

## **The Guideline Committee, National Collaborating Centre and NICE project team, and declarations of interests**

### ***Guideline Committee***

The Guideline Committee members listed are those for the 2016 update. For the composition of (the) previous Guideline Committee(s), see the full guideline.

#### **David Oliver (Guideline Chair)**

Consultant in Palliative Medicine, Wisdom Hospice, Rochester and Honorary Reader, University of Kent

#### **Sharon Abrahams (co-opted expert member)**

Personal Chair of Neuropsychology, University of Edinburgh

#### **Robert Angus**

Consultant Physician in Respiratory and High-Dependency Medicine, Aintree University Hospital NHS Foundation Trust

#### **Steven Bloch**

Senior Lecturer and Speech and Language Therapist, University College London

#### **Karen James (co-opted expert member)**

Principal Social Worker, St Christopher's Hospice, Bromley

#### **Julie Brignall-Morley**

Community Matron in Neurological Conditions, Rotherham Doncaster and South Humber NHS Foundation Trust

#### **Angeline Brooks (co-opted expert member)**

Specialist Neurosciences Dietitian, King's College Hospital NHS Foundation Trust

## DRAFT FOR CONSULTATION

### **Caroline Brown**

Principal Physiotherapist in Emergency, Cardiothoracic and Specialised Medicine, University Hospitals of North Midlands NHS Trust

### **Annette Edwards**

Consultant in Palliative Medicine, Leeds Teaching Hospitals NHS Trust

### **Roch Maher**

Patient/carer representative (until April 2015)

### **Rachael Marsden**

Motor Neurone Disease Advanced Nurse Practitioner and Care Centre Coordinator, Oxford University Hospitals NHS Trust

### **Christopher McDermott**

Reader and Honorary Consultant Neurologist, University of Sheffield

### **Aleks Radunovic**

Consultant Neurologist and Honorary Clinical Senior Lecturer, Barts Health NHS Trust and Barking, Havering and Redbridge University Hospitals NHS Trust

### **Jennifer Rolfe**

Specialist Occupational Therapist, Oxford University Hospitals NHS Trust

### **Ian Smith**

Consultant Chest Physician and Deputy Medical Director, Papworth Hospital NHS Foundation Trust

### **Sandra Smith**

Patient/carer representative

### **Rachel Starer**

General Practitioner, Didcot Health Centre

### **Jean Waters**

Patient/carer representative

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***National Clinical Guideline Centre***

**Alexander Allen**

Research Fellow

**Liz Avital**

Associate Director (until March 2015)

**Katie Broomfield**

Document Editor/Process Assistant

**Jill Cobb**

Information Scientist

**Dalia Dawoud**

Health Economist

**Caroline Farmer**

Senior Research Fellow

**Edward Griffin**

Health Economist

**Alexander Haines**

Senior Health Economist

**Yasmina Hedhli**

Project Manager (until May 2015)

**Sadia Janjua**

Research Fellow

**Katie Jones**

Senior Project Manager

**Julie Neilson**

Senior Research Fellow

## DRAFT FOR CONSULTATION

### **Norma O'Flynn**

Clinical Director and Deputy Chief Operating Officer (from March 2015)

### **Amelia Unsworth**

Project Manager (from May 2015)

### ***NICE project team***

#### **Sharon Summers-Ma**

Guideline Lead

#### **Mark Baker**

Clinical Adviser

#### **Caroline Keir**

Guideline Commissioning Manager

#### **Margaret Ghلامي**

Guideline Coordinator

#### **Steven Barnes**

Technical Lead

#### **Paul Crosland**

Health Economist

#### **Sarah Palombella**

Editor

#### **Alix Johnson**

Public Involvement Adviser

### ***Declarations of interests***

The following members of the Guideline Committee made declarations of interests. All other members of the Committee stated that they had no interests to declare. The conflicts of interest policy (2007) was followed until September 2014, when an [updated policy](#) was published.

