

## Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 15

**Date:** 20/07/2020

**Location:** Video-conference

**Minutes:** Final

<b>Committee members present:</b>	
Peter Barry (Chair)	(Present for notes 1 – 4)
Ilora Finlay (Vice-chair)	(Present for notes 1 – 4)
Theo Anbu	(Present for notes 1 – 4)
Michael Beadsworth	(Present for notes 1 – 4)
Joanne Bond-Kendall	(Present for notes 1 – 4)
Saran Bonser	(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)
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)

<b>In attendance:</b>		
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 Research Fellow	(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)

**Apologies:**

Luis Nacul	GP
------------	----

**1. Welcome and objectives for the meeting**

The Chair welcomed the Committee members and attendees to the fifteenth 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:

- Information and support

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

Name	Job title, organisation	Declarations of Interest	Decision taken
Ilora Finlay	Hon Prof of Palliative Medicine, Cardiff University and Chair of National Mental Capacity Forum	Husband is doing research project into family impact of ME. No research grant, charitable or other funding involved. No involvement in the project.	No action other than the process of open declaration.
Caroline Kingdon	Research Nurse, London School of	Edited and contributed to Nina Muirhead's CPD module on	No action other than the process

	Hygiene and Tropical Medicine	CF/ME.	of open declaration.
		Part of a newly-formed group called Nurses for ME	No action other than the process of open declaration.
Charles Shepherd	Honorary Medical adviser, ME Association	Statement published on the ME Association website in response to the NICE statement on Graded Exercise Therapy in the context of COVID-19.	Excluded from all further discussions on Graded Exercise Therapy.
Michael Beadsworth	Consultant in Infectious Diseases, Clinical Director Specialist and Academic Medicine, Clinical Lead CFS/ME Regional Services, Royal Liverpool University Hospital	Submitted research study follow up Covid-19 for fatigue. Will be a co-investigator, being led by Glasgow as part of ISARIC.	No action other than the process of open declaration.
Chris Burton	Professor of Primary Medical Care, University of Sheffield	Currently planning research study examining fatigue and other symptoms post covid19 infection.	No action other than the process of open declaration.

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) The committee discussed and made amendments to the recommendations on information and support.

**4. Any other business**

None.

**Date of next meeting:** 24/07/2020

**Location of next meeting:** Video-conference