



DRAFT Minutes of CMRC Meeting 11 November 2015

Present:

Stephen Holgate (SH)	Sonya Chowdhury (SC)	Charles Shepherd (CS)
Esther Crawley (EC)	Ed Sykes (ES)	Steph Garfield (SG)
Mary Jane Willow (MJW)	Mark Edwards (ME)	Allison Wallace (AW)
Des Walsh (DW)		

Joined via teleconference:

Carmine Pariante (CP)	Julia Newton (JN)
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Apologies:

Neha Issar-Brown (NIB)	Zoe Gotts (ZG)	Alastair Miller (AM)
Hugh Perry (HP)	Jan McKendrick (JM)	Paul Little (PL)

	Agenda Item	Action
	<p>Welcome & Introductions</p> <p>SH opened the meeting and welcomed new members (AW from Wellcome; SG from NIHR and ME and CP, researchers alongside DW who is replacing Joe as he has a new job).</p> <p>No additional conflicts of interest were recorded.</p>	
1	<p>Minutes & Matters Arising</p> <p>All actions completed or addressed below in main agenda.</p> <p>Decision The Board approved the minutes of the last meeting. All actions have been undertaken/are addressed in the main agenda.</p>	
2	<p>Conferences</p> <p>2.1 Conference 2015 SC presented a report based on post conference evaluation. The feedback is excellent overall with some good suggestions for improvements for future conferences. The plenary sessions were thought to be appropriate and met need. The livestreaming was appreciated and increased accessibility. There were issues with the sound at times which was due to the speakers not talking into the microphone. This could have been mitigated through the use of a lapel mic but unfortunately the one booked was not working.</p> <p>The social media coverage was very high. On Twitter, SC tweeted 449 times over the two days. Additional tweets from Action for M.E. meant that the reach was 130,000 with nearly 4,000 people engaging directly with the tweets and many are still being retweeted now. Other delegates were tweeting and there was</p>	

2.2	<p>Facebook engagement.</p> <p>The sponsorship of four student places by MEA worked well. CS stated the intent to pursue this next year. Content was good and feedback was that the quality of discussion was high. Do we need to do more workshops next year? The engagement internationally was very good. There was a great round-up with George Davey-Smith. The lunchtime session on media was well-attended and feedback was good.</p> <p>It was also noted that as the science increases both in quantity and quality, this will impact positively on future conferences.</p> <p>SC will add the feedback from the conference to the final conference report.</p> <p>SH thanked the support of MRC, Wellcome Trust and Arthritis Research UK which subsidised the conference.</p> <p>Conference 2016</p> <p>SH has identified a possible venue in Southampton – Chilworth Manor on the university science park. SH and PL will be the academic hosts. SC exploring capacity and cost at present with SH's PA.</p> <p>A small sub-committee will be convened to develop the proposed programme to be agreed by the Board: SH/SC/PL.</p> <p>Sponsors for the event will be identified and approached.</p>	<p>CS</p> <p>SC</p> <p>SC</p> <p>SH/SC/PL</p> <p>SC/SH</p>
3.	<p>Grand Challenge</p> <p>SH launched the challenge formally at the conference and this was followed up by George's presentation at the end of day two. This is a national study collecting a large sample size (10,000+) of data focused on phenotyping and subtyping data using statistical analysis and bringing in genomics and other areas. George Davey-Smith is very keen to be involved.</p> <p>The Wellcome Trust has a new collaborative awards scheme which AW's colleague has flagged with SH. AW outlined that this fund is for a collaboration of this nature up to £4m. There will need to be a PI but each collaborator has to play a proactive part within the project. A meeting will be convened with the Wellcome Trust to explore further.</p> <p>Following a meeting, an outline will need to be submitted to be reviewed by a Panel which will then potentially lead to an invite for application submission. There is a detailed process that will need to be considered.</p> <p>A Grand Challenge meeting is being convened in April and an outline application could be considered for September 2016. SH will circulate the application process.</p> <p>This could be a sole Wellcome Trust activity or a fully collaborative approach. DW highlighted that the MRC are awaiting the Comprehensive Spending Review</p>	<p>AW/SH</p> <p>SH</p>

