

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 14

Date: 13/07/2020

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 – 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 2 – 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) |
| Susan Watson | | (Present for notes 1 – 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) |
| 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) |

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|------------------|---|---------------------------|
| David Wonderling | NGC Head of Health Economics | (Present for notes 1 – 4) |
| Rupert Franklin | NICE Senior Guideline Commissioning Manager | (Present for notes 1 – 4) |
| Simran Chawla | Public Involvement Advisor, NICE | (Present for notes 1 – 4) |

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| Apologies: | |
| Michael Beadsworth | Consultant in Infectious Diseases, Clinical Director Specialist and Academic Medicine, Clinical Lead CFS/ME Regional Services, Royal Liverpool University Hospital |
| Dorinda Jack | Lay member |
| Luis Nacul | GP |
| Alan Stanton | Consultant Community Paediatrician, University Hospitals, Birmingham |

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the fourteenth 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:

- Monitoring and review

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 |
|------------|--|---|---|
| Jo Daniels | Senior Lecturer in Clinical Psychology, University of Bath, Chartered Clinical Psychologist, | Article – Why reassuring the public may not be the best way to end lockdown. https://www.kcl.ac.uk/news/why-reassuring-the-public-may-not-be-the-best-way-to-end- | No action other than the process of open declaration. |

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|------------------|--|---|---|--|
| Theo Anbu | North Bristol NHS Trust Consultant General Paediatrician and lead for Paediatric CFS/ME, Alder Hey Children's NHS Foundation Trust, Liverpool | lockdown British Association for CFS/ME (BACME) - Post-Viral Fatigue Guideline | No action other than the process of open declaration. | |
| Caroline Kingdon | Research Nurse, London School of Hygiene and Tropical Medicine | Paper: Health Care Responsibility and Compassion-Visiting the Housebound Patient Severely Affected by ME/CFS https://www.mdpi.com/2227-9032/8/3/197/pdf | No action other than the process of open declaration. | |
| Charles Shepherd | Honorary Medical adviser, ME Association | Contributed to a video made with a Wellcome Trust medical education grant: http://www.dialogues-mecfs.co.uk/films/severeme/ | No action other than the process of open declaration. | |
| Luis Nacul | GP | Contributed to a video made with a Wellcome Trust medical education grant: http://www.dialogues-mecfs.co.uk/films/severeme/ | No action other than the process of open declaration. | |
| William Weir | Consultant Physician, London | Contributed to a video made with a Wellcome Trust medical education grant: http://www.dialogues-mecfs.co.uk/films/severeme/ | No action other than the process of open declaration. | |

The Chair and a senior member of the Developer's team noted that the interests declared did not prevent the attendees from fully participating in the meeting.

3. Presentations, questions and discussion

- a) The committee were informed of the new timeline for this guideline.
- b) The committee were informed that NICE have put out a statement about graded exercise therapy in the context of COVID-19.
- c) Karin VanBart presented the monitoring review evidence report. Kate Kelley presented the feedback in this area from the severe ME/CFS sub-group. The committee discussed and drafted recommendation.

4. Any other business

None.

Date of next meeting: 20/07/2020

Location of next meeting: Video-conference