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<b>Member</b>	<b>Interest declared</b>	<b>Type of interest</b>	<b>Decision taken</b>
David Oliver (Chair)	Sponsored attendance (by scientific organising committee, not pharmaceutical company) to MND symposium, World congress of Neurology, Congress of European Federation of Neurological Societies, Austrian Society for Neurology.	Non-specific personal pecuniary interest	Declare and participate
David Oliver (Chair)	Involvement (not Principal investigator) of study of withdrawal of NIV, funded by the MND Association.	Specific non-personal pecuniary interest	Declare and participate
David Oliver (Chair)	Member of Board of European Association for Palliative Care (EAPC). 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'.	Specific personal non-pecuniary interest	Declare and participate
David Oliver (Chair)	Honorary President of Mid-Kent Branch of MND Association. Member of Research advisory committee of MND Association.	Specific personal non-pecuniary interest	Declare and participate
David Oliver (Chair)	Author of MND A Family Affair, Principal author/editor of Palliative care for ALS - From diagnosis to bereavement.	Specific personal pecuniary interest	Declare and participate
David Oliver (Chair)	Editor of End of Life Care in Neurological Disease. Many papers on MND published in 2010.	Specific personal non-pecuniary interest	Declare and participate
David Oliver (Chair)	Gave a lecture to the MND Association of Australia Conference. Received funding for travel from MND Association of Australia, and funding for travel from MND Association of Victoria.	Specific personal pecuniary interest	Declare and participate
David Oliver (Chair)	Gave advice to Motor Neurone Disease Association on whether to update leaflet on death and dying.	Specific personal non-pecuniary interest	Declare and participate
David Oliver (Chair)	Involvement in MND Association End of life guide 2012-13 (before GDG). Spoken of at the MND symposium in December 2014.	Specific personal non-pecuniary interest	Declare and participate
David Oliver (Chair)	Involvement in a project on withdrawal of NIV, in particular the effects on professionals, with a hospice in Leicester.	Specific non-personal	Declare and participate

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	Funded by the MND. This is study 'involvement of healthcare professionals in withdrawal of MND' organised by Christina Faull at LOROS.	pecuniary interest	
David Oliver (Chair)	Speaking on 'Ethical and Clinical Dilemmas in MND ventilation' at Primary Care and Public Health 2015, NEC, Birmingham, 21 May 2015. No payment except expenses.	Reasonable travel expenses	Declare and participate
David Oliver (Chair)	<p>Papers published in 2014/15:</p> <p>Veronese S, Valle A, Chio A, Calvo A, Oliver D. the last months of life of people with amyotrophic lateral sclerosis in mechanical invasive ventilation: a qualitative study. ALS and FTD 2014; 15:499-504.</p> <p>Watermeyer TJ, Brown RG, Sidle KCL, Oliver DJ, Allen C, Karlsson J, Ellis CM, Shaw CE, Al-Chalabi A, Goldstein LH. Executive dysfunction predicts social cognition impairment in amyotrophic lateral sclerosis. J Neurol. 2015; DOI 10.1007/s00415-015-7761-0</p> <p>Oliver D. Reflections on neurological palliative care - editorial. European Journal of Palliative Care 2014; 21:2.</p> <p>Oliver D. Palliative care and neurology. Kongress Highlights. Neurologisch Supplementum 3 / 2014.</p> <p>Oliver D. Palliative care for people with progressive neurological disease: what is the role? Journal of Palliative Care 2014; 30: 298-301.</p> <p>Speaking in 2014/ 2015:</p> <p>Speaker at Special Interest group 11th Conference of Austrian Society for Neurology Salzburg March 2014</p> <p>Speaker on Palliative Care Guidelines EFNS / ENS Congress in Istanbul</p>	Specific personal non-pecuniary interest	Declare and participate

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	<p>Speaker of Neurological palliative care JPN meeting on Neurodegenerative disease Amsterdam</p> <p>Palliative care speaker at Curtin University, Perth, Australia MND Ask the Experts afternoon, Harry Perkins Institute of Medical research, Perth</p> <p>Planning ahead – dynamic changes and pathways of care 7th National MND Conference of MND Association of Australia Gold Coast, Australia Association for Palliative Medicine Neurological Palliative Care Special Interest Group Manchester</p> <p>Ethical dilemmas in Non-invasive ventilation in MND Breathing matters – conference on NIV</p>		
Sharon Abrahams	Received a grant for cognitive change and ALS staging, funded by the ALSA to the University of Edinburgh.	Non-specific non-personal pecuniary interest	Declare and participate
Sharon Abrahams	Attended the MNDA training day on cognitive change in MND (November 2014). Assisted with producing MNDA literature on the subject.	Non-specific personal non-pecuniary interest	Declare and participate
Sharon Abrahams	Involved in a small research project for MND Scotland looking at barriers to cognitive screening for MND in Scotland. This involves some interviews of patients and healthcare professionals on their views on cognitive screening, with the aim of identifying any problems they perceive which would hinder more widespread implementation of cognitive screening in Scotland. There has been no money involved. This is based on a screening measure we have developed that is currently being used in many centres across Europe.	Non-specific personal non-pecuniary interest	Declare and participate
Sharon	Worked on consensus documents (peer	Specific	Declare