	<p>to know budget. However, there are a number of opportunities that could be considered from the MRC in respect of funding. There is some feedback from previous unsuccessful applications that should be considered in respect of future applications.</p> <p>SH highlighted the IOM and the statement that ME/CFS is not a single disease entity and there needs to be new methodology applied to phenotyping alongside the importance of genomics etc. NIH announced last week the setting up of a new panel to tackle ME/CFS. SH identified the need to have a broader, more inclusive definition to enable the development of disease clusters will be an important consideration. This will more than likely provide the evidence that ME/CFS is not a single disease entity. SH will circulate the IOM and associated reports.</p> <p>SH/EC met this morning to develop an outline plan for a meeting in April in Bristol to bring together the critical scientists to deliver on this agenda. A list of invitees has been developed and SH will write to them. The first principle is that this is a very high-level science-led endeavour.</p> <p>There will be one charity representation which the charities on the Board can agree.</p> <p>We also need to agree whether it is an adults/children's or study of both - need to consider whether there may be different results between the adults and children.</p> <p>There will need to be a decision about collecting the right type of clinical data as well as phenotyping the patients by objective measurements (e.g. physiology – known immunology measures; sleep; cognition; psychological; post-exercise fatigue, pain amongst other components). SH highlighted that with the asthma study, cluster analyses was undertaken on 300+ phenotypic data which identified 8 different types of asthma. Another consideration is what data is used (new vs previously collected) – need to ensure standard operating procedures.</p> <p>The level of expertise needed will need to be high and across a range of areas to ensure we collect good clinical phenotypes. Therefore we will need good physiological phenotypers, need sleep and pain experts, as well as across all the 'omics.</p> <p>The partnership needs to be set up and then the project will be broken down into phases for implementation. SH has agreed to fund the meeting in April and associated costs.</p> <p>Decision: The Board approved the plans for implementation.</p>	<p>SH</p> <p>SC/CS/MJW/JM</p> <p>SH/EC</p>
4	<p>Code of Conduct for Communication</p> <p>MJW and ES have produced a draft code for consideration by the Board. This is to ensure clarity regarding how communications and how members can and</p>	

	<p>should engage in scientific debate as well as in relation to CMRC matters.</p> <p>There was a discussion in relation to specific points which will feed into some further amendments and be re-circulated for final approval.</p> <p>Once approved, the final draft will be placed on the new website.</p>	<p>MJW</p> <p>SC</p>
5	<p>Outcomes of the ARUK QoL grant review</p> <p>SH highlighted that the quality of life call received 18 applications. There were a number of grants that were of very high quality and cut across other ME/CFS co-morbid areas.</p>	
6	<p>Current/Future Projects</p> <p>a) Uber scoping research: SC provided an update on progress made. There is a draft paper that is being worked on and SC hopes that the paper will be ready for consideration by the Board at the next meeting. SC to liaise with SG to engage NIHR.</p> <p>b) Website: SC has not been able to prioritise this but has a meeting planned with ES to look at content next week.</p> <p>c) Screening research applications: ME agreed to lead this area of work. This project will be launched alongside the website.</p>	<p>SC</p> <p>SC/ES</p> <p>ME/SC</p>
7	<p>CMRC Support and Development</p> <p>SH outlined the CMRC has been supported by Action for M.E. for the last three years without any real recompense. SH outlined that a contribution to conference organisation alongside the secretariat is required to professionalise the CMRC and to ensure the administrative support that is required. It was noted that to pay an external conference organiser would cost £10,000 (as per previous quotes). MJ identified that AYME currently receive £8,000 funding for organising the BACME conference and that this would seem appropriate for the CMRC to pay. Members also acknowledged that a similar amount would be appropriate for admin/organisation support for its other work.</p> <p>SH stated that there are plans to grow the CMRC work and it is not sustainable or appropriate for one of the charities to continue to do this work with no financial support. Ideally, the CMRC would have dedicated admin support allocated within Action for M.E. alongside expertise to continue managing the separate bank account, website and other aspects of work.</p> <p>Decision It was agreed that once the accounts have been finalised post conference, a decision would be taken by the Board.</p>	<p>SH</p>
5	<p>Membership of CMRC</p> <p>SC outlined that membership has continued to grow, as anticipated, due to the membership discount offered when booking the conference. Renewals have been processed. Latest figures will be provided at the next meeting</p>	<p>SC</p>

6	AOB None	
	Date of next meeting 15 January 2016 – ES to explore venue at SMC to enable us to hold and to livestream the AGM after the meeting.	

