

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 8

Date: 23/10/2019

Location: Holiday Inn London Regents Park

Minutes: Confirmed

Committee members present:	
Peter Barry (Chair)	(Present for notes 1 – 4)
Ilora Finlay (Vice-Chair)	(Present for notes 1 – 3c)
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)
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)
Jennifer McIntosh	(Present for notes 1 – 4)
Gabrielle Murphy	(Present for notes 1 – 4)
Luis Nacul (via skype)	(Present for notes 3b-3c)
Alan Stanton	(Present for notes 1 – 4)
Susan Watson	(Present for notes 1 – 4)
William Weir	(Present for notes 1 – 4)
Charles Shepherd (co-optee)	(Present for notes 1 – 3b)

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)
Nina Muirhead	Expert Witness	(Present for note 3b)
Norma O’Flynn	NGC Chief Operating Officer	(Present for notes 3b – 4)
Maria Smyth	NGC Senior Research Fellow	(Present for notes 1 – 4)
Karin VanBart	NGC Trainee Systematic Reviewer	(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)

Apologies:

Michael Beadsworth	Consultant in Infectious Diseases, Clinical Director Specialist and Academic Medicine, Clinical Lead CFS/ME Regional Services, Royal Liverpool University Hospital
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1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the eighth 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 confirmed that, for the purpose of managing conflicts of interest, the matters under discussion were:

- Information, education and support for health and social care professionals providing care for people with ME/CFS
- Non-pharmacological interventions

The Chair asked everyone to verbally declare any interests that have arisen since the last meeting.

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Caroline Kingdon	Research Nurse, London School of Hygiene and Tropical Medicine	Cliff, Jacqueline M; King, Elizabeth C; Lee, Ji-Sook; Sepúlveda, Nuno; Wolf, Asia-Sophia; Kingdon, Caroline; Bowman, Erinna; Dockrell, Hazel M; Nacul, Luis; Lacerda, Eliana; +1 more... (2019) Cellular immune function in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). <i>Frontiers in Immunology</i>	Direct Non-financial	No action taken
		Nacul, Luis; de Barros, Barbara; Kingdon, Caroline C; Cliff, Jacqueline M; Clark, Taane G; Mudie, Kathleen; Dockrell, Hazel M; Lacerda, Eliana M; (2019) Evidence of Clinical Pathology Abnormalities in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) from an Analytic Cross-Sectional Study. <i>Diagnostics (Basel, Switzerland)</i> , 9 (2). p. 41. ISSN 2075-4418	Direct Non-financial	No action taken
		Lacerda, Eliana M; McDermott, Clare; Kingdon, Caroline C; Butterworth, Jack; Cliff, Jacqueline M; Nacul, Luis; (2019) Hope, disappointment and perseverance: Reflections of people with Myalgic encephalomyelitis/Chronic	Direct Non-financial	No action taken

