

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 19

Date: 10/08/2020
Location: Video-conference
Minutes: Final

Committee members present:	
Peter Barry (Chair)	(Present for notes 1 – 4)
Ilora Finlay (Vice-chair)	(Present for notes 1 – 4)
Theo Anbu	(Present for notes 1 – 3j)
Michael Beadsworth	(Present for notes 1 – 3d)
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)
Dorinda Jack	(Present for notes 1 – 4)
Nicola Kidby	(Present for notes 1 – 4)
Caroline Kingdon	(Present for notes 1 – 3d)
Adam Lowe	(Present for notes 1 – 4)
Luis Nacul	(Present for notes 3b and 3j – 4)
Jennifer McIntosh	(Present for notes 1 – 4)
Gabrielle Murphy	(Present for notes 1 – 3c and 3e – 3j)
Alan Stanton	(Present for notes 1 – 3c)
Susan Watson	(Present for notes 1 – 4)
William Weir	(Present for notes 1 – 4)
Charles Shepherd (co-optee)	(Present for notes 1 – 3c and 3e – 3j)

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 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)
Joanna Perkin	Pathways Editor, NICE	(Present for notes 1 – 3a)

1. Welcome and objectives for the meeting

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

The Chair informed the Committee that no apologies had been received for this meeting.

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:

- Cognitive behavioural therapy
- Activity management
- Sleep
- Orthostatic intolerance
- Pain
- Nausea
- Medicines management

- Treatments

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
Charles Shepherd	Honorary Medical adviser, ME Association	<p>Interview with a journalist from the Independent on the new draft guideline from NICE on the management of primary chronic pain</p> <p>Letter to Professor Chris Whitty (DoH) and Professor Stephen Powis (NHS England) regarding concerns about the new management advice from NHS England for fatigue in post COVID syndrome. The MEA letter has been followed up by the Daily Telegraph and Sean O’Neil, Chief Reporter at The Times. MEA website link to letter: https://meassociation.org.uk/2020/08/mea-statement-nhs-england-guidance-on-the-management-of-post-covid-fatigue-syndromes/</p>	<p>No action other than the process of open declaration.</p> <p>Will already step out for discussions on activity management.</p>

The Chair and a senior member of the Developer’s team noted that previous interests declared meant that Luis Nacul would step out for discussions on CBT and activity management, and Charles Shepherd and Gabrielle Murphy would step out for discussions on activity management.

3. Presentations, questions and discussion

- Joanna Perkin gave a presentation on NICE pathways.
- David Wonderling gave an update on health economics.
- The committee discussed and drafted recommendations on CBT.
- The committee discussed and drafted recommendations on activity management.
- The committee discussed and drafted recommendations on sleep.
- The committee discussed and drafted recommendations on orthostatic intolerance.
- The committee discussed and drafted recommendations on pain.

- h) The committee discussed and drafted recommendations on nausea.
- i) The committee discussed and drafted recommendations on medicines management.
- j) The committee discussed and drafted recommendations on treatments.

4. Any other business

None.

Date of next meeting: 14/08/2020

Location of next meeting: Video-conference