

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 26

Date: 22/03/2021

Location: Video-conference

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)
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)
Jennifer McIntosh	(Present for notes 1 – 4)
Gabrielle Murphy	(Present for notes 1 – 4)
William Weir	(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)
Sarah Catchpole	NICE Senior Medical Editor	(Present for notes 1 – 4)
Rupert Franklin	NICE Senior Guideline	(Present for notes 1 – 4)

	Commissioning Manager	
Ian Mather	NICE Business Analyst	(Present for notes 1 – 4)

Apologies:	
Michael Beadsworth	Consultant in Infectious Diseases, Clinical Director Specialist and Academic Medicine, Clinical Lead CFS/ME Regional Services, Royal Liverpool University Hospital
Ilorra Finlay	Hon Prof of Palliative Medicine, Cardiff University and Chair of National Mental Capacity Forum
Dorinda Jack	Lay member
Luis Nacul	GP
Alan Stanton	Consultant Community Paediatrician, University Hospitals, Birmingham
Susan Watson	Team Manager, York and Selby IAPT, Tees Esk and Wear Valleys NHS Foundation Trust.

1. Welcome and objectives for the meeting
<p>The Chair welcomed the Committee members and attendees to the twenty sixth meeting of the ME/CFS guideline.</p> <p>The Chair informed the Committee that apologies had been received for this meeting. These are noted above.</p>
2. Declarations of interest
<p>The Chair asked everyone to verbally declare any interests that have arisen since the last meeting. There were no new interests to be declared. 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.</p>
3. Presentations, questions and discussion
<p>a) The committee reviewed and discussed stakeholder comments and recommendations on care for people with severe or very severe ME/CFS.</p> <p>b) The committee reviewed and discussed stakeholder comments and recommendations on investigations to carry out if ME/CFS is suspected in order to exclude other diagnoses.</p>

- c) The committee reviewed and discussed stakeholder comments and recommendations on orthostatic intolerance.
- d) The committee reviewed and discussed stakeholder comments and recommendations on assessment and care planning by a specialist ME/CFS team.
- e) The committee reviewed and discussed stakeholder comments and recommendations on multidisciplinary teams.

4. Any other business

None.

Date of next meeting: 19/04/21