

Date and Time: Tuesday 24 June 2014, 10am-4pm

Minutes: Confirmed

Guideline Development Group Meeting 3

Place: NCGC, 180 Great Portland Street, London, W1W 5QZ

Present:

David Oliver	Consultant in palliative medicine and Medical director, Wisdom Hospice
Liz Avital	Associate director, NCGC
Katie Jones	Senior project manager, NCGC
Julie Neilson	Senior research fellow, NCGC
Caroline Farmer	Research fellow, NCGC
Elisabetta Fenu	Health economic lead, NCGC
Edward Griffin	Health economist, NCGC
Katie Broomfield	Document editor/process assistant, NCGC
Jean Waters	Patient/carer member
Sandra Smith	Patient/carer member
Roch Mayer	Patient/carer member
Steven Bloch	Lecturer & faculty of brain sciences graduate tutor, London
Julie Brignall-Morley	Community matron in Neurological conditions, Yorkshire
Jennifer Rolfe	MND Specialist occupational therapist, Oxford
Caroline Brown	Principal physiotherapist in Emergency, Cardiothoracic and Specialised medicine, Staffordshire
Chris McDermott	Consultant neurologist, Sheffield
Aleksander Radunovic	Consultant neurologist, London
Annette Edwards	Consultant in palliative care medicine, Leeds
Rachael Marsden	MND Care centre coordinator and Advanced nurse practitioner, Oxford

Apologies:

Robert Angus (co-optee)	Respiratory physician
Rachel Starer	General practitioner

In attendance:

Caroline Keir	Guideline commissioning manager, NICE	
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Observers:

Yasmina Hedhli	Project manager, NCGC	
Quyen Chu	Senior project manager, NCGC	

1. DO welcomed the group to the third meeting of this GDG. Apologies were received from RA and RS. The Chair asked all GDG members to declare any relevant conflicts of

interest. All declared that they knew of no personal specific, personal non-specific, non-personal specific or non-personal non-specific interest in the development of this guideline.

2. The minutes of the last meeting of this group were agreed as a true and accurate account of the meeting.

3. Considerations for non-randomised studies:

CJ gave a presentation on considerations for the GDG in the use of non-randomised studies (cohort studies).

4 Clinical evidence for the pharmacological management of muscle stiffness, muscle weakness and cramps

JN gave a presentation on the clinical evidence for this review question. She noted that the evidence for this GDG builds on the evidence presented at GDG2 with the addition of Gabapentin.

5 Economic evidence for the pharmacological management of muscle stiffness, weakness and cramps

EG gave a presentation on the economic evidence for this review question.

6 LETs for the pharmacological management of muscle stiffness, muscle weakness and cramps

The GDG drafted LETs for this review question.

7 Clinical evidence for the pharmacological management of breathing difficulties

CF gave a presentation on the clinical evidence for this review question.

8 Economic evidence for the pharmacological management of breathing difficulties

EG gave a presentation on the economic evidence for this review question. The GDG were notified that the Midazolam oromucosal solution dose was changed to a dosage of 10 x 10mg syringes per year as it was very high previously.

9 LETs for the pharmacological management of breathing difficulties

The GDG drafted LETs for this review question.

10 Clinical evidence for cough assistance techniques

JN gave a presentation of the clinical evidence for this review question. It was noted that, following discussions with RA in the pre-GDG, 'peak cough flow' was amended to 'change in peak cough flow' as this is clearer.

11 Economic evidence for cough assistance techniques

EG gave a presentation on the economic evidence for this review question.

12 LETs for the review question on cough assistance techniques

The GDG drafted LETs for this review question.

13 Health economic plan

EG thanked the GDG for their comments on the economic plan distributed for their comment. He noted the following developments to the economic plan:

- Inclusion of Rafiq abstract of MI-E v BS RCT in cough assist
- Priority change for original economic analysis: previously = cough assist (high), MDT care (medium), saliva management (medium). Presently = MDT care (high)

14 Discussions on draft protocols

The GDG discussed the following protocols:

- i) Saliva
- ii) Communication problems
- iii) Nutrition and weight management
- iv) Timing of placement of gastrostomy tube

15 AOB

Team action - KJ and LA to look at timing of the discussion of papers.

16 Close of meeting

Date, time and venue of the next meeting

29 July 2014, 10am-4pm, Boardroom NCGC