for conduct which will be finalised at the next executive meeting.	
7	Current/Future Projects <p>a) Uber: SC and CP met before the meeting and identified proposed amendments for the report. SC has liaised with SB/NIHR and has had input from two volunteers who have provided excellent support. SC will send the amendments back to Uber for a further draft to be compiled. The report will be circulated to Board members imminently.</p> <p>b) Website: SC has been working on content. This needs to be reviewed by a couple of members before being sent to the developer for the wireframes to be developed.</p> <p>c) Screening panel: Will be launched with the website.</p>	<p>SC</p> <p>SC</p> <p>SC/ME</p>
5	Membership of CMRC <p>A professional membership application was discussed. As it was not clear that the applicant meets the criteria, further information needs to be requested.</p>	SC
6	Finance <p>SC presented the accounts for 2015-16 and projected budget for 2016-17. SC left the room while a discussion took place regarding payment for the Secretariat and conference organisation. The budget for 2015 was approved.</p> <p>It was agreed that commitments could not be finalised until more was known about the income stream for 2016 which required discussions with the funders. EC to discuss with SH.</p>	EC/SH
7	AOB <p>None</p>	
	Date of next meeting <p>27 April 2016 – ES to explore venue at SMC to enable us to hold and to livestream the AGM after the meeting.</p>	

Minutes taken & typed by SC; Chair approved: 15.1.16