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Abrahams	reviewed publications) on management guidelines for MND.	personal non-pecuniary interest	and participate
Sharon Abrahams	On the committee of ENCALS group – European cognitive screening.	Non-specific personal non-pecuniary interest	Declare and participate
Sharon Abrahams	On the editorial board for ALS journal.	Non-specific personal non-pecuniary interest	Declare and participate
Sharon Abrahams	Supervises a number of PhD students funded by university centres and charities.	Non-specific personal non-pecuniary interest	Declare and participate
Robert Angus	In receipt of a grant from the small business research initiative through NHS England to look at remote monitoring of ventilation and respiratory symptoms.	Non-specific personal pecuniary interest	Declare and participate
Robert Angus	Continuing work on telemedicine/telemonitoring funded by a grant from NHS England.	Non-specific personal pecuniary interest	Declare and participate
Steven Bloch	Chair of the MNDA AAC best practice guidelines group. These best practice guidelines for AAC/MND were produced independently by a group of clinicians in 2012. There was no funding or commercial interest. The MNDA agreed to site them on their own website: <a href="http://www.mndassociation.org/forprofessionals/aac-for-mnd/">http://www.mndassociation.org/forprofessionals/aac-for-mnd/</a> . The guidelines remain available for public access.	Specific personal non-pecuniary interest	Declare and participate
Julie Brignall Morley	Regularly attends local MNDA meetings and meets with the Regional Care Advisor to discuss local issues and needs.	Specific personal non-pecuniary interest	Declare and participate
Angeline Brooks (co-opted expert adviser)	I have been asked by the MNDA to contribute to an online learning module being developed by Northampton University for carers, aimed at increasing their knowledge around nutritional support	Specific personal non-pecuniary interest	Declare and participate



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	in dysphagia. There is no financial reward for this project.		
Caroline Brown	Involved in writing ACPRC/BTS Guidelines 2009 on respiratory complications in neuromuscular disease Section G.	Specific personal non-pecuniary interest	Declare and participate
Caroline Brown	Attended a training day on E70 (a type of cough assist device) organised by Responics (free event organised for clinicians) (November 2012).	Non-specific personal non-pecuniary interest	Declare and participate
Caroline Brown	Teaching for 2 days at the Department of Health and Rehabilitation at Keele University delivering on their ATMRP MSc module on the topic of managing respiratory complications in Neuromuscular Disease. In return, the Therapies Directorate at the University Hospital of North Staffordshire received a free place on the module for one of their physiotherapists. To ensure that the delegates could not interpret the content of the lecture as reflecting in any way the content of the NICE MND Guideline, my colleague delivered the theory lecture and I taught on the practical techniques workshops. A PowerPoint slide was used at the beginning of the lecture to clarify to delegates that the content of the presentation did not reflect the content of the NICE MND Guidelines but was based on the BTS/ACPRC Physiotherapy Guidelines (2009) for the spontaneously breathing adult, Section 6, managing respiratory complications in neuromuscular disease.	Specific personal non-pecuniary interest	Declare and participate
Caroline Brown	Accepted a request to sit as an expert on a project of guideline consensus development for the ENMC (European Neuro-Muscular Centre). 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'.	Specific personal non-pecuniary interest	Declare and participate
Annette Edwards	I am co-director of Leeds MND Care Centre, jointly with Dr Jung, consultant neurologist. My post does not receive any funding. However the MNDA fund	Specific personal non-pecuniary	Declare and participate

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	sessions of a dietician, Speech and Language Therapist, physiotherapist and Care Centre Co-ordinator.	interest	
Annette Edwards	Leeds MND Care Centre has a new post for specialist wheelchair provision (occupational therapist). The money came from the DOH through the MNDA to Leeds teaching hospitals to appoint a postholder (started in November 2013).	Non-specific non-personal pecuniary interest	Declare and participate
Annette Edwards	As a palliative care consultant with an interest in MND, and as coordinator of the palliative care in progressive neurological disease special interest forum, I am involved with other palliative care professionals in audits. These include: 1a. Looking to identify triggers for end of life in patients with progressive neurological disease 1b. Looking at practices for managing discontinuation of ventilation in MND. This was an addendum to a wider piece of work "Withdrawal of Assisted Ventilation at the Request of a Patient with Motor Neurone Disease: Guidance for Professionals" The Guidance was supported by a grant from the MNDA and endorsed by the Association for Palliative Medicine of Great Britain and Ireland. I have only been involved in the group meeting to draw up the audit proforma. This has involved a face to face meeting and ongoing work by email / teleconference. I have not been on the group responsible for developing the guidance itself. The whole document is currently out for consultation.	Specific non-personal pecuniary interest	Declare and participate
Roch Maher	I support the aims of the group Dignity in Dying on whose behalf I submitted an affidavit in support of their aim in the Nicholson/Lamb/Martin case. The case is currently under consideration in the Supreme Court having been heard in December. Judgement is due by the end of April.	Non-specific personal non-pecuniary interest	Declare and participate
Roch Maher	I am a member of the local branch (West London and Middlesex) of the MND Association. I support the overall aims of the association and occasionally speak on behalf of the organisation. I also review documents for the organisation's Personal Guide before publication. I have given evidence on behalf of the organisation to the All Party Parliamentary Group	Specific personal non-pecuniary interest	Declare and participate

