

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 10

Date: 11/12/2019

Location: Holiday Inn London Regents Park

Minutes: Confirmed

| Committee members present: | |
|-----------------------------------|----------------------------|
| Peter Barry (Chair) | (Present for notes 3b – 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) |
| Michael Beadsworth | (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 – 3b) |
| Dorinda Jack | (Present for notes 1 – 4) |
| Nicola Kidby | (Present for notes 1 – 3a) |
| 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 3b – 4) |
| Alan Stanton | (Present for notes 1 – 4) |
| Susan Watson | (Present for notes 1 – 3b) |
| 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) |
| 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 – 3a) |
| 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: | |
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| Luis Nacul (The Chair and senior member of the Developer's team requested LM did not attend meeting due to conflicts of interests preventing participation in discussions on recommendations for non-pharmacological interventions.) | GP |

| 1. Welcome and objectives for the meeting |
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| <p>The Vice-Chair welcomed the Committee members and attendees to the tenth meeting of the ME/CFS guideline.</p> <p>The Vice-Chair informed the Committee that apologies had been received. These are noted above.</p> |
| 2. Confirmation of matter under discussion, and declarations of interest |

The Vice-Chair confirmed that, for the purpose of managing conflicts of interest, the matters under discussion were:

- Non-pharmacological interventions
- Experiences of people who have had interventions for ME/CFS
- Precautionary management strategies

The Vice-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 |
|------------------|--|---|----------------------|------------------|
| Charles Shepherd | Honorary Medical adviser, ME Association | In my capacity as Medical Adviser to the ME Association, where I supervise all research grant applications to the MEA Ramsay Research Fund and the progress of research that is being funded, the RRF has awarded a grant of £25,000 to Dr Keith Geraghty and colleagues at the University of Manchester to carry out a patient questionnaire study relating to pre-diagnosis clinical assessment and management of ME/CFS. We are hoping that some of the preliminary information will be in a format that could be made available to NICE in 2020 if there is | Direct Non-financial | No action taken. |

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| | | still time to submit it. | | |
| <p>The Vice-Chair and a senior member of the Developer’s team noted that previous interests declared prevented Gabrielle Murphy from participating in discussions on recommendations for non-pharmacological interventions.</p> | | | | |
| <p>3. Presentations, questions and discussion</p> | | | | |
| <p>a) The committee reviewed the draft recommendations for the non-pharmacological interventions evidence review.</p> <p>b) The committee discussed and drafted recommendations for the experiences of people who have had interventions for ME/CFS evidence review.</p> <p>c) The committee discussed and drafted recommendations for the precautionary management strategies evidence review.</p> | | | | |
| <p>4. Any other business</p> | | | | |
| <p>The committee were informed that two additional meeting dates had been scheduled: 17th & 18th March 2020.</p> | | | | |

Date of next meeting: 29/01/2020

Location of next meeting: Holiday Inn, Regents Park