DRAFT Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 21 March 2017

Present:

Stephen Holgate (SH)	Sonya Chowdhury (SC)	Jan McKendrick (JM)
Esther Crawley (EC)	Gabrielle Murphy (GM)	Mark Edwards (MEd)
Mark Edwards – EMIG (ME)	Charles Shepherd (CS)	Mark Jones - UCB (MJ)
Mike Dalrymple (MRCT)	Ed Sykes (ES)	James Brodie – GWPharma (JB)

Joined via phone:

Claire Kidgell (CK)	Julia Newton (JN)

Apologies:

Allison Wallace (AW)	Des Walsh (DW)	Neha Issar-Brown (NIB)
Raliza Stoyanova (RS)	Hugh Perry (HP)	Carmine Pariante (CP)
Paul Little (PL)	Mary Jane Willow (MJW)	Zoe Gotts (ZG)
Chris Ponting (CPP)		

	Agenda Item	Action
	Welcome & Introductions SH opened the meeting and welcomed members. GM was welcomed to the Board as an observer on behalf of BACME, replacing Alastair Miller. No additional conflicts of interest were recorded. Guests were also welcomed to the meeting and provided introductions on their interest in the illness/purpose for attending. SC reported that MJW will be standing down from the Board due to the pending closure of AYME on 3 April 2017 and the launch of Children's Services by Action for M.E. MJW will transfer to Action for M.E. as the new Head of Children's Services. Action for M.E. representation will continue to be provided by SC.	
1	**Minutes & Matters Arising** The minutes of the last meeting (16 November 2016) were approved as an accurate record of the last meeting. **Matters Arising** All actions have been completed or will be discussed as part of the main agenda. NIB will report to the Board regarding the Highlight Notice at the next meeting.	NIB

2	**What good looks like: how to optimise the academia, charity and industry partnership** SH provided an introduction and background to the discussion. He outlined that this is an area of medical science that has been significantly neglected for many years. He would like to see a formal UK report identifying why this considerable group of people have been ignored and why medical scientists have not wanted to get involved in this field. An important step was made by the Institutes of Medicine (IOM) in their report published in 2015. SH recommended that colleagues read the report if they haven't already as it reinforced the need for the illness to be mainstreamed with the recognition and focus it deserves. As a result, the NIH, has pledged a commitment with funding to set up centres of excellence with a critical mass of expertise. This demonstrates that the illness has been taken seriously by the establishment in the US. However, this has not happened here in the UK. This perpetuates the disbelief from some medical professionals and a stand-off with the patient community, a lack of research funding and researchers and not wishing to enter the field. A few charities, small in comparison to other illness fields, have worked to initiate and fund research into the illness. Things started to progress when MRC issued the Highlight Notice following a workshop in Oxford with presentations and engagement from scientists from a range of disciplines. This resulted in five applications being funded. With that principle in mind, a group, including SH, set up the CMRC. Besides the members, the CMRC Board includes observers from all three mainstream funders, the SMC and BACME. The focus of the CMRC is to promote collaborative effort within the field and to stimulate greater interest from outside the field. The CMRC's annual science conferences have been well attended and included people with M.E. and carers. A report is produced after each conference and most presentations are livestreamed (except for those including unpublished data). One of the main challenges that continues to be addressed is that this illness, or cluster of illnesses, is a psychiatric illness, **which it is not**. This resulted in patients being referred to psychiatrists and there continued to be a lack of effort and research into the biological nature of the illness. The CMRC initiated an endeavour to bring together the very best UK scientists from a range of disciplines including the omics, informatics and other areas to form an Alliance with a view to establish a well-characterised bioresource with a range of data from 12,000 participants. The grant submitted to Wellcome was unsuccessful; a grant is about to be	

	submitted to the MRC tissue banking call. The model of getting people together to work in this way is a viable model and that is why we have invited a broad range of guests to engage with the ambition. The question to industry is that while recognising the percentages of people affected by this illness/cluster of illnesses, how can we better engage with industry to transform this field; not just from a funding perspective but in respect of legitimising the illness within the medical profession. This will then give a message to funders and others that this is serious and needs to be taken seriously. ME added that in his experience, academia and industry collaboration can lead to transformation at the level that we are looking to achieve. While it is early in respect of pharma engagement, it is never too early to start the conversation and explore potential synergies. ME posed the question of 'what looks good to industry/MRCT and what do you feel you can collectively contribute back?' The following themes/issues were discussed: • There is experience in some pharma's of working in orphan disease areas – including a focus on rare diseases. There is also strong recognition of the power of charity and patient advocacy groups to engage with regulators to develop something meaningful for patients • How can we establish well-validated outcome measures and meaningful clinical outpoints that can lead to effective trials and therefore move to a sound development business case; what level of efficacy is required? • Repurposing of compounds can be explored while recognising that we don't always understand how some compounds work • You can't not believe patients if they tell you something works; there must be something in their experience and it should be listened to • There is considerable value in a non-hypothesis or hypothesis-generating approach • Importance of developing biomarkers and stratifying the illness (or illnesses) as a starting point. • Collaborations that progress and succeed need a real focus; guests felt that there is a real focus with the CMRC and MEGA work • Cross-fertilisation across disciplines and fields is important • The more clinical information that you can collate the better • The informatics and the power of bringing what is needed is significant to achieve genuine stratification with predictive markers that you can then properly test • Early biomarkers of what recovery looks like is important alongside of outcomes and how these can be brought together • We need to find drugs that we can take early into clinic (which are	

	also safe) and then identify how we can take those trials forward • Establishing the right tests to avoid false patterns is critical and there is a lot of expertise in this methodology from other illness fields • There was a strong message from industry guests about the importance of a bioresource of the MEGA level as a critical starting point • The role of microbiomes especially given the experience of many people whose illness starts with infection/gut infection • There could be biomarkers of the cause or of the effect • Consideration of faeces samples within the bioresource • This illness is massive in respect of disease burden; it is not a rare disease • Importance of building meaningful collaborations which include charities alongside industry, research and clinical practice.	
3	**MEGA Update** EC provided an update on the latest application which has been developed within two weeks once permission to apply from Bristol University was received. The MEGA team has been working on the application which will be submitted to the MRC tissue banking call imminently. This application will be for sample collection only due to the nature of the call. Analysis, including GWAS (genome wide association study,) will be required as a second stage. The Patient Advisory Group met yesterday evening with EC and SC's colleague. There has been considerable input and the design of the study has changed as a result.	
4	**Conference 2017** SH shared his experience of the importance of patient input in driving the research agenda within the arthritis field and reinforced the importance of part of the conference being open for anyone to attend. It was also highlighted that researchers repeatedly ask for confidential space to enable them to share results and consider new collaborations. It was agreed that the conference would continue to provide a day that was open with most of the speakers presenting and a second day that is closed for researchers to explore new collaborations. SC presented the budget for the conference and provided an update on the programme which is now almost complete. Tickets will go on sale in April with an earlybird discount. *SC left the meeting.*	
5	**Action Plan Update**	

5.1 5.2	**Website** ES has been working on this and asked how we reached consensus over content. There are two options to register disagreement - we can do this for each item that we disagree on or as a header for the page. EC suggested that a sub group meets for 2 hours before the next meeting and goes through all the issues so that there was consensus. It was agreed that EC, GM and the three charities would be invited to attend this meeting. **Funders' Meeting** Esther described who was attending the funders meeting and the purpose. SH gave his apologies but asked that funding for the conference is put on the agenda	ES
6	**AOB** None	

Minutes taken by SC (until item 5); EC thereafter
Chair Approved: SH 22.3.17 by email