

## DRAFT Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 16 November 2016

### Present:

Stephen Holgate (SH)	Sonya Chowdhury (SC)	Jan McKendrick (JM)
Esther Crawley (EC)	Claire Kidgell (CK)	Alastair Miller (AM)
Mark Edwards – EMIG (ME)	Neha Issar-Brown (NIB)	Charles Shepherd (CS)

### Joined via phone:

Carmine Pariante (CP; left at 2 pm)	Julia Newton (JN; left at 2.15 pm)
Chris Ponting (CPP)	

### Apologies:

Mark Edwards (MEd)	Allison Wallace (AW)	Des Walsh (DW)
Raliza Stoyanova (RS)	Ed Sykes (ES)	Hugh Perry (HP)
Paul Little (PL)	Mary Jane Willow (MJW)	Zoe Gotts (ZG)

	Agenda Item	Action
	<p><b>Welcome &amp; Introductions</b></p> <p>SH opened the meeting and welcomed members. CK was welcomed to the Board as an observer on behalf of NIHR, replacing Steph. No additional conflicts of interest were recorded.</p> <p>It was noted that this is AM's last meeting as he is standing down as Chair of BACME. Gabriella Murphy will be replacing him and AM will liaise with her to hand over the role. AM was formally thanked for his input.</p>	
1	<p><b>Minutes &amp; Matters Arising</b></p> <p>The minutes taken by EC were approved as an accurate record of the last teleconference call meeting.</p> <p><b>Matters Arising</b></p> <p>All actions have been completed. It was noted that the research scoping report was launched at the conference. Letters have been drafted for the report to be sent to mainstream funders but need to be finalised and sent. SC will also send a link to the report to Board members.</p>	SC/SH
2	<p><b>Conference</b></p> <p>SC introduced the report that she prepared which included the evaluation form feedback which indicated a good level of satisfaction overall. However, there were some areas that can be improved on for next year. HP and NIB had highlighted that the quality of abstracts was not as high as</p>	

	<p>previous years and this meant that the two prizes were not awarded in the way originally anticipated. One prize of £500 was awarded to Alice Russell. This raises the question of institutional supervision for abstract and poster submission.</p> <p>One of the aims of the CMRC is to bring in new researchers to the field and it was agreed that this should be a core focus for the next conference. All Board members to consider at least three people/groups they could invite personally to activate greater engagement and cross-fertilisation especially in neurosciences, immunology and stratification of complex illnesses. We should also look to better engage industry and ME will explore this further. All members to send details of contacts to him.</p> <p>It was agreed that Board members should all take a more proactive role in the planning and marketing of the conference next year and to send SC an outline of what action they can take to assist/lead areas. It was also agreed that a small planning committee would be established to assist with programming and other aspects – to email SC if willing to be involved.</p> <p>Feedback from Associate Members highlighted the desire for the whole conference to be open to them especially given the distance some had travelled. Since the first conference, we have opened up more sessions and most presentations have been livestreamed; the only exception being where presenters requested they weren't. The planning group will consider this further to ensure the conference is accessible without compromising the aim that researchers have time to share their work/explore collaborations which may not always be appropriate to do in a public arena.</p> <p>SC reported that she has already been in discussion with US-invited speakers for this year's conference who are potentially able to attend next year. This will be considered by the planning group within programming.</p> <p>CPP highlighted that there are a number of pivotal issues where strong consensus has not been achieved and it would be good to utilise the conference to explore these areas in an open way e.g. cohort criteria. It would ensure researchers fully understand the issues, concerns (from across the field including patient community) and scientific evidence base that does exist. He added that this is critical for stratifying the illness.</p> <p>NIB highlighted that the MRC is keen to support early stage career researchers hence the poster prize offer. Given the need to develop practice, the MRC can offer other opportunities to develop practice e.g. observe boards to better understand peer review process and so forth. NIB added that the MRC will continue to support the conference.</p>	<p>All</p> <p>All</p> <p>All</p> <p>Conf planning group</p> <p>Conf planning group</p> <p>Conf planning group</p> <p>NIB</p>
--	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	------------------------------------------------------------------------------------------------------------------------------

3	<p><b>MRC Highlight Notice</b></p> <p>There is a bigger piece of work being undertaken within the MRC to review highlight notices which are used to specifically target increasing research in a particular area. There is a need to increase the number and quality of applications as this has been a particular issue in this field. The last ME/CFS highlight notice was based on a priority-setting exercise with a follow-up highlight notice identifying neuroscience as a specific area of interest.</p> <p>The MRC will be updating the ME/CFS highlight notice on the back of the conference and research scoping report. It will take need to account of the growing scientific knowledge in this area. The conference report will be a good starting point to flesh out some high level points that could be considered as part of the highlight notice review. This could be used as a framework for the conference to attract greater interest from outside the community as well as inside. The ME/CFS highlight notice applies across all boards within the MRC so that applications will be given priority (after assessment of scientific quality).</p> <p>The research emerging from other countries should be used as a stimulus for this development. NIB would welcome any further thoughts. A process for review is being developed but this Board should play an active part in this and will review this at its next meeting.</p>	NIB
4	<p><b>MEGA Update</b></p> <p>EC provided a report back to the Board on progress. It was highlighted that the CMRC <i>per se</i> is not a member of the MEGA team. Some individuals on the Board will be named co-applicants, however, as part of the MEGA team that has been established.</p> <p>As the CMRC kick-started the establishment of the MEGA team through its Grand Challenge workshop in April, it was agreed that reports back to the Board would continue so that all Board members are appraised of progress. The CMRC has no formal role in decision-making about the study or its design but will continue to support the development of the website to establish a communications channel for the team while funding is being sought and to ensure meaningful engagement with the wider field.</p> <p>EC stated that MEGA will be submitting an outline bid in January. The outline bid describes the resource which will be a collection of data and samples from 10,000 adults and 2,000 children (final numbers to be agreed). The resource will be open access for researchers to use and therefore the MEGA team will ensure sample collection is designed to allow this to happen.</p> <p>The outline bid focuses on the money needed, the need for the resource,</p>	

	<p>the management of the resource and who will use the resource and what for. There is no detail required about what data we will be collecting or detailed aspects of study design.</p> <p>If the outline gets through the first stage, we will then submit a full grant in a few months' time when key decisions will need to be made re the design of the study.</p> <p>The urgent piece of work now is on the finances and costing the sample collection, freezers etc. We also need to create a list of the community of researchers who are likely to use it to demonstrate how many people will use it.</p> <p>We need the views of adults and children with CFS/ME before the outline to check we are on track and then the detailed views and input from adults and children with CFS/ME on the methods before the full proposal (if we get that far). This is just setting up a Bioresource. Most of the science will be done with future grants making use of the resource.</p> <p>The Advisory Group of people with ME/CFS, primary carers and others interested in the illness needs to be established. SC is working on the recruitment material and process which will be launched with the new website imminently. SC is working with website developers to set this up and all content will be signed off by the MEGA team.</p> <p>SC requested support for recruiting members of the Advisory Group to assist in ensuring it is an open and transparent process. As SC is representing the other charities, it was agreed that CS and JM would consider how best to manage the process and send ideas to SC for inclusion. If possible, they will also assist with the selection process. EC suggested that PL could assist given his work with the NIHR on patient and public engagement (PPI) and that he is a member of the MEGA team. EC will ask PL to assist. SC suggested pursuing initial contacts with NIH. It was agreed that this would be progressed accordingly.</p>	<p>CS/JM/SC</p> <p>EC SC</p>
--	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------

Minutes taken by SC

Approved by Chair: 26.11.16