

DRAFT Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 8 November 2018

Present:

Stephen Holgate (SH) – Chair Chris Ponting (CPP) Charles Shepherd (CS)
Phil Murray (PM)

Confirmed attendance by phone

Sonya Chowdhury (SC) Mark Jones (MJ) Neil Harrison (NH)
Opal Webster-Philp (OWP) Jo Elson (JE) Carmine Pariente (CP)
Colin Smith (CSm) – until 2.45 Rachel Ephgrave (RE)

Observers in attendance by phone

Libuse Ratcliffe (LR), BACME Chair

Apologies

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

	Agenda Item	Action
	<p>Welcome & Introductions SH opened the meeting.</p> <p>It was formally recorded that Mark Edwards (EMIG) has resigned given his prior commitment for a defined period of time. Mark was formally thanked for his input.</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"> • High level report – on hold. • James Lind Alliance – Priority Setting Partnership: SC feedback that there is a first working group meeting in a couple of weeks and she will provide an email update to the Board following the call. • PAG: recruitment in progress with interviews in December. • IAFME (International Alliance for ME) Consensus Document: SC stated this has been shared previously with the CMRC Board. They are awaiting a response from EUROMENE and for the IAFME formalisation through a Memorandum of Understanding between its members to be completed and then the document will be sent, with a covering letter, to WHO. SC sought approval for the Board to sign (a few individual members have also signed). • David Nutt study: there was no input at the conference and there 	

	<p>has still not been an update on progress. SH will follow this up with MRC for an update.</p> <p>Decision The Board approved the minutes of the last meeting as an accurate record of the meeting.</p> <p>The Board approved signing the IAFME consensus document as the CMRC.</p>	SH
2 2.1	<p>Conference</p> <p>Conference 2018 Report SC introduced the draft report she has prepared and referred to the following:</p> <p>The conference provided a varied programme with both days and the dinner being open to Associate Members. The breakdown of attendees was as follows:</p> <ul style="list-style-type: none"> • Total delegates: 95 • Professionals (excluding students): 75 • Student members: 10 • Associate members: 12 • Number of waivers provided to Associate members: 4 • Number of countries represented: 6 <p>Overall, the venue worked well but there were a few issues which have been addressed directly with the venue. Overall, the feedback was very positive and we had 100% increase in the number of feedback forms completed in comparison to last year! 97% of respondents rated the conference as very good or good which reflects verbal feedback given during the event.</p> <p>We had several international speakers as well as UK speakers. As the Board will recall, these were invited following suggestions from Board members as well as oral presenters being selected following peer review. Briefings were provided to all invited speakers and workshop facilitators. The input from Versus (formerly ARUK) was valued by delegates with the opportunity to hear from eminent researchers from outside the CFS/ME field, highlighted as very important.</p> <p>Three workshops were held and details fed back. The workshops were well received and as an output to the biomedical research priorities workshop, working groups are in the process of being established to develop strategies and implement actions plans on: Medical Education (3 members), Mitochondrial Biology (5 members), Immunology (5</p>	SC

<p>2.2</p>	<p>members), Omics & Big Data (6 members).</p> <p>Particular note should be taken of the feedback regarding the workshop on activity management which, given the controversy in this area, was very positive.</p> <p>Our #CMRC2018 tweets about the conference were seen 24,240 times, and actively interacted with (liked, replied to, retweeted etc.) more than 5,200 times. We posted three times on Facebook about the conference</p> <ul style="list-style-type: none"> • <i>Today is the first day of the 2018 CFS/ME Research Collaborative conference</i> reached 2,190 people • <i>After a great first day at the UK CFS/M.E. Research Conference, we're ready for day two</i> reached 1,670 people • <i>#CMRC2018 conference: first films now available</i> reached 3,815 people <p>The majority of presentations were filmed and these are available on the Action for M.E. YouTube channel. Within the first two weeks of posting, the 15 films had been watched 2,630 times. The most popular film is Dr Nina Muirhead's presentation (37% of views), followed by David Tuller (15% of views).</p> <p>SC had planned to table the latest accounts at the meeting today, post conference, but as she is accessing the meeting remotely and the team is still chasing a few speakers, she will send via email once the reconciliation is done. Students, funded by MEA, have written reports so SC will include links in the report.</p> <p>SH stated that SC and the team did an extraordinary job that really excelled in putting together a very good programme and supporting the conference overall. The interchange between delegates was, in part, due the atmosphere created by the Action for M.E. team. The workshops were very interactive and engaging and there was good input internationally.</p> <p>SC invited input, comments and questions on the report. Discussion regarding the level of presentations which, for some non-researchers, was inaccessible. SH suggested that all speakers provide a lay summary ahead of each presentation or a lay summary at the beginning and the end.</p> <p>Conference 2019 As per the paper, SC recommends that the 2019 conference is moved to March 2020 for logistical reasons with capacity. Additionally, we know there is likely to be more research to report on at that stage. Planning will not commence until March 2019.</p> <p>Decision</p>	<p>SC</p>
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	The Board approved a conference date of March 2020 with a proposal and draft budget to be approved at the April 2019 meeting.	
3	<p>Strategic Priority – Big Data/Bioresource</p> <p>We responded to a series of questions from the MRC grants boards raised following the presentation by SH, SH, CPP to the Population and Systems Medicine Board earlier this year. As an output from this, there have been further discussions which have led to an invite to provide a further submission, this time to the Strategy Board.</p> <p>There have been discussions with other funding bodies/individuals to consider collaborations to drive forward and PC has been very helpful given his experience of working with an NIHR-funded Bioresource.</p> <p>There was considerable discussion on different elements of what a big data study would constitute and how this could be progressed, with whom we might engage and work with collaboratively.</p>	
4	<p>Working Groups</p> <p>The groups were formed as an output from the last conference and are intended to bring together different parts of the field to identify how people can work together, set up consortia and potentially submit collaborative grant applications.</p> <p>They will be asked to consider a series of prioritised research questions to present to the CMRC for consideration re the above alongside the PAG. SH to write to the groups and ask for responses to be sent to him. SC to send names/addresses.</p> <ul style="list-style-type: none"> • Omics & Big Data Group: • Immunology Group: • Mitochondrial Biology Group: JE has been asked to lead this group. • Medical Education Group: SC gave feedback that she, Nina Muirhead and Deb Brown had had initial discussions are pulling together draft terms of reference which she is happy to share with the other groups. CS has agreed to join the group. <p>Governance: Terms of reference for each group need to be developed and then approved by the CMRC Board.</p>	<p>SH</p> <p>SC</p>
5	<p>AOB</p> <p>CS highlighted the NIH Accelerated Research Meeting in April.</p> <p>SC informed the Board that she will be taking up to three months for surgery from 29 November. Ros Czarnowska, Interim Deputy CEO, will be</p>	

	covering in her absence. RC has been connected with SH/ CPP but if any Board members need assistance, please contact Anna Whitson, in the first instance.	
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Minutes taken by SC
Approved by SH/ CPP