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	investigation into palliative care.		
Roch Maher	I am a member of the user panel at the Princess Alice Hospice in Esher.	Non-specific personal non-pecuniary interest	Declare and participate
Rachael Marsden	My post has funding from the MNDA through Oxford University, and is under a 4-yearly contract. The MNDA pay the University; the University pay the OUH who pay me.	Non-specific personal pecuniary interest	Declare and participate
Rachael Marsden	Director of Living Experience, a very small training company for care assistances in the community (local level).	Non-specific personal non-pecuniary interest	Declare and participate
Rachael Marsden	Holds a few shares in GW Pharmaceuticals.	Non-specific personal pecuniary interest	Declare and participate
Rachael Marsden	Research nurse for DIPALS trial.	Non-specific personal non-pecuniary interest	Declare and participate
Rachael Marsden	<p>Various publications:</p> <p>Savulescu J. Marsden R. Hope T (1998) Sex, drugs and the invasion of privacy. <i>BMJ</i> 316 921 -4</p> <p>Kevin Talbot and Rachael Marsden. Motor neuron disease: the Facts. Oxford University Press, Jan 2008, ISBN-13: 978-0-19-920691-9</p> <p>Ex-PLISSIT study: Marsden R, Botell R (2010) Discussing Sexuality with patients in a motor neurone disease clinic. <i>Nursing standard.</i> 25, 15-17</p> <p>Martin R Turner, Jakub Scaber, John A Goodfellow, Rachael Marsden, Melanie E Lord, Kevin Talbot. The diagnostic pathway and prognosis in bulbar-onset amyotrophic lateral sclerosis. <i>J Neurol Sci.</i> 2010. Epub ahead of press</p>	Specific personal non-pecuniary interest	Declare and participate

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	<p>Turner MR, Brockington A, Scaber J, Hollinger H, Marsden R, Shaw PJ, Talbot K. Pattern of spread and prognosis in lower limb-onset ALS. Amyotroph Lateral Sclerosis. [Epub ahead of press]</p> <p>Marsden R (2011) Motor Neuron disease: an overview. Primary Health Care. 21,10, 31-36</p> <p>Kevin Talbot, Martin Turner, Rachael Marsden and Rachel Botell. Motor neuron disease: a practical manual. Oxford University Press, ISBN-10 019954736X</p>		
Rachael Marsden	I have been an advisor to the BBC for 5 episodes of Casualty. I have only advised on how an actor would portray a person living with MND. I also suggested the story line for giving a person living with MND oxygen with bad effect.	Non-specific personal non-pecuniary interest	Declare and participate
Rachael Marsden	I am an advisor for the ITV soap Hollyoaks.	Non-specific personal non-pecuniary interest	Declare and participate
Rachael Marsden	We are starting a study which is being sponsored by GlaxoSmithKline (GSK) in collaboration with McLaren Applied Technologies (MAT). The purpose of this study is to test the use of a device (sensor and electrodes) to measure participant's movement, activity and heart rate as it relates to their amyotrophic lateral sclerosis (ALS). The study will also measure certain aspects of participant's speech, and how that relates to their ALS. There is no treatment provided in this study. It is jointly funded by GSK & McLaren; funds go to the university.	Specific non-personal pecuniary interest	Declare and participate
Rachael Marsden	I am reading the TV scripts for Doctors (a daytime drama which will feature a person living with MND), Casualty and Hollyoaks. No payment is received for this.	Non-specific personal non-pecuniary interest	Declare and participate
Christopher McDermott	Subsistence received from Synapse Biomedical (manufacturer of diaphragm pacing) following a training session on diaphragm pacing.	Non-specific personal non-pecuniary	Declare and participate