Minutes taken & typed by SC

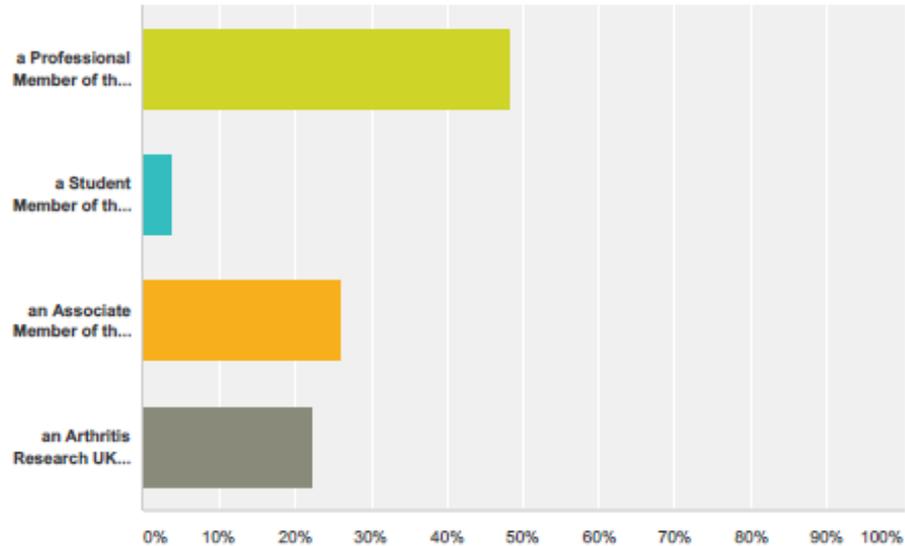
Chair approved:

PAPER 2: Conference 2015 Evaluation

The following provides responses to an online evaluation form (collated on 7.11.15); please note a further reminder for completion will be sent on 10.11.15 to delegates.

Q1 Please indicate if you attended the conference as

Answered: 27 Skipped: 1



Answer Choices	Responses
a Professional Member of the CMRC	48.15% 13
a Student Member of the CMRC	3.70% 1
an Associate Member of the CMRC	25.93% 7
an Arthritis Research UK patient group representative	22.22% 6
Total	27

Q2 For Professional and Student Members only – what value do you feel participation in the conference will add/has added to you in your role?

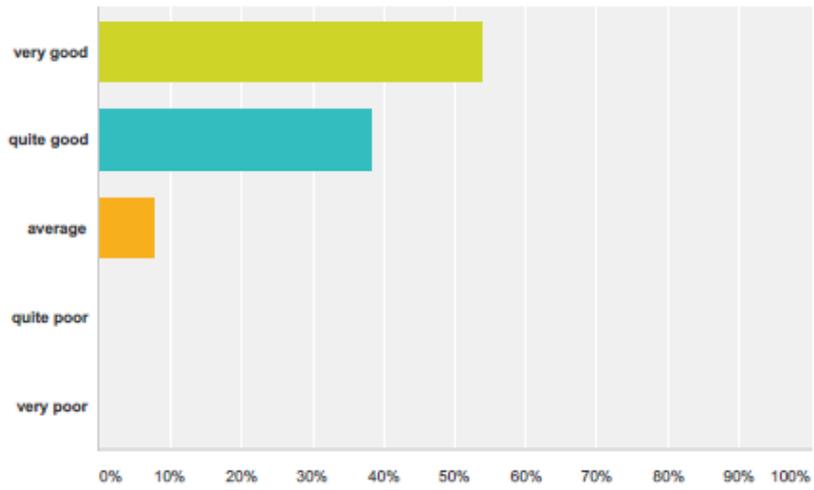
Answered: 13 Skipped: 15

- Generally it was good to hear talks from diverse areas of study. There were also some talks specific to my area of study that were very interesting indeed and provided some aspects to reflect on for future work
- Helps keep my perspective and understanding wide. With so few 'specialists' in this area, I find I can work in a 'silo' too easily. I need to keep in touch with the breadth of research and management nationally and internationally.
- Some useful research developments
- Networking

