

**Date and Time:** *Monday 20 April 2015; 10am-4pm*

**Minutes:** Final

**Guideline Development Group Meeting 10**

**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

**NCGC technical team:**

Norma O'Flynn	Guideline Lead/Clinical Director, NCGC
Alex Haines	Health Economist, NCGC
Alex Allen	Research Fellow, NCGC
Katie Broomfield	Document Editor/Process Assistant, NCGC

**Apologies:**

Julie Neilson	Senior Research Fellow
Yasmina Hedhli	Project Manager, NCGC
Aleksander Radunovic	Consultant Neurologist, London

**In attendance:**

Caroline Keir	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 tenth meeting of this GDG.

1.2 Apologies were received from JN, YH and AR.

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:

- David Oliver has previously declared involvement in a project on withdrawal of NIV, in particular the effects on professionals, with a hospice in Leicester (funded by the MND). This is a personal non-pecuniary interest and he participated in the meeting.
- Chris McDermott has previously declared involvement in a publication on experiences of withdrawal of NIV. This was classed as a personal non-pecuniary interest and he participated in the meeting.

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; no new declarations were received and hence no action was required.

## **2. Agree previous GDG 8 meeting notes & NICE minutes**

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

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

## **3. Review question: NIV: Management of discontinuation**

AA gave a presentation on this review question to the group. There was no clinical or economic evidence. The GDG drafted recommendations.

## **4. Review question: NIV: Experience of discontinuation**

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

## **5. Review of CG105 recommendations (excluding MDTs)**

The GDG reviewed the recommendations from CG105, excluding MDTs, and made amendments and comments to the document to reflect areas which need to be updated in light of the current evidence and recommendations for this guideline.

## **6. Recap of coordination of care clinical evidence**

AA re-presented the original clinical evidence for the review question on coordination of care.

## **7. Economic model results**

AH gave a presentation on the economic model results for the review question on coordination of care.

## **8. MDT recommendations**

The GDG reviewed the recommendations on MDTs from CG105 and made draft amendments based on the clinical and economic evidence presented.

## **9. NICE presentation on the role of the editor**

SP gave a presentation on the role of the NICE editor.

## **10. AOB**

Nil

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

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