

## DRAFT Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 6 June 2017

### Present:

Stephen Holgate (SH)	Sonya Chowdhury (SC)	Julia Newton (JN)
Esther Crawley (EC)	Gabrielle Murphy (GM)	Mark Jones - UCB (MJ)
Mark Edwards – EMIG (ME)	Charles Shepherd (CS)	Neha Issar-Brown (NIB)
Ed Sykes (ES)		

### Joined via phone:

Carmine Pariente (CP)	Chris Ponting (CPP)
-----------------------	---------------------

### Apologies:

Allison Wallace (AW)	Des Walsh (DW)	Hugh Perry (HP)
Claire Kidgell (CK)	Paul Little (PL)	James Brodie – GWPharma (JB)
Mike Dalrymple (MRCT)		

	Agenda Item	Action
	<p><b>Welcome &amp; Introductions</b></p> <p>SH opened the meeting and welcomed members.</p> <p>It was formally noted that MERUK has resigned from the CMRC Board of the CMRC. The Board noted the resignation and SH will write to thank them formally for their input to date.</p>	SH
1	<p>Members discussed the purpose of the CMRC which guides its work: To improve the quality of science. As per the Charter, the CMRC will do this by driving increased interest and investment in CFS/ME research.</p> <p>The objectives are to:</p> <ul style="list-style-type: none"> <li>• Develop, inform and update a national strategy for CFS/ME research</li> <li>• Facilitate all high quality peer reviewed research into all aspects of CFS/ME in both adults and children. This will include: basic mechanistic research; translational research; epidemiological research; health resource use research and research investigating all types of treatment and prevention of CFS/ME</li> <li>• Encourage multidisciplinary research by facilitating links with those already active in the field and involving scientists in other fields to undertake research in CFS/ME</li> <li>• Facilitate investment in essential research infrastructure e.g. bioresources, technology</li> <li>• Platforms, well phenotyped patient cohorts to deliver high quality research in CFS/ME and promote increased research capacity in the field</li> <li>• Work collaboratively to raise the profile of CFS/ME research in the</li> </ul>	

	<p>UK in both professional and public domains</p> <ul style="list-style-type: none"> <li>• Promote, facilitate and support the development of a good career structure for CFS/ME researchers</li> <li>• Foster research collaborations and communication between clinicians, researchers, people with M.E./CFS, professional bodies, industry and charities with research interests in this field.</li> <li>• Promote conditions in which more research can take place in NHS bodies within the UK, including supporting clinicians and researchers conducting all types of peer reviewed research</li> <li>• Work collaboratively with funders, charities and researchers to increase the financial support for CFS/ME research in the UK</li> <li>• Raise awareness of the achievements of the CFS/ME research community</li> <li>• Liaise with UK and international agencies and funders to share information and respond to consultations and forge new partnerships where appropriate.</li> </ul> <p>Members discussed the varying perspectives within the wider community and how this impacts on the work of the CMRC.</p> <p>NIB noted that there has been an increase in the numbers of grants to the MRC that are being submitted but we are not where we need to be and further work needs to be done.</p> <p>It was agreed all will consider the vision for the CMRC, where we feel the best chance of building further collaborations is (including external to the M.E. arena) and send to SH. To include exemplars of what this would look like and to consider activity against the objectives.</p>	<p>All SH</p>
<p>2</p>	<p><b>Minutes &amp; Matters Arising</b></p> <p>The minutes of the last meeting (21 March 2017) were approved as an accurate record of the last meeting.</p> <p><b>Matters Arising</b> All actions have been completed or will be discussed as part of the main agenda.</p>	
<p>3</p>	<p><b>Outcome from the Funders' Meeting</b></p> <p>The meeting was held at the end of May and included a range of funders including the NIH and provided a robust forum for exploring the challenges/difficulties in the field and differing perspectives alongside developments in the science. The meeting was attended by two pharmaceutical companies, MRC, NIHR, Action for M.E., MEA, NIH and was chaired by HP. The meeting, initiated by the CMRC in response to the</p>	

	<p>scoping report led by SC (presented at last conference), was to explore how to work more collaboratively to address the issues and key findings highlighted in the report. There was considerable discussion about the differing and sometimes opposing views within the field and the importance of listening to these and ensuring a purpose-led approach to tackling the gaps and barriers in the field.</p> <p>There are a number of opportunities for forging new relationships, sharing data and taking a more synergistic and strategic approach. There were a number of short, medium and long-term actions that will now be considered and an action plan developed.</p>	SC/SH/HP/EC
4	<p><b>Conference 2017</b></p> <p>SC proposed a change to the programme as a result of discussion at the funders' meeting to have more dedicated time to explore and develop collaborations. The Board approved the proposal and work will now be undertaken to redesign the session.</p> <p>Don Staines has confirmed attendance and the programme will be adjusted to include his participation.</p> <p>All to assist with promoting and marketing the conference.</p>	<p>SC</p> <p>SC</p> <p>All</p>
5	<p><b>Comprehensive Review of ME/CFS</b></p> <p>The purpose is to seek a report to take an independent look at the UK current status of the ME/CFS field: where we have got to and where we need to get to. Evidence would be sought from all key stakeholder groups to develop a high level report (as the IOM report was) to use with government and others to galvanise action. We do not have the resources available that the IOM had at its disposal but there is potential scope to seek an independent report by approaching a range of organisations. The report would need to be independent, high level and have the 'clout' to be used at governmental level.</p> <p>It was agreed that a couple of independent forums to be identified and a collaborative letter would be coordinated to send to them.</p>	
6	<p><b>MEGA Update</b></p> <p>Further meetings of the patient advisory group, the scientific group and both groups jointly have taken place. Work is progressing.</p>	
7	<p><b>Action Plan</b></p> <p><b>Website:</b> There was a meeting this morning to progress and content will</p>	All

	be circulated to members. Images are needed.	
6	<p><b>AOB</b></p> <p>SC/CS shared that they had been to a private viewing of Unrest. It was a very powerful and emotive film. SC to explore possibility of doing something with the CMRC.</p>	

Notes taken by SC

Approved by SH: 09.06.2017