Luis Nacul	GP	<p>Fatigue Syndrome (ME/CFS) and Multiple Sclerosis participating in biomedical research. A qualitative focus group study. Health expectations. ISSN 1369-7625</p> <p>Submitted for publication: Nacul, L.; O'Boyle, S.; Nacul, F.E.; Mudie, K.; Kingdon, C.C.; Cliff, J.M.; Clark, T.G.; Dockrell, H.M.; Lacerda, E.M. How Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) Progresses: A Framework for Research and the Prevention, Treatment, and Rehabilitation in ME/CFS. <i>Preprints</i> 2019, 2019090188</p> <p>Cliff Jacqueline M., King Elizabeth C., Lee Ji-Sook, Sepúlveda Nuno, Wolf Asia-Sophia, Kingdon Caroline, Bowman Erinna, Dockrell Hazel M., Nacul Luis, Lacerda Eliana, Riley Eleanor M. Cellular Immune Function in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). <i>Frontiers in Immunology</i> 2019.</p> <p>Nacul L, de Barros B, Kingdon CC, Cliff JM, Clark TG⁵, Mudie K, Dockrell HM, Lacerda EM. Evidence of Clinical Pathology Abnormalities in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) from an Analytic Cross-Sectional Study. <i>Diagnostics (Basel)</i>. 2019 Apr 10;9(2). pii: E41.</p> <p>Eliana M. Lacerda, Clare McDermott, Caroline C.</p>	<p>Direct Non-financial</p> <p>Direct Non-financial</p> <p>Direct Non-financial</p> <p>Direct Non-</p>	<p>Declare and withdraw from drafting research recommendations.</p> <p>No action taken</p> <p>No action taken</p>	
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		<p>Friedberg F, Sunnquist MA, Nacul L. Rethinking the standard of care for Myalgic encephalomyelitis/ chronic fatigue syndrome. J GEN INTERN MED DOI 10.1007/s11606-019-05375-y. ISSN 0884-8734</p>	Direct Non-financial	Declare and withdraw from drafting recommendations on the non-pharmacological management of ME/CFS	
		<p>Research grant: Interdisciplinary Canadian Collaborative ME Research Network. Canadian Institutes of Health Research. Total CAD\$ 1.4 Million (co-PI)</p>	Direct, financial	Declare and withdraw from drafting research recommendations.	
		<p>Research grant: Biobanks, Big Data and ME: establishing a global registry and biobank in Australia to drive discovery of blood biomarkers. Judith Jane Mason & Harold Stannet Williams Memorial Foundation ('The Mason foundation') total Aus\$1,030,000. (Co-investigator)</p>	Direct, financial	Declare and withdraw from drafting research recommendations.	
		<p>European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE) (funded by European Cooperation in Science and Technology. COST Action CA 15111.</p>	Direct Non-financial	Declare and withdraw from drafting research recommendations.	

		<p>Management Committee (UK Substitute Member) Working Group 4 - Working group on clinical research enablers and diagnostic criteria (Vice-chair)</p> <p>Nacul, L.; O'Boyle, S.; Nacul, F.E.; Mudie, K.; Kingdon, C.C.; Cliff, J.M.; Clark, T.G.; Dockrell, H.M.; Lacerda, E.M. How Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) Progresses: A Framework for Research and the Prevention, Treatment, and Rehabilitation in ME/CFS. Preprints 2019, 2019090188</p> <p>Lucas S Rodrigues, Luiz H da Silva Nali, Cibele O D Leal, Ester C Sabino, Eliana M Lacerda, Caroline C Kingdon, Luis Nacul, Camila M Romano. HERV-K and HERV-W transcriptional activity in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome bioRxiv 693465</p> <p>Eliana M. Lacerda, Keith Geraghty, Caroline C. Kingdon, Luigi Palla, Luis Nacul. A Logistic Regression Analysis of Risk Factors in ME/CFS Pathogenesis (BMC Neurology accepted)</p>	<p>Direct Non-financial</p> <p>Direct Non-financial</p> <p>Direct Non-financial</p>	<p>Declare and withdraw from drafting research recommendations.</p> <p>No action taken</p> <p>No action taken</p>
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The Chair and a senior member of the Developer's team noted that previous interests declared prevented Charles Shepherd from participating in discussions on recommendations for information, education and support for health and social care professionals providing care for people with ME/CFS and Luis Nacul, Gabrielle Murphy and Charles Shepherd from participating in discussions on recommendations for non-pharmacological interventions.

3. Presentations, questions and discussion

- a) The committee reviewed the draft recommendations for the information, education and support for health and social care professionals evidence review.
- b) The committee discussed the evidence review for non-pharmacological interventions.
- c) David Wonderling presented the health economic analysis for cognitive behavioural therapy.
- d) The committee discussed recommendations for cognitive behavioural therapy.
- e) David Wonderling presented the health economic analysis for graded exercise therapy.

4. Any other business

None.

Date of next meeting: 10/12/2019

Location of next meeting: Holiday Inn, Regents Park