

**Date and Time:** *Tuesday 12 May 2015; 10am-4pm*

**Minutes:** Final

**Guideline Development Group Meeting 12**

**Place:** *Boardroom, National Clinical Guideline Centre*

**Present:**

**GDG members:**

David Oliver	Consultant in Palliative Medicine Wisdom Hospice (Chair)
Aleksander Radunovic (PM only)	Consultant Neurologist, London
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
Karen James	Principial Social Worker, London
Robert Angus (PM only)	Consultant Physician in Respiratory and High Dependency Medicine, Liverpool
Ian Smith	Consultant Chest Physician and Clinical Director, Cambridgeshire

**NCGC technical team:**

Norma O'Flynn	Clinical Director, NCGC
Alex Haines	Health Economist, NCGC
Alex Allen	Research Fellow, NCGC
Yasmina Hedhli	Project Manager, NCGC
Julie Neilson	Senior Research Fellow, NCGC

**Apologies:**

Karen James	Principal Social Worker, London
Katie Broomfield	Document Editor/Process Assistant, NCGC
Caroline Keir	Guideline Commissioning Manager, NICE

**In attendance:**

Katie Perryman-Ford	Guideline Commissioning Manager, NICE
Sarah Palombella	Senior medical editor, NICE

## 1. Welcome, apologies and declarations of interest

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

1.2 Apologies were received from KJ, KB and CK.

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

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 for this GDG meeting:

The chair then requested updates to the existing declarations of interests from GDG members.

<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>
RM	Is starting a study which is being sponsored by Glaxo Smith Klein in collaboration with McLaren Applied Technologies. The study will test a device which uses sensors and electrodes to measure movement, activity and heart rate, as it relates to Amyotrophic Lateral Sclerosis (ALS). The study will also measure certain aspects of speech and the relation to ALS.	Personal non-pecuniary non-specific	No action taken
	Reading all the scripts for 'doctors', a tv drama, which has a storyline about a person with MND.	Personal pecuniary 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>			

No other declarations were received and hence no action was required.

## 2. Review question: Coordination of care

JN gave a presentation on new evidence that had been found during reruns. AH gave an update on the economic model. The group then refined the recommendations that had been made for coordination of care and multidisciplinary teams.

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

AA gave a presentation on new evidence that had been found during reruns. The GDG considered this evidence and decided to keep the recommendation and research recommendation that had been previously drafted.

#### **4. Review of recommendations drafted to date**

The GDG reviewed the recommendations that had been made to date, which had been edited by SP since the last meeting. The group agreed further changes.

#### **5. Review of research recommendations**

The GDG reviewed the areas identified for potential research recommendations. Members of the GDG volunteered to develop the research recommendations using the NICE format.

#### **6. Timelines**

The group were told of the next steps, including deadlines, for bringing the guideline together.

#### **7. AOB**

There was no other business.

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

**GDG13:** 10 November 2015, 10am-4pm.