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		interest	
Christopher McDermott	Expenses received from MNDA for overnight accommodation when speaking.	Reasonable travel expenses	Declare and participate
Christopher McDermott	Support for cough assist trial (free devices) from Respironics.	Specific personal non-pecuniary interest	Declare and participate
Christopher McDermott	Support for diaphragm pacing study (free devices) from Synapse biomedical.	Specific personal non-pecuniary interest	Declare and participate
Christopher McDermott	Support for telehealth study from Cogent Healthcare Systems.	Non-specific non-personal pecuniary interest	Declare and participate
Christopher McDermott	Inventor of a new head support, seeking a commercial partner.	Specific personal non-pecuniary interest	Declare and participate
Christopher McDermott	MNDA, MRC, JPND, NIHR grant support for MND-related research programmes.	Specific non-personal pecuniary interest	Declare and participate
Christopher McDermott	<p>Various publications on care for MND:</p> <p>1: McGeachan AJ, Hobson EV, Shaw PJ, McDermott CJ. Developing an outcome measure for excessive saliva management in MND and an evaluation of saliva burden in Sheffield. Amyotroph Lateral Scler Frontotemporal Degener. 2015 Mar;16(1-2):108-13. doi: 10.3109/21678421.2014.951942. Epub 2014 Sep 16. PubMed PMID: 25225845.</p> <p>2: Jenkins TM, Hollinger H, McDermott CJ. The evidence for symptomatic treatments in amyotrophic lateral sclerosis. Curr Opin Neurol. 2014 Oct;27(5):524-31. doi: 10.1097/WCO.000000000000135.</p>	Specific personal non-pecuniary interest	Declare and participate

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	<p>Review. PubMed PMID: 25110934.</p> <p>3: Stavroulakis T, Baird WO, Baxter SK, Walsh T, Shaw PJ, McDermott CJ. The impact of gastrostomy in motor neurone disease: challenges and benefits from a patient and carer perspective. <i>BMJ Support Palliat Care</i>. 2014 May 21. pii: bmjincare-2013-000609. doi: 10.1136/bmjincare-2013-000609. [Epub ahead of print] PubMed PMID: 24848262.</p> <p>4: Stavroulakis T, Baird WO, Baxter SK, Walsh T, Shaw PJ, McDermott CJ. Factors influencing decision-making in relation to timing of gastrostomy insertion in patients with motor neurone disease. <i>BMJ Support Palliat Care</i>. 2014 Mar;4(1):57-63. doi: 10.1136/bmjincare-2013-000497. Epub 2013 Dec 11. PubMed PMID: 24644772.</p> <p>5: Lenglet T, Lacomblez L, Abitbol JL, Ludolph A, Mora JS, Robberecht W, Shaw PJ, Pruss RM, Cuvier V, Meininger V; Mitotarget study group. A phase II-III trial of olesoxime in subjects with amyotrophic lateral sclerosis. <i>Eur J Neurol</i>. 2014 Mar;21(3):529-36. doi: 10.1111/ene.12344. Epub 2014 Jan 21. PubMed PMID: 24447620.6.</p> <p>6. Gastrostomy in patients with amyotrophic lateral sclerosis (ProGas): a prospective cohort study, ProGas Study Group. <i>Lancet Neurology</i> 2015 DOI: <a href="http://dx.doi.org/10.1016/S1474-4422(15)00104-0">http://dx.doi.org/10.1016/S1474-4422(15)00104-0</a></p>		
Christopher McDermott	Has been asked to write an article for a GP magazine on MND, for which an honorarium will be paid to the department.	Specific non-personal pecuniary interest	Declare and participate
Christopher McDermott	Article published in Current opinion in neurology on management of MND.	Specific non-	Declare and

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	Honorarium paid to department.	personal pecuniary interest	participate
Christopher McDermott	Multiple presentations on care management at Brussels international MND symposium. No payment was received for this.	Specific personal non-pecuniary interest	Declare and participate
Christopher McDermott	In receipt of departmental funding for telehealth study from Abbott pharmaceuticals.	Non-specific non-personal pecuniary interest	Declare and participate
Christopher McDermott	MNDA funding for collar project (departmental).	Specific non-personal pecuniary interest	Declare and participate
Christopher McDermott	Investigator in study on use of MDT for people with MND (Aridegbe, 2013).	Specific personal non-pecuniary interest	Declare and acted as an expert adviser for the GDG
Christopher McDermott	Involvement in a publication on experiences of withdrawal of NIV.	Specific personal non-pecuniary interest	Declare and participate
Aleks Radunovic	Director of Barts MND Care Centre. Whilst I don't receive any funding for my role, the MND Association funds care centre coordinator time to support the centre.	Specific personal non-pecuniary interest	Declare and participate
Aleks Radunovic	Member of the MND Association Outcomes Standards Sub-group.	Specific personal non-pecuniary interest	Declare and participