

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 2

Date: 29/03/2019

Location: Diploma Suite, Holiday Inn London Bloomsbury

Minutes: Confirmed

Committee members present:		
Peter Barry (Chair)		(Present for notes 1 – 6)
Ilora Finlay (Vice-Chair)		(Present for notes 1 – 6)
Theo Anbu		(Present for notes 1 – 6)
Joanne Bond-Kendall		(Present for notes 1 – 6)
Saran Bonser		(Present for notes 1 – 6)
Sally Burch		(Present for notes 1 – 6)
Chris Burton		(Present for notes 1 – 6)
Tony Crouch		(Present for notes 1 – 6)
Jo Daniels		(Present for notes 1 – 6)
Dorinda Jack		(Present for notes 1 – 6)
Nicola Kidby		(Present for notes 1 – 6)
Caroline Kingdon		(Present for notes 1 – 6)
Adam Lowe		(Present for notes 1 – 6)
Jennifer McIntosh		(Present for notes 1 – 6)
Gabrielle Murphy		(Present for notes 1 – 6)
Luis Nacul		(Present for notes 1 – 6)
Alan Stanton		(Present for notes 1 – 6)
William Weir		(Present for notes 1 – 6)
Charles Shepherd (co-optee)		(Present for notes 1 – 6)

In attendance:		
Agnes Cuyas	NGC Information Specialist	(Present for notes 4 - 6)
Kate Kelley	NGC Guideline Lead	(Present for notes 1 – 6)
Amy Kelsey	NGC Senior Project	(Present for notes 1 – 6)

	Manager	
Mark Perry	NGC Senior Research Fellow	(Present for notes 1 – 6)
Maria Smyth	NGC Senior Research Fellow	(Present for notes 1 – 6)
Melina Vasileiou	NGC Research Fellow	(Present for notes 1 – 6)
David Wonderling	NGC Head of Health Economics	(Present for notes 1 – 6)
Rupert Franklin	NICE Senior Guideline Commissioning Manager	(Present for notes 1 – 6)
Ian Mather	NICE Resource and Impact Lead	(Present for notes 1 – 6)
Simran Chawla	NICE Patient and Public Involvement Adviser	(Present for notes 4 - 6)

Observers:

None.

Apologies:

Michael Beadsworth	Consultant in Infectious Diseases, Clinical Director Specialist and Academic Medicine, Clinical Lead CFS/ME Regional Services, Royal Liverpool University Hospital
Susan Watson	Senior Occupational Therapist, Leeds and West Yorkshire CFS/ME Service

1. Welcome and objectives for the meeting

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

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:

- Diagnostic criteria

- Barriers and facilitators to diagnosis
- Pre-diagnosis management strategies

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
Luis Nacul	GP	<p>Infrastructure and translational research in ME/CFS. Emerge Australia 2019 ME/CFS International Research Symposium, Geelong, Australia 12-15 March 2019.</p> <p>Medical director for the "Complex Chronic Diseases Program" at the BC Women's Hospital in Vancouver, Canada.</p>	<p>Direct, 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 the interests declared did not prevent the attendees from fully participating in the meeting.

3. Minutes of last meeting

The Chair asked the Committee if it wanted any changes made to the minutes of the last

meeting. The Committee agreed that the minutes were a true and accurate account of the meeting.

4. Presentations, questions and discussion

The Chair introduced Mark Perry, NGC Senior Research Fellow, who gave a presentation on the Diagnostic criteria evidence review. The committee discussed the evidence review and were given the opportunity to ask questions. The committee drafted 2 recommendations. The Chair thanked MP for his presentation.

The Committee discussed the following draft review protocols and were given the opportunity to ask questions.

- Barriers and facilitators to diagnose
- Pre-diagnosis management strategies

The Chair introduced David Wonderling, NGC Head of Health Economics, who gave a presentation on health economic prioritisation. The committee were given the opportunity to ask questions. The Chair thanked DW for his presentation.

The Chair introduced Ian Mather, NICE Resource and Impact Lead, who gave a presentation on resource impact assessment. The committee were given the opportunity to ask questions. The Chair thanked IM for his presentation

5. Other issues

Kate Kelley informed the committee that a call for evidence survey would be circulated.

6. Any other business

The Chair reminded the committee of the earlier start time and change of venue for the next committee meeting.

Date of next meeting: 20/05/2019

Location of next meeting: Holiday Inn Regents Park