

Date and Time: *Wednesday 10 December 2014; 10am-4.30pm*

Minutes: Draft

Guideline Development Group Meeting 6

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
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, University Hospital of North Midlands NHS Trust
Chris McDermott	Consultant Neurologist, Sheffield
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

Apologies:

Aleksander Radunovic	Consultant Neurologist, London
Roch Maher	Patient/Carer Member
Elisabetta Fenu	Health Economics Lead, NCGC
Caroline Farmer	Research Fellow, NCGC
Jill Cobb	Information Scientist, NCGC

In attendance:

Caroline Keir	Guideline commissioning manager, NICE	
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Observers:

Sharlene Ting	Technical Analyst, NICE (10 th December)	
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Notes

1. Welcome, apologies and declarations of interest

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

- 1.1.1 The Chair introduced the following new members to the group: Ian Smith, Consultant Chest Physician and Clinical Director, and Sharon Abrahams, Senior Lecturer and Consultant Clinical Neuropsychologist (co-opted member).
- 1.1.2 Sharlene Ting, Technical Analyst (NICE) was present as an observer.

1.2 Apologies were received from AR, CF, JC, EF and RM.

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
SA	1. Grant for Cognitive change and ALS staging. Funded by the ALSA to the University of Edinburgh. 2. Occasional consultations with private patients for neuropsychological assessment and diagnosis. 3. Attended the MNDA training day on cognitive change in MND (November 2014). Assisted with producing MNDA literature on the subject. 4. Involved in a small research project for MND Scotland looking at barriers to cognitive screening for MND in Scotland. 5. Has worked on consensus documents (peer reviewed publications) on management guidelines for MND (see emailed publications, short CV and recent review on cognitive change). 6. On the committee of ENCALS group –	1. Non-personal financial specific 2. Personal financial specific 3. Personal non-financial specific 4. Non-personal non-financial specific 5. Personal non-financial non-specific 6. Personal non-financial specific 7. Personal non-financial specific 8. Non-personal	No action taken

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	European cognitive screening. 7. On the editorial board for ALS journal. 8. Supervises a number of PhD students funded by university centres and charities.	non-financial non-specific	
RA	Continuing work on telemedicine /telemonitoring via a grant from NHS England	Personal financial specific	No action taken
SB	Possible PhD student to be part funded by the MNDA. Award would cover UCL fees (not awarded to the department directly).	Personal financial specific	No action taken
AE	As palliative care consultant with an interest in MND, and as co-ordinator of the palliative care in progressive neurological disease special interest forum, AE is involved with other palliative care professionals in audits. These include: 1a.Looking to identify triggers for end of life in patients with progressive neurological disease 1b. Looking at practices of managing discontinuation of ventilation in MND Leeds teaching hospitals NHS department are involved in writing a grant for a Loris study funded by the MNDA, but AE has declined participation in any aspect of this work.	1a.Personal non-financial non-specific 1b.Personal non-financial non-specific	No action taken
RM	Advisor for the ITV soap Hollyoaks	Personal financial specific	No action taken
CMD	1. Article published in Current opinion in neurology on management of MND. Honorarium £75 paid to department. 2. Multiple presentations on care management at Brussels international MNDA symposium. 3. In receipt of departmental funding for telehealth study from Abbott pharmaceuticals. 4. MNDA funding for collar project (departmental).	1.Non-personal financial specific 2.Personal non- financial non- specific 3.Non-personal financial specific 4.Non-personal financial specific	No action taken
DO	1. Involvement in MND Association End of life guide 2012-13 (before GDG). Spoken of at the MND symposium in December 2014. 2. Involvement in a project on withdrawal of NIV, in particular the effects on professionals, with a hospice in Leicester. Funded by the MNDA.	1. Personal non- financial specific 2. Non-personal financial specific	No action taken
JR	1. Interviewed by Wendy Grey, NHS – improving Quality, for NHS England wheelchair summit. Was being asked about my clinical experiences of wheelchair services and the current model of service delivery I give in my clinical practice. 2. Attended International Symposium on MND/ALS and presented a poster on my work with MNDA on development of Neuro Wheelchair (as previously disclosed at interview and on appointment to role on GDG).	1. Personal non- financial specific 2. Personal non- financial non- specific	No action taken
IS	1. 2006-2010: unconditional grant from ResMed Ltd (manufacturer of home ventilation equipment). This was used to support three research fellows who have published on methods	1. Non-personal financial specific 2. Personal non- financial non-	No action taken

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	<p>of assisted ventilation in COPD flight assessments in people with obesity and compliance with CPAP therapy.</p> <p>2. Has published research on the respiratory care of people living with MND including weaning from invasive ventilation and surveillance for ventilator failure.</p> <p>3. MD in write-up on surveillance pre-development of respiratory failure. The abstract was presented at the BTS last week.</p>	<p>specific</p> <p>3. Personal non-financial non-specific</p>	
SS	Has given advice on the MNDA cognitive impairment information leaflets.	Personal non-final specific	No action taken
JBM, CB, RS & JW	None	N/A	None
<p>NICE DOI policy classifications are:</p> <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. Agree previous GDG5 meeting notes & NICE minutes

The meeting notes and NICE minutes of the last meeting were reviewed by the GDG and no amendments were required to the minutes.

The notes and NICE minutes were then agreed as a true and accurate record of the meeting.

2. Review question: Psychological support

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

3. Review question: End of life care

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

4. Protocols

JN presented to the group on the draft protocols for cognitive assessment, assessment tools for disease progression, frequency of assessment, discontinuation of NIV (quantitative) and discontinuation of NIV (qualitative).

5. AOB

Nil

Date, time and venue of the next meeting

GDG7: Thursday 11 December, 9,30am-4pm