

**Date and Time:** *Tuesday 21nd April 2015; 10am-4pm*

**Minutes:** Final

**Guideline Development Group Meeting 11**

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

**Present:**

**GDG members:**

|                       |  |
|-----------------------|--|
| David Oliver          | Consultant in Palliative Medicine Wisdom Hospice (Chair)   |
| Aleksander Radunovic  | 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<br>Specialised Medicine, University Hospital of North Midlands<br>NHS Trust |
| Chris McDermott       | Consultant Neurologist, Sheffield  |
| Annette Edwards       | Consultant in Palliative Care Medicine, Leeds  |
| Rachael Marsden       | MND Care Centre Coordinator and Advanced Nurse<br>Practitioner, Oxford   |
| Rachel Starer         | General Practitioner, Oxfordshire  |
| Karen James           | Principial Social Worker, London   |
| Robert Angus          | Consultant Physician in Respiratory and High Dependency<br>Medicine, Liverpool   |
| Ian Smith             | Consultant Chest Physician and Clinical Director,<br>Cambridgeshire  |

**NCGC technical team:**

|                |                          |
|----------------|--------------------------|
| Liz Avital     | Associate Director, NCGC |
| Alex Haines    | Health Economist, NCGC   |
| Alex Allen     | Research Fellow, NCGC    |
| Yasmina Hedhli | Project Manager, NCGC    |

**Apologies:**

|                  |   |
|------------------|---|
| Julie Neilson    | Senior Research Fellow                  |
| Katie Broomfield | Document Editor/Process Assistant, NCGC |
| Norma O' Flynn   | Clinical Director                       |

**In attendance:**

|                  |                                       |
|------------------|---------------------------------------|
| Caroline Keir    | Guideline Commissioning Manager, NICE |
| Sarah Palombella | Senior medical editor, NICE           |

## **Notes**

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

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

1.2 Apologies were received from JN and KB.

1.3 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.

The chair then requested updates to the existing declarations of interests from GDG members; no new declarations were received and hence no action was required.

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

AA gave a presentation on the clinical evidence for prognostic tools for estimating survival. This was an update of this review and included a further 9 studies, in addition to the 2 in the original review. The GDG drafted a recommendation.

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

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

### **4. Review of research recommendations**

The GDG reviewed the research recommendations that had been drafted to date. Further areas for potential research were identified.

### **5. Dissemination**

The GDG discussed different methods of disseminating the guideline, including a number of relevant conferences and publications.

### **6. Arrangements for writing up the guideline**

Members of the group agreed to take responsibility for each of the guideline chapters. This would include writing an introduction to the chapter and reviewing the chapter, once complete.

### **7. AOB**

Nil

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

**GDG12:** Tuesday 12 May 2015, 10am-4pm.