

## Notes of CMRC Telephone Conference 26<sup>th</sup> August 2016

Present: Stephen Holgate (SH, Chair), Chris Ponting(CP), Mary Jane Willows (MW), Mark Edwards(ME), Esther Crawley (EC), Paul Little (PL)

No.	Agenda Item	Notes
	Welcome, Introduction & Apologies	
1	Minutes & Matters Arising	The minutes were approved. Whether there were gaps in board membership were discussed. It was noted that several new board members had been recently appointed. <b>Action:</b> Discuss further in Newcastle.
2	Conference 2016 Update	Not clear what numbers are. EC: raised issue of large teams being unable to afford all members to attend. Discussion on bursaries. Has NIHR funded? Sonya was chasing. Tom Walley is coming. SH: We must get a more secure funding stream in place. We need to diversify Great programme. Stephen not here second day. EC asked to close <b>Action:</b> SH will remind board to register. Chase NIHR funding. EC to close conference
3	MEGA Update	EC: MEGA communication plan complete. Everybody needs to do their blogs. PL: need broad inclusion. Hope this will come out. EC: George DS likely to discuss this. Use migraine example. SH: impressed with the immunopsychiatry work (Pariente) as discussed recently on the Today programme. It captures the great diversity problem that we have in CFS.
4	Request from Derek Pheby	DP letter was discussed. SH planning to bring up his plans in terms of patient characterisation. Either in the patient session or after the first session. <b>Action:</b> SH will discuss with Sonya and Tom
5	Current/Future Projects <ul style="list-style-type: none"> <li>• Uber Scoping</li> <li>• Website</li> </ul>	<b>Uber document</b> SH: the Uber report is looking good. Overall summary, still very little funding. Very useful instrument to go to MRC council, Wellcome etc. Powerful document. Particularly with Charter and TOR PL: it will be helpful and should go to NIHR SH: would like to hold a funders workshop with key people from research community. Connection to US funders would be essential. Need to plan something for next year around the documents (Uber, charter, TOR). Try and get a small group to meet together for a day or so. Use MEGA as an illustration. Must bring funders together. Only together will we get sufficient funders together. EC: should we publicise Uber report? Disparity between prevalence and funding. Chris: Approach Wellcome Trust because they have very good relationship with NIH and other funding organisations. Individuals in the trust who have a lot of experience of working hand in hand with other funders. SH: thanked Sonya, Neil Abbott, Carmine for reviewing the report <b>Action:</b> Discuss with those coming from funders in Newcastle ALL discuss further in Newcastle and think about how we put the funders together. <b>EC</b> Discuss with Ed re publicity and Sonya. Press release.

		<p><b>Website.</b> Everybody needs to give brief descriptors on what we are about. Encourage Ed to get this up and running as quickly as possible.</p> <p><b>Action:</b> SH to ask people to send pieces in for Website</p>
6	Charter and Terms of Reference	<p>Approved</p> <p>ME: Charter is central document. Key is agreement around a key national strategy and research plan. This is fundamental to funders workshop. Suggests Aims and objectives are split into annual plan with a couple of objectives to be done each year.</p> <p>SH: this is a delivery plan</p> <p>ME: there is little de nova research in this area. Drugs are tried but this isn't with an informed basis of knowing where the targets are.</p> <p>SH: we should all reflect on that and take out chunks to develop over the year. Developing a delivery plan seems sensible.</p> <p><b>Action:</b> put on agenda for next meeting. Ask everybody to think about short term deliverables. For example, funders workshop.</p>
7	AOB	No AOB. Meeting closed