- The conference has allowed me to network with various people nationally and overseas. To gain experience in sharing otherwise detailed information in a clear manner to allow everyone to understand the pathology of CFS/ME. I have also gained a broad understanding of CFS/ME from listening to the presentations and viewing the posters.
- It was really useful to get a comprehensive picture of the advances, gaps and challenges in CFS/ME research.
- More knowledge about ongoing studies.
- Much better understanding of the wider research going on. Also motivated by meeting patients.
- It has supported me with new, scientific data which I can call upon to spread awareness of the disease and address further medical community. It also enabled me to create a bigger network.
- Meeting and networking with other researchers in the field and experts in other specialities which could benefit my own CFS/ME studies. Forming new research collaborations.
- The CMRC conference is of immense value for biomedical researchers in the field of CFS/ME. At the moment, each research team is searching for answers under their particular streetlamp. The CMRC conference is the only meeting point (in Europe, possibly globally) at which these teams come together to report their findings, and to generate ideas for future research and collaborations.
- Increased knowledge of what's going on in the field. Potential collaborations.
- Excellent networking opportunities.

Q3 How would you rate the conference overall?

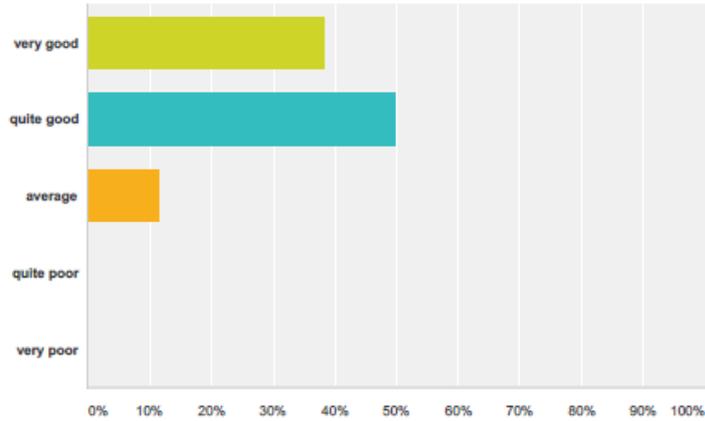
Answered: 26 Skipped: 2



Answer Choices	Responses
very good	53.85% 14
quite good	38.46% 10
average	7.69% 2
quite poor	0.00% 0
very poor	0.00% 0
Total Respondents: 26	

Q4 How would you rate the venue and facilities?

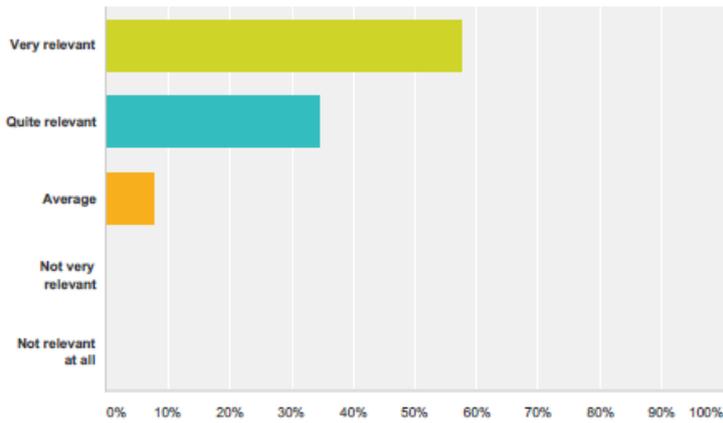
Answered: 26 Skipped: 2



Answer Choices	Responses	Count
very good	38.46%	10
quite good	50.00%	13
average	11.54%	3
quite poor	0.00%	0
very poor	0.00%	0
Total Respondents: 26		

Q5 How relevant was the conference for you and your personal/professional interests?

