

Paper 1: *DRAFT* Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 15 January 2020

Present:

Stephen Holgate (SH) – Chair
Anna Gregorowski (AG)
Susan O’Shea (SS)

Charles Shepherd (CS)
Sonya Chowdhury (SC)

Chris Ponting (CP)
Anita Lim (AL)

Observing

Andy Devereux-Cooke (ADC)

Rachael Ephgrave

Attended by phone

Opal Webster-Philp (OWP)
Margaret Mar (MM)
Deb Brown (DB)

Sam Bromiley (SB)
Phil Murray (PM)
Jo Elson (JE)

Nina Muirhead (NM)
Jim Wilson (JW)
Stephen Meader (SM)

Apologies

Colin Smith

Carmine Pariante

	Agenda Item	Action
	<p>Welcome & Introductions SH opened the meeting and introductions made.</p>	
1	<p>Minutes and Matters Arising Slight amendments made to the minutes for accuracy</p> <p>Decision The Board approved the minutes of the last meeting as an accurate record of the meeting subject to any agreed amendments.</p>	SB
2	<p>Mainstream Research Funding</p> <p>2.1 Biomed Application SH confirmed the deadline for submission of the BioMed application is 23rd January. CP said the proposal writing and planning has gone very well and there is a compelling argument for funding. This will go to peer review and MRC will give them an opportunity to respond. He stated that patient and public involvement has been very important.</p> <p>SC said it has been phenomenal how the community has come together in support of the partnership and application. The PAG has been superb and worked to tight timescales and contributed significantly. A short consultation is out asking for ideas for recruitment with over 500</p>	SC/CP

2.3	<p>responses. Also a survey whereby people can indicate support has had an encouraging response with over 6,400 signups. They will be meeting with a marketing agency to help create a plan to recruit at least 40,000 knowing there will be a drop-out rate for varying reasons.</p> <p>ADC said the attempts to engage with the patient population is worth noting as even the best studies previously will not have had this level of engagement. There is a lot of goodwill attracted to the project already because of this engagement. Still parts to iron out but currently it is unprecedented.</p> <p>SH said to SM that the workshop they led before Christmas was a very important step because it gave the opportunity for patients, carers, clinicians and researchers to take equal ownership. MM thanked SC and her team for the work that has gone into this which has been very substantial.</p> <p>SM said the next step after submission is peer review. This process is expected to take up to a month when the partnership will then have 10 days to provide a response to the review. There will be a panel meeting for this application and then a recommendation to MRC strategy board on 25th March.</p> <p>Decision The Board agreed to put an item on the next agenda to discuss any lessons learnt from this process.</p> <p>Future Research SH opened up a discussion asking those present whether they had any ideas on the future research they want to do and questions they would like to answer following this study. A discussion was had highlighting the areas of interest to members of the CMRC. The PAG has recently discussed this and identified areas of priority such as diagnosis, treatment, prevention, access to medical and social services and investigating hereditary links.</p> <p>SC said that the process for decision-making is critical so that it's not just personal ideas but that there is rigour behind it in the way we arrived at the Biomed application. This is something which can also be covered during the CMRC conference in March.</p> <p>Decision SH to write to individuals we know who have expressed interest in developing new research and ask an open question on the next steps.</p>	<p>SB</p> <p>SH</p>
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3	<p>CMRC Working Groups</p>	
3.1	<p>Medical Education Group:</p>	
	<p>NM said they have met quarterly. The group has grown in number and interest with 10 doctors now involved along with representatives from Scotland, Northern Ireland and Wales.</p>	
	<p>There are several education initiatives taking place in Cardiff, Cambridge, Buckinghamshire and NI. They are currently trying to collect info from doctors and patients about what direction education needs to go in to support healthcare professionals in caring for patients and also to communicate latest biomed research. They are also looking at a potential public health campaign for 2021.</p>	
	<p>Abstracts relating to medical education are being submitted to CMRC in relation to medical education. They will be looking into putting out statements informing community on the work of the group.</p>	
	<p>Immunology:</p>	
3.2	<p>SH detailed how important this area was and the need to get the working group activated again. Several names were considered to lead this. It was discussed that they could create an opportunity at conference to discuss new opportunities and garner interest.</p>	
	<p>Omics and Big Data:</p>	
3.2	<p>CP said that they have not held a meeting due to the work being done for the BioMed application. It was agreed to invite someone from the Biobank to the April meeting to aid further discussion.</p>	
	<p>Mitochondrial biology:</p>	
3.3	<p>JE said that the group is looking to identify avenues of funding for pieces of work and have recently put in a grant to the MRC with others to bring in extra money to shift some of the ideas of the working group forward.</p>	
	<p>Priority setting partnership (PSP):</p>	
3.4	<p>SC introduced the PSP paper.. The NIHR and the Scottish Chief Scientist's Office has been approached for funding for this piece of work.</p>	
	<p>There are three key questions the working group would like the Board to consider. Firstly, the recruitment of an Information Specialist who will manage data and support the PSP. Second is the recruitment of a steering group to oversee the PSP and organise its activities. Thirdly, consider an appropriate initial information or awareness session which will Provide an overview of the PSP.</p>	
	<p>PR:</p>	
3.4	<p>OPW thanked MM for her help stewarding group and that they are now looking for a new chair. They would like someone who can work collaboratively and is respected among the M.E and research</p>	

3.5	<p>communities. It is essential it is someone who can translate the science into lay-man’s terms. In the meantime, e DB and OPW will be coordinating the group in partnership with professional on the group.</p> <p>Learning from other charities is important so a Cancer research meeting organised to discuss best practice in this area of engagement. The group will consider the key messages that we want to run through the group to the world of M.E. and these will be brought back to a future meeting.</p> <p>SH said that in the meeting in March there should be an item considering the future of the CMRC and how we see different functionalities. Robust governance structure and legal protection.</p> <p>Decision The Board agreed that there will be an item on the agenda at the next meeting to discuss the future of the CMRC.</p>	SB
4	<p>Conference SC has been working on avenues of funding. Work is underway to increase registrations for the conference.</p> <p>MEA are providing bursaries for students again this year with 6 places available.</p> <p>SC said the conference is now CPD certified and additional work will be done to garner interest among healthcare professionals.</p>	SC
7	<p>AOB CS said Carol Monaghan MP has reformed the APPG for M.E. with 30 MPs come along. They will be producing a report on Biomedical Research at some point in the future. 11th February next meeting.</p> <p>BACME will be having a conference on May 20th 2020 at Burton Hospital Education Centre. For more information got to https://www.bacme.info/civicrm/event/info?id=4</p>	

Minutes taken by SB 15.01.20

Approved by SH 15.01.20

