

Date and Time: *Wednesday 14 January 2015; 10am-4pm*

Minutes: Draft

Guideline Development Group Meeting 8

Place: *Boardroom, National Clinical Guideline Centre*

Present:

GDG members:

David Oliver	Consultant in Palliative Medicine Wisdom Hospice (Chair)
Jean Waters	Patient/Carer Member
Sandra Smith	Patient/Carer Member
Roch Maher	Patient/Carer Member
Steven Bloch	Lecturer & Faculty of Brain Sciences Graduate Tutor, London Community Matron in Neurological Conditions, Yorkshire
Julie Brignall-Morley	MND Specialist Occupational Therapist, Oxford
Jennifer Rolfe	Principal Physiotherapist in Emergency, Cardiothoracic and Specialised Medicine, University Hospital of North Midlands NHS Trust
Caroline Brown	
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, Oxfordshire
Robert Angus	Consultant Physician in Respiratory and High Dependency Medicine, Liverpool
Ian Smith	Consultant Chest Physician and Clinical Director, Cambridgeshire
Sharon Abrahams (co-optee)	Senior Lecturer and Consultant Clinical Neuropsychologist

NCGC technical team:

Liz Avital	Associate Director, NCGC
Julie Neilson	Senior Research Fellow, NCGC
Alex Haines	Health Economist, NCGC
Katie Broomfield	Document Editor/Process Assistant, NCGC
Caroline Farmer	Research Fellow, NCGC
Alex Allen	Research Fellow, NCGC

Apologies:

Elisabetta Fenu	Health Economics Lead, NCGC
Jill Cobb	Information Scientist, NCGC
Yasmina Hedhli	Project Manager, NCGC

In attendance:

Caroline Keir Alix Johnson	Guideline Commissioning Manager, NICE Patient and Public Involvement Adviser, NICE
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Notes

1. Welcome, apologies and declarations of interest

Notes

1.1 The Chair welcomed the group to the eighth meeting of this GDG.

1.2 Apologies were received from EF, KJ, YH and JC.

1.3 The Chair reviewed and requested updates to the declarations of interest register.

1.3.1 The Chair declared that in relation to the **previous declarations** recorded in the DOI register, for this meeting, the following should apply:

- The DOI register was made available to the GDG chair. The chair reviewed the DOI register and deemed that none of the original DOIs were in conflict with the agenda topics and clinical questions under discussion at the meeting. No action was required.

1.3.2 **New declarations** of interest received for this GDG meeting include:

GDG Declarations of Interest			
N.B. The Chair and GDG members were recruited to this guideline using NICE DOI policy published October 2008.			
Insert initials	Declaration	Classification (as per the NICE DOI policy wording*)	Chairs action
IS	My consultant colleague at Papworth is considering an application to the MNDA following their recent call for evidence relating to the impact of MND Care Centres. In addition there has been an offer of an unconditional educational grant to fund a fellow under his supervision from B and D Electromedical Ltd who manufacture ventilatory support devices. This is not linked to any particular study as yet and is likely to fund work relating to sleep apnoea.	Non-personal financial specific	No action taken
RA	Continued involvement in the SBRI project	Personal financial non-specific	No action taken
NICE DOI policy classifications are: <ul style="list-style-type: none"> • Personal financial specific • Personal financial non-specific • Personal non-financial specific • Personal non-financial non-specific • Non-personal financial specific • Non-personal financial non-specific 			

1. Review question: Knowledge to communicate diagnosis, prognosis and ongoing care appropriately

JN presented the clinical evidence for this review question to the group. There was no economic evidence. The GDG considered the evidence and drafted recommendations.

2. Health economic update

AH gave a presentation on the HE model for the coordination of care review.

3. Review question: Frequency of cognitive assessment

Notes

There was no clinical or economic evidence for this review question. The GDG drafted recommendations based on informal consensus.

4. Protocols

The GDG discussed the protocols for assessment tools for disease progression, discontinuation of NIV (quantitative) and discontinuation of NIV (qualitative).

5. AOB

Nil

Date, time and venue of the next meeting

GDG9: Tuesday 10 March, 10am-4pm