

Myalgic encephalomyelitis (or encephalopathy)/Chronic fatigue syndrome (ME/CFS) Committee meeting 4

Date: 08/07/2019

Location: Trinity room, Holiday Inn London Regents Park

Minutes: Final

| Committee members present: | |
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| Peter Barry (Chair) | (Present for notes 1 – 6) |
| Ilora Finlay (Vice-Chair) | (Present for notes 1 – 6) |
| Theo Anbu | (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 1 – 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 1 – 6) |
| Susan Watson | (Present for notes 1 – 6) |
| William Weir | (Present for notes 1 – 6) |
| Charles Shepherd (co-optee) | (Present for notes 1 – 6) |

| In attendance: | | |
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| Agnes Cuyas | NGC Information Specialist | (Present for notes 4 – 6) |

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| Kate Kelley | NGC Guideline Lead | (Present for notes 1 – 6) |
| Amy Kelsey | NGC Senior Project Manager | (Present for notes 1 – 6) |
| Mark Perry | NGC Senior Research Fellow | (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) |
| David Wonderling | NGC Head of Health Economics | (Present for notes 1 – 6) |
| Rupert Franklin | NICE Senior Guideline Commissioning Manager | (Present for notes 1 – 6) |
| Sarah Catchpole | NICE Senior Medical Editor | (Present for notes 1 – 4) |

Observers:

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| Kate Ashmore | NGC Project Manager |
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Apologies:

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| Melina Vasileiou | NGC Research Fellow |
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1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the fourth meeting of the ME/CFS guideline. The Committee members and attendees introduced themselves.

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:

- Barriers and facilitators to diagnosis
- Monitoring and review

- Multidisciplinary care
- Pharmacological interventions
- Non-pharmacological interventions

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

The Chair introduced David Wonderling, NGC Head of Health Economics, who presented the results of the Health Economic prioritisation exercise. The committee discussed the results and were given the opportunity to ask questions. The Chair thanked DW for his presentation.

The Chair Sarah Catchpole, NICE Editor, who gave a presentation on the role of the NICE editor in guideline development. The committee discussed the presentation and were given the opportunity to ask questions. The Chair thanked SC for her presentation.

The Chair introduced Maria Smyth, NGC Senior Research Fellow, who gave a presentation on an introduction to qualitative methods. The Chair then introduced Mark Perry, NGC Senior Research Fellow, who gave a presentation on the Barriers and facilitators to diagnosis evidence review. The committee discussed the evidence review and were given the opportunity to ask questions. The committee drafted recommendations. The Chair thanked MS and MP for their presentations.

The Committee discussed and made further edits to the draft Diagnostic criteria recommendations.

The Committee discussed the following draft review protocols and were given the opportunity to ask questions.

- Monitoring and review
- Multidisciplinary care

5. Other issues

Kate Kelley discussed the call for evidence survey results with the committee and updated

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| them on the focus groups. |
| 6. Any other business |
| None. |

Date of next meeting: 05&06/09/2019

Location of next meeting: Holiday Inn Regents Park