

Date and Time: Tuesday 29 July 2014, 10am-4pm

Minutes: Confirmed

Guideline Development Group Meeting 4

Place: Boardroom, 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 (AM only)	Senior project manager, NCGC
Julie Neilson	Senior research fellow, NCGC
Caroline Farmer	Research fellow, 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
Liz 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
Rachel Starer	General practitioner, Oxford

In attendance:

Robert Angus (PM only)	Respiratory physician, Liverpool	
NICE Staff:		
Caroline Keir	Guideline commissioning manager, NICE	

Observers:

Alexander Haines	Health economist, NCGC	
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Notes:

1) Welcome, declarations of interest and GDG3 minutes

The chair welcomed the group to the fourth meeting of this GDG. No apologies were received, and it was noted that the agenda listing for EG as an apology is incorrect as he is an attendee for this meeting. AH attended as an observer.

No new declarations of interest were received.

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

2) CG105 consultation

LA explained the position of the GDG as a registered stakeholder for this guideline. The GDG were in agreement that they would like to propose the CG105 guideline be combined with this current MND guideline in development, with appropriate team follow-up actions determined.

3) List of review questions

LA gave a presentation on the question on communicating diagnosis/prognosis. The GDG agreed to change the question to focus on content of information communicated to patients at diagnosis rather than the delivery of that information.

The GDG also discussed the psychosocial support scope area, and drafted a review question on psychological/emotional support.

4) Presentation on AAC devices

SB gave a presentation on AAC devices which introduced the GDG to the different technologies and categories pertinent to this question.

5) Clinical evidence for the review question on AAC devices

JN gave a presentation on the clinical evidence for the AAC devices review question. JN notified the GDG that the search strategy was revised from qualitative studies to RCTs and cohort studies.

6) Economic evidence for the review question on AAC devices

EG discussed the economic aspects of this review question.

7) LETRs for the review question on AAC devices

The GDG drafted LETRs for this review question.

8) Clinical evidence for the review question on saliva management

CF gave a presentation on the clinical evidence for the saliva management review question. CF checked the 1-5 scale used in the Jackson paper and informed the GDG that this scale was not used due to the lack of baseline outcomes, which were present in the 0-100 scale used.

9) Economic evidence for the review question on saliva management

EG discussed the economic aspects of this review question.

10) LETRs for the review question on saliva management

LETRs were drafted for this review question.

11) Timing of gastrostomy draft protocol

The GDG considered and made amendments to this draft protocol covering some changes to wording and outcome levels.

12) MDT and coordination of care protocols

The GDG considered these protocols and decided that the MDT question would be removed and the coordination of care question would be changed to ask whether the coordination of care and support across health and social care improves patient outcomes.

13) Close of meeting.

Date, time and venue of the next meeting:

Wednesday 24th September, 10am-4pm, Boardroom NCGC