

**Date and Time:** *Wednesday 12<sup>th</sup> March 2014, 10.30am – 4.30pm*

**Minutes:** Confirmed

**Guideline Development Group Meeting 1  
Motor Neurone Disease**

**Place:** *National Clinical Guideline Centre  
180 Great Portland Street  
London*

**Present:** David Oliver (Chair)  
Julie Brignall Morley  
Elizabeth (Caroline) Brown  
Annette Edwards  
Rachael Marsden (AM only)  
Roch Mayer  
Chris McDermott  
Aleksander Radunovic  
Jennifer Rolfe (AM only)  
Sandra Smith  
Jean Waters

**In attendance:**

NICE Staff: Katie Perryman-Ford	NICE guideline commissioning manager	(Present for notes 1 – 3)
Alix Johnson	Patient and public involvement advisor	(Present for notes 1 – 3)
NCGC Staff: Katie Jones Liz Avital Julie Neilson Sadia Janjua Elisabetta Fenu Edward Griffin Jill Cobb	Project manager Associate Director Senior research fellow Research fellow Health economic lead Health economist Information scientist	

**Notes**

1. DO welcomed the group to the first meeting of this GDG. Apologies were received from Stephen Illingworth (*GDG member*).
2. The Chair introduced KPF, Guidelines commissioning manager at NICE and AJ, Public involvement manager at NICE. KPF presented on the work of NICE and AJ presented on patient and public involvement. LA gave a short presentation on the NCGC and declarations of interest. The Chair asked all GDG members to declare any relevant conflicts of interest. The GDG declared the following conflicts of interest:

## Notes

DO declared a personal pecuniary interest in that sponsored attendance (by scientific organising committee, not pharmaceutical company) to MND symposium, World congress of Neurology, Congress of European Federation of Neurological Societies, Audtrian Society for Neurology. Involvement (not Principal investigator) of study of withdrawal of NIV, funded by the MND Association. He also declared a non personal pecuniary interest in that he was a member of Board of European Association for Palliative Care (EAPC) and was Chair of EAPC Taskforce of Neurological Palliative Care - publication of Palliative care for Patients with Progression Neurological Disease: A consensus paper based on available evidence'. He also declared a personal non-pecuniary interest in that he was Honorary President of Mid-Kent Branch of MND Association and a member of Research advisory committee of the MND Association. He was also author of MND: A Family Affair, Principal author/editor of Palliative care for ALS - From diagnosis to bereavement and editor of End of Life Care in Neurological Disease.

AE declared a non-personal pecuniary interest in that her department hosts a post of Specialist wheelchair provider (Occupational therapist) which is funded by the MND Association.

CB declared a personal pecuniary interest in that she had been invited to teach on respiratory complications in neuromuscular disease at a study day organised by B&D medical and would receive travel and accommodation expenses for attending. She also declared a non-personal non-pecuniary interest in that she was responsible for organising feedback on B&D products within the department.

JBM declared a personal non-pecuniary interest in that she attends regularly local MNDA meetings and meets with the regional care advisor to discuss local issues and needs.

CMD declared a personal pecuniary interest in that he received expenses from Synapse Biomedical who manufacture a diaphragm pacing device and expenses from the MND Association for presenting at an event and that he had received financial support from the MND Association, MRC, JPND and NIHR for MND related research programmes. He also declared a personal non-pecuniary interest in that his department had received free cough assist devices from Respironics to support a clinical trial and free diaphragm pacing devices from Synapse Biomedical to support a clinical trial. He had also received support for a trial on telehealth from Cogent. He also declared that he was the inventor of a new head support and was currently seeking a commercial partner for the product.

RM declared a non-personal pecuniary interest in that her post was funded by the MND Association, via Oxford University and was renewed every four years. She also declared a personal pecuniary interest in that she was director a company 'Living Experience' who provide training for care assistants in the community and that she held some shares in GW Pharmaceuticals. She also declared a personal non-pecuniary interest in that she was a research nurse for a clinical trial on diaphragm pacing.

SS declared a personal non-pecuniary interest in that she was a trustee for the MND Association and member of the Care Committee. She was also one of 14 campaign contacts for the MNDA National Engagement committee in a voluntary capacity and a Committee member of the MND association Merseyside branch.

RM declared a personal non-pecuniary interest in that he supports the aims of the group Dignity in Dying on whose behalf he submitted an affidavit in support of their aims in the Niclenson/Lamb/Martin case. He also declared that he was a member of the local branch (West London and Middlesex) of the MND Association and supports the overall aims of the organisation, reviewing documents on behalf of the organisations and speaking on their behalf. He also declared that he has given evidence on behalf of the All Party Parliamentary Group investigation into palliative care.

The remaining GDG all declared that they knew of no personal specific, personal non-specific, non-personal specific or non-personal non-specific interest in the development of this guideline.

## **Notes**

3. JC presented on searching for the evidence. The GDG discussed the issues presented in relation to this guideline and the Chair thanked JC for her presentation.
4. JN presented on the methods for systematic reviewing. The GDG discussed the issues presented in relation to this guideline and the Chair thanked JN for her presentation.
5. EF presented on health economic evidence and the GDG discussed possible priorities for health economic modelling and other issues presented in relation to this guideline and the Chair thanked EF for her presentation.
6. SJ presented on the development of protocols and the GDG discussed issues presented in relation to this guideline.

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

Tuesday 29<sup>th</sup> April 2014, 10am – 4pm, Boardroom, NCGC, 180 Great Portland Street, London.