

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 11

Date: 29/01/2020

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 – 4)
Sally Burch		(Present for notes 1 – 4)
Chris Burton		(Present for notes 1 – 4)
Tony Crouch		(Present for notes 2 – 4)
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 – 4)
Luis Nacul		(Present for notes 1 – 4)
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)
David Wonderling	NGC Head of Health Economics	(Present for notes 1 – 4)
Rupert Franklin	NICE Senior Guideline Commissioning Manager	(Present for notes 1 – 4)
Sarah Catchpole	Senior Medical Editor, NICE	(Present for notes 1 – 4)
Simran Chawla	Public Involvement Advisor, NICE	(Present for notes 1 – 4)
Professor Aneez Esmail	University of Manchester Centre for Primary Care	(Present for note 3a, via phone)

Apologies:

Ilora Finlay	Vice-Chair
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1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the eleventh meeting of the ME/CFS guideline.

The Chair informed the Committee that apologies had been received. These are noted above.

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:

- People with severe 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
Charles Shepherd	Honorary Medical adviser, ME	Assisting Carol Monaghan MP	Direct – non-	No action taken

	Association	with the re-establishment of the All Party Parliamentary Group on ME at Westminster. Advising on the preparation of an APPG report that will cover aspects of ME/CFS that are also being discussed by the NICE guideline committee (i.e research, clinical trials, management, issues affecting children and adolescents)	financial		
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The Chair and a senior member of the Developer's team noted that the interests declared did not prevent the attendees from fully participating in the meeting.

3. Presentations, questions and discussion

- a) Kate Kelley gave a presentation on the report on people with severe ME/CFS produced by the University of Manchester Centre for Primary Care and Professor Esmail answered questions from the committee over the phone.
- b) Maria Smyth presented the evidence on people with severe ME/CFS as a reminder to the committee. The committee discussed.
- c) The committee drafted recommendation.

4. Any other business

None.

Date of next meeting: 30/01/2019

Location of next meeting: Holiday Inn, Regents Park

