

## Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 5

**Date:** 05/09/2019

**Location:** Trinity room, Holiday Inn London Regents Park

**Minutes:** Final

<b>Committee members present:</b>	
Peter Barry (Chair)	(Present for notes 1 – 6)
Michael Beadsworth	(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 4c – 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 4b – 6)
Susan Watson	(Present for notes 1 – 6)
Charles Shepherd (co-optee)	(Present for notes 1 – 6)

<b>In attendance:</b>		
Kate Ashmore	NGC Project Manager	(Present for notes 1 – 6)
Richard Clubbe	NGC Research Fellow	(Present for notes 4 – 6)
Jonathan Edwards	Expert Witness	(Present for note 4c)

Kate Kelley	NGC Guideline Lead	(Present for notes 1 – 6)
Maria Smyth	NGC Senior Research Fellow	(Present for notes 1 – 6)
Karin VanBart	NGC Trainee Systematic Reviewer	(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 4 – 6)
Simran Chawla	Public Involvement Advisor	(Present for notes 4 – 6)

### **Apologies:**

Theo Anbu	Consultant General Paediatrician and Lead for Paediatric CFS/ME, Alder Hey Children's NHS Foundation Trust, Liverpool
Ilorra Finlay (Vice-Chair)	Hon Prof of Palliative Medicine, Cardiff University and Chair of National Mental Capacity Forum
William Weir	Consultant Physician, London

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

The Chair welcomed the Committee members and attendees to the fifth 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 asked everyone to verbally declare any interests that have arisen since the last meeting. There were no new declarations of interest.

### **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**

- a) The Committee discussed the following draft review protocols and were given the opportunity to ask questions.
- Information, education and support for healthcare professionals
  - Information, education and support for patients
  - Experiences of people receiving interventions for ME/CFS
  - Barriers and facilitators to care
  - Barriers and facilitators to providing information
- b) Kate Kelley, NGC Guideline Lead, gave a presentation on understanding analysis and quality assessment. The committee discussed the presentation and were given the opportunity to ask questions. The Chair thanked KK for her presentation.
- c) The Chair introduced Jonathan Edwards, expert witness, who gave a presentation on the difficulties of conducting intervention trials for the treatment of ME/CFS. The committee discussed the presentation and were given the opportunity to ask questions. The Chair thanked JE for his presentation.
- d) Kate Kelley, NGC Guideline Lead, gave a presentation on the pharmacological interventions evidence review. The committee discussed the evidence review and were given the opportunity to ask questions.

**6. Any other business**

None.

**Date of next meeting:** 06/09/2019

**Location of next meeting:** Holiday Inn Regents Park