

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 22

Date: 05/03/2021
Location: Video-conference
Minutes: Final

Committee members present:	
Peter Barry (Chair)	(Present for notes 1 – 4)
Ilora Finlay (Vice-chair)	(Present for notes 1 – 3d)
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 3b – 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)
Gabrielle Murphy	(Present for notes 1 – 3d)
Luis Nacul	(Present for notes 3a – 3d)
Alan Stanton	(Present for notes 3c – 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 – 3c)
Melina Vasileiou	NGC Senior Research Fellow	(Present for notes 3c – 4)
David Wonderling	NGC Head of Health Economics	(Present for notes 1 – 4)
Rupert Franklin	NICE Senior Guideline Commissioning Manager	(Present for notes 1 – 3c, 3e - 4)
Sarah Catchpole	NICE Senior Medical Editor	(Present for notes 1 – 4)
Simran Chawla	NICE Public Involvement Advisor	(Present for notes 1 – 3c, 3e - 4)
Ian Mather	NICE Business Analyst	(Present for notes 1 – 3c)

Apologies:

Michael Beadsworth	Consultant in Infectious Diseases, Clinical Director Specialist and Academic Medicine, Clinical Lead CFS/ME Regional Services, Royal Liverpool University Hospital
Jennifer McIntosh	Senior Specialist Dietician, Mill Lodge CAMHS, Leeds and York Partnership NHS Foundation Trust
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 second 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
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Charles Shepherd	Honorary Medical adviser, ME Association	Advocacy work to try and make sure that people with ME/CFS can be vaccinated against Covid-19 through inclusion in JCVI group 6 on the basis that they have an underlying health condition that is likely to be exacerbated by Covid-19. This has involved media input including an item in The Times and an interview for BBC News last week and correspondence with the JCVI, CMO - Professor Chris Whitty, various health boards and CCGs and parliamentary colleagues.	No action other than the process of open declaration
Theo Anbu	Consultant General Paediatrician and lead for Paediatric CFS/ME, Alder Hey Children's NHS Foundation Trust, Liverpool	Appointed as the paediatrician in the BNFC Paediatric Formulary Committee on a voluntary basis. Clinical lead for CYP long COVID clinic for Cheshire&Merseyside, Lancaster and South Cumbria region as part of the North West Coastal Network. This is a new service and has special funding for Feb 2021 and March 2021 and possibly for the next financial year.	No action other than the process of open declaration No action other than the process of open declaration
Luis Nacul	GP	Papers: Systematic Review of the Epidemiological Burden of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Across Europe: Current Evidence and EUROMENE Research Recommendations for Epidemiology	No action other than the process of open declaration

		<p>J Clin Med. 2020 May; 9(5): 1557</p> <p>Review of the Quality Control Checks Performed by Current Genome-Wide and Targeted-Genome Association Studies on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Front Pediatr. 2020; 8: 293</p> <p>Health Care Responsibility and Compassion-Visiting the Housebound Patient Severely Affected by ME/CFS. Healthcare (Basel) 2020 Sep; 8(3): 197. Published online 2020 Jul 4. doi: 10.3390/healthcare8030197.</p> <p>E.EUROPEAN ME NETWORK (EUROMENE) Expert Consensus on the Diagnosis, Service Provision and Care of People with ME/CFS in Europe. Preprints 2020, 2020090688 (as a member of EUROMENE)</p>		
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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) The committee reviewed and discussed stakeholder comments and recommendations on suspecting and diagnosing ME/CFS.
- b) The committee reviewed and discussed stakeholder comments and recommendations on time to make a diagnosis of ME/CFS.
- c) The committee reviewed and discussed stakeholder comments on indirectness in GRADE ratings.
- d) The committee reviewed and discussed stakeholder comments and recommendations on diagnostic criteria and symptoms of ME/CFS.
- e) The committee reviewed and discussed stakeholder comments and recommendations on awareness of ME/CFS.

4. Any other business

None.

Date of next meeting: 08/03/21