

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 12

Date: 30/01/2020

Location: Holiday Inn London Regents Park

Minutes: Final

Committee members present:	
Peter Barry (Chair)	(Present for notes 1 – 4)
Theo Anbu	(Present for notes 1 – 4)
Joanne Bond-Kendall	(Present for notes 1 – 4)
Saran Bonser	(Present for notes 1 – 4)
Michael Beadsworth	(Present for notes 1 – 3b)
Sally Burch	(Present for notes 1 – 4)
Chris Burton	(Present for notes 1 – 3b)
Tony Crouch	(Present for notes 1 – 3b)
Jo Daniels	(Present for notes 1 – 4)
Dorinda Jack	(Present for notes 1 – 4)
Nicola Kidby	(Present for notes 1 – 4)
Caroline Kingdon	(Present for notes 1 – 4)
Adam Lowe	(Present for notes 1 – 4)
Jennifer McIntosh	(Present for notes 1 – 4)
Gabrielle Murphy	(Present for notes 1 – 3b)
Luis Nacul	(Present for notes 1 – 3b)
Alan Stanton	(Present for notes 1 – 4)
Susan Watson	(Present for notes 1 – 4)
William Weir	(Present for notes 1 – 4)
Charles Shepherd (co-optee)	(Present for notes 1 – 4)

In attendance:		
Kate Ashmore	NGC Project Manager	(Present for notes 1 – 4)
Richard Clubbe	NGC Research Fellow	(Present for notes 1 – 4)
Kate Kelley	NGC Guideline Lead	(Present for notes 1 – 4)
Maria Smyth	NGC Senior Research Fellow	(Present for notes 1 – 4)
Karin VanBart	NGC Trainee Systematic Reviewer	(Present for notes 1 – 4)
Melina Vasileiou	NGC Research Fellow	(Present for notes 1 – 4)
Rupert Franklin	NICE Senior Guideline Commissioning Manager	(Present for notes 1 – 4)
Simran Chawla	Public Involvement Advisor, NICE	(Present for notes 1 – 3a)
Kim Chapman	Clinical Trial Unit Operations Manager, Oxford Clinical Allied Technology and Trial Services Unit	(Present for notes 1 – 3a)
Professor Helen Dawes	Director Centre for Movement, Occupational and Rehabilitation Sciences, Oxford Clinical Allied Technology and Trial Services Unit	(Present for notes 1 – 3a)

Apologies:	
Ilora Finlay	Vice-Chair
David Wonderling	NGC Head of Health Economics

1. Welcome and objectives for the meeting
<p>The Chair welcomed the Committee members and attendees to the eleventh meeting of the ME/CFS guideline.</p> <p>The Chair informed the Committee that apologies had been received. These are noted above.</p>
2. Confirmation of matter under discussion, and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matters under discussion were:

- Children and young people with ME/CFS

The Chair asked everyone to verbally declare any interests that have arisen since the last meeting.

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Chris Burton	Professor of Primary Medical Care, University of Sheffield	<p>Membership of UK Functional Neurological Disorders Forum</p> <p>Publication – in press. "Functional somatic disorders: discussion paper for a new common classification for research and clinical use" (this does not mention ME/CFS directly and takes the position that a wide variety of disorders characterised by physical symptoms are due to complex causal mechanisms)</p>	<p>Direct – non-financial</p> <p>Direct – non-financial</p>	<p>No action taken</p> <p>No action taken</p>

The Chair and a senior member of the Developer's team noted that previous interests declared prevented Gabrielle Murphy and Luis Nacul from participating in discussions around exercise related therapies.

3. Presentations, questions and discussion

- a) Kim Chapman gave a presentation on the report on children and young people with ME/CFS produced by the Oxford Clinical Allied Technology and Trial Services Unit. She, along with Helen Dawes, then answered questions from the committee.

b) Maria Smyth and Melina Vasileiou reminded the committee of the evidence on children/young people with ME/CFS. The committee discussed.

4. Any other business

The Chair informed the committee that there would be an additional meeting date in April.

Date of next meeting: 17/03/2020

Location of next meeting: Holiday Inn, Regents Park