

**Date and Time:** *Tuesday 10 March 2015; 10am-4pm*

**Minutes:** Draft

**Guideline Development Group Meeting 9**

**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
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

**NCGC technical team:**

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

**Observers:**

Yasmina Hedhli	Project Manager, NCGC
Norma O'Flynn	Guideline Lead/Clinical Director, NCGC
Peter Rouse	Health Economist, NCGC

**Apologies:**

Roch Maher	Patient/carer member
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**In attendance:**

Caroline Keir	Guideline Commissioning Manager, NICE
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**Notes**

**1. Welcome, apologies and declarations of interest**

## Notes

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

1.2 Apologies were received from 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:

<b>GDG Declarations of Interest</b>			
N.B. The Chair and GDG members were recruited to this guideline using NICE DOI policy published October 2008.			
<b>Insert initials</b>	<b>Declaration</b>	<b>Classification (as per the NICE DOI policy wording*)</b>	<b>Chairs action</b>
CB	Accepted a request to sit as an expert on a project of guideline consensus development for the ENMC (European Neuro-Muscular Centre) if funding of the project is granted and it does not conflict with my NICE MND GDG role. The project includes 20 world experts for a 2-3 days closed doors meeting. The conference will be held in the Netherlands, all flights and accommodations (hotel, restaurant) will be covered by the ENMC. The guidelines topic is "Airway clearance techniques in NMDs".	Personal non-pecuniary non-specific	No action taken
JW	Appointed to the Wheelchair Leadership Alliance, which is chaired by Baroness Grey-Thompson and supported by NHSIQ, charged with campaigning to redevelop NHS wheelchair services.	Personal non-financial specific	No action taken
RS	Talking to a group of health care professionals about integrated care between primary and secondary services with reference to MND organised by the Oxford MND Centre on 18/3/15. There is no payment for the event.	Personal non-financial non-specific	No action taken
NICE DOI policy classifications are: <ul style="list-style-type: none"> <li>• Personal financial specific</li> <li>• Personal financial non-specific</li> <li>• Personal non-financial specific</li> <li>• Personal non-financial non-specific</li> <li>• Non-personal financial specific</li> <li>• Non-personal financial non-specific</li> </ul>			

## 1. Review question: Timeliness of diagnosis

## Notes

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. Economic model (MDT)**

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

### **3. Review question: Prognostic tools for estimating survival**

AA presented the clinical evidence for this review question to the group. There was no economic evidence. The GDG drafted recommendations based on informal consensus.

### **4. Review question: Frequency of assessment to assess disease progression**

JN gave a presentation on this review question to the group which identified no clinical evidence. There was no economic evidence. The GDG considered the evidence and drafted recommendations.

### **5. LETRs from GDG8**

The group discussed and reviewed the LETRs on communication of diagnosis and frequency of cognitive assessment drafted at the previous meeting.

### **6. AOB**

Nil

### **Date, time and venue of the next meeting**

**GDG10:** Monday 20 April 2015, 10am-4pm

**GDG11:** Tuesday 21 April 2015, 10am-4pm