

# Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 21

**Date:** 01/03/2021

**Location:** Video-conference

Minutes: Final

Committee members present:		
Peter Barry (Chair)	(Present for notes 1 – 4)	
Ilora Finlay (Vice-chair)	(Present for notes 3a – 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 1 – 4)	
Jo Daniels	(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)	
Gabrielle Murphy	(Present for notes 1 – 4)	
Alan Stanton	(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)
Kate Kelley	NGC Guideline Lead	(Present for notes 1 – 4)
Karin VanBart	NGC Research Fellow	(Present for notes 1 – 4)
Melina Vasileiou	NGC Senior 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	NICE Senior Medical Editor	(Present for notes 1 – 4)
Ian Mather	NICE Business Analyst	(Present for notes 1 – 4)

Apologies:	
Theo Anbu	Consultant General Paediatrician and lead for Paediatric CFS/ME, Alder Hey Children's NHS Foundation Trust, Liverpool
Dorinda Jack	Lay member
Jennifer McIntosh	Senior Specialist Dietician, Mill Lodge CAMHS, Leeds and York Partnership NHS Foundation Trust
Luis Nacul	GP
Susan Watson	Team Manager, York and Selby IAPT, Tees Esk and Wear Valleys NHS Foundation Trust.

## 1. Welcome and objectives for the meeting

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

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

#### 2. Declarations of interest

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
Jo Bond- Kendall	Senior Physiotherapist, Specialist Paediatric CFS/ME, Bath	Invited to talk on Physical activity / exercise for Children and young people with ME/CFS, at UCL; MSc Physiotherapy course.	No action other than the process of open declaration
Jo	Senior Lecturer in Clinical	Paper published: Fanous, M.	No action other

Daniels	Psychology, University of Bath, Chartered Clinical Psychologist, North Bristol NHS Trust	Rynincks, K & Daniels, J. (2020) Staff perceptions of the short health anxiety inventory in CFS/ME specialist clinic. The Cognitive Behaviour Therapist, 13 (e52) doi.org/10.1017/S1754470X20000525	than the process of open declaration
Ilora Finlay	Hon Prof of Palliative Medicine, Cardiff University and Chair of National Mental Capacity Forum	On the All Party Parliamentary Group on Coronavirus which took evidence on Long Covid but I stepped back from the evidence taking and did not having anything to do with the correspondence either to the press or Prime Minister.	No action other than the process of open declaration

The Chair and a senior member of the Developer's team noted that previous interests declared did not prevent the attendees from fully participating in the meeting.

## 3. Presentations, questions and discussion

- a) Kate Kelley presented an overview of the stakeholder comments received during consultation.
- b) The committee reviewed and discussed recommendations on baseline tests, training, rest and sleep, and pain.

### 4. Any other business

None.

Date of next meeting: 05/03/21