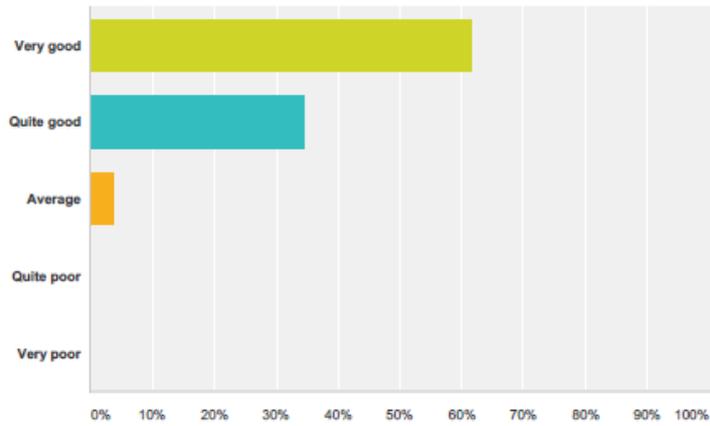
Answered: 26 Skipped: 2



Answer Choices	Responses	Count
Very relevant	57.69%	15
Quite relevant	34.62%	9
Average	7.69%	2
Not very relevant	0.00%	0
Not relevant at all	0.00%	0
Total		26

Q6 How would you rate the quality of the presentations?

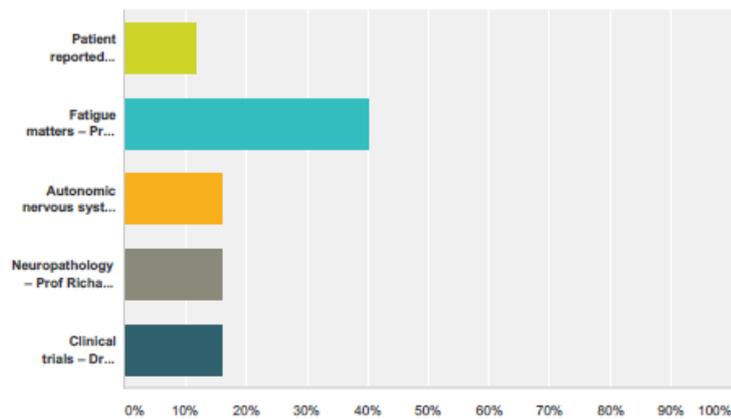
Answered: 26 Skipped: 2



Answer Choices	Responses	Count
Very good	61.54%	16
Quite good	34.62%	9
Average	3.85%	1
Quite poor	0.00%	0
Very poor	0.00%	0
Total		26

Q7 Which workshop did you attend?

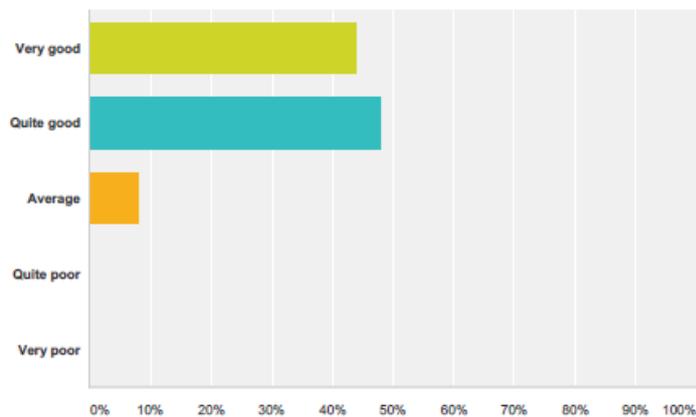
Answered: 25 Skipped: 3



Answer Choices	Responses	Count
Patient reported outcome measures - Dr Kirstie Haywood	12.00%	3
Fatigue matters – Prof Julia Newton and Chris Macdonald	40.00%	10
Autonomic nervous system – Dr James Frith	16.00%	4
Neuropathology – Prof Richard Reynolds	16.00%	4
Clinical trials – Dr Esther Crawley	16.00%	4
Total		25

Q8 How would you rate the workshop you attended?

Answered: 25 Skipped: 3



Answer Choices	Responses	Count
Very good	44.00%	11
Quite good	48.00%	12
Average	8.00%	2
Quite poor	0.00%	0
Very poor	0.00%	0
Total		25

Q9 What plenary sessions, presentations and workshops would you like to see at next year's CMRC conference?

Answered: 14 Skipped: 14

- As an immunologist, maybe a session on the immunology of CFS/ME??
- Any more insight into immuno-modulatory effect of anti-biotics and therefore their potential role in symptomatic treatment of CFS/ME??
- Continued focus on neuropathology and immunology; better clarity by presenters on which case definitions they're using (seemed clear some presenters using quite broad definitions while others using much narrower) -- we need to ensure we're talking about the same disease. mix of workshops for clinicians and researchers.
- Sorry to have missed the Montoya keynote speech this time - would it be possible to make available transcripts to Associate Members? Could we cover pain? Often major disabling symptom.
- Some concentration on how research can better engage with tackling the persisting major problems of misdiagnosis, delayed diagnosis and limited diagnostic consideration / investigation.
- Symptoms more important than labels; complimentary treatments; Caring for myself during a flareup.
- Patients' point of view. Maybe have a patient give a talk or deliver a workshop if they are well enough. Or do pre-recorded videos of them saying how much they appreciate the amount of research and time that is put into their condition.
- Maybe something on the challenges of conducting research on the most poorly patients.

- Development of fatigue through different illnesses.
- Perhaps some more consideration of the similarity of fatigue in ME and MA. More genetics....getting a plan together for a well powered GWAS.
- We definitely need more people stories - actual lives being positively impacted by the recent findings. Scientific facts are crucial, but we're losing quite a lot of impact by focusing just on the data. I enjoyed breaking the beat by social and PR presentations.
- Co-morbidity issues.
- Potential drug targets? A round-up for collaboration of all ongoing pharmaceutical management/treatment research?
- What psychology can offer to improving the lives of people with CFS.

Q10 Please share any additional comments or feedback you have about the conference.

Answered: 11 Skipped: 17

- Just to say thanks to the organisers. I really enjoyed the conference and it was very relevant to my work.
- Payment scheme was a bit confusing (what type of delegate one should be, if accommodation was provided on certain dates, etc.)
- Thank you for another great conference. So encouraging that collaborations are growing. Feels like M.E. might be beginning to come in from the cold.
- I have raised potential criticisms, but fully support the initiative and thank those who put in so much effort in leading it.
- I appreciate the invitation, respect the professionals and stay positive.
- A great opportunity to discuss fatigue problems with various professionals.
- Very well done, looking forward to next year.
- Refreshments to supply all attendees. Some of us travelled long distances.
- Keep up the good work. The atmosphere was positive, people welcoming and communicative.
- Please allow Associate Members to participate more fully in next year's conference. At least let us attend the dinner!
- My comments are a bit picky, I know, but thought I'd give feedback for ways of making the conference accessible and inclusive of people with M.E., which are just practicalities really. Really enjoyed the conference though, thanks.

Additional feedback sent via email

- Just a quick note of thanks to yourself and everyone involved in organising the ME/CFS meeting in Newcastle this week. I thought that the event was really well organised, was very friendly and generally went off very well indeed.
- I really enjoyed whole event and it has certainly given me some food for thought regarding my own work which I am currently reflecting on, and will discuss over the next few weeks with my local collaborators.
- As well as this, it was good to meet up with others with different areas of interest as well as getting a patient perspective which is very humbling.
- Congratulations to you and the committee for organising the conference. I thought the conference was excellent in quality, content and flow. There were, I'm sure, new insights for

many who attended, not least the news of the availability of the Gene (DNA) database for research. The need to produce common diagnostic criteria for research has often affected the value of research outcomes because of confounding factors, such as those referred to by Professor George Davey Smith.

- Researchers in the medical sciences and professions are gripped by the mystery of CFS/ME and the loss of function for those who are severely affected, knowing that the answers will also help those who are affected in a less severe or milder way.
- I do not take it lightly that I was privileged to attend the conference and I was proud to display my poster. Thank you for the opportunity to do so.
- Thanks for that, of course it's fine to pass on my email - I have had a couple of emails and one person in particular wants to collaborate on a research proposal. Will let you know what results from our discussions.
- An incredibly relevant and insightful conference. The best I've been to for developing my own learning but also for new collaborations and sharing insight.

Paper 2: Conference Summary Report

Title of Report	Conference Summary		
Date of Report	9 th September 2014	Date of Board Meeting	24 th September 2014
Author	Sonya Chowdhury, Action for M.E.		
Purpose/Scope	To provide a summary of key data and feedback from the conference to inform the debrief discussion		
Recommendations	N/A		

Key stats	
1	<p>The Headlines:</p> <ul style="list-style-type: none"> • 72 delegates on Monday of which 52 stayed overnight (2 delegates arrived without booking) and a further 6 stayed for dinner. • 68 delegates on Tuesday. • 1 researcher didn't attend as his cover for clinic cancelled at the last minute. • 58 people were booked for the Monday afternoon (incl. 2 facilitators, Sally & Sara). • Of the 56 booked participants, 12 did not attend due to ill-health. • 22 additional conference delegates joined the workshop on Monday afternoon bringing the total participants for the workshop to 66 (not incl. Sally - facilitator). • In addition to the three international speakers, we also had 2 delegates from The Netherlands (one was an MRC-funded guest and the other, her colleague). • Twitter: My tweets from the conference received 9,992 views with 149 retweets and 84 favourited. The Lipkin tweets were the most popular. Action for M.E. also tweeted but given high social media activity of the charity, it is not possible to easily break down statistics in the same way. • Facebook: Action for M.E. produced summaries at the beginning and end of each day on behalf of the CMRC. • 33 abstracts were accepted and presented.
Feedback	
2	<p>There has been considerable feedback given directly to members of the Board. Highlights include:</p> <ul style="list-style-type: none"> • "I genuinely think that the collaborative could lead in the development of good PPI and setting up consensus-based decision-making around PPI." (Professor) • "Just a line to congratulate you on an outstandingly good conference, in which Stephen Holgate was again an outstandingly good chairman...To my mind, research into ME has taken a major step forward and results will come in due course." (researcher) • "The overwhelming feedback I have encountered online from patients and those others who attended or who have reacted to the posted comments from Sonya, Charles and Professor Jonathan Edwards: have been very positive and welcoming." (person with M.E. who was unable to attend).

	<ul style="list-style-type: none"> • “Unfortunately I wasn't there, but from what has emerged since, the conference appears to have been a watershed for research in the UK, certainly in combination with the MRC-funded studies in progress. I've been ill for almost twenty years and research in the UK in that time has never looked remotely as dynamic or exciting as it does now. I hope that in a reasonable time this will lead to a greater understanding and better treatments for this illness. Patient reaction on social media and forums has generally been very positive to the conference. There has been a real buzz about the conference, both for the calibre of the presenters and the range of areas covered. I think many original doubters now appreciate the value of the CMRC (though inevitably not all!).” (person with M.E. who was unable to attend). • “The quality of science in the UK is exceptionally high. The conference is one of the best I have been to” (Professor). • “A very good conference with lots of fascinating science from people who were extremely self-critical and fielding good probing questions.” (Professor who attended the conference posting on an international forum).
Finance	
3	The invoice and final costs are awaited from the venue (due end of the month). There are some outstanding delegate fees that are being chased currently. MRC-funded presenters are submitting expenses at the time of writing this report. The budget will be reconciled once all these have been received.
4	An Associate Member has made a £25 donation to the CMRC and an Action for M.E. supporter has made a donation of £1,000 to Action for M.E. to contribute to the some of the cost of providing secretariat support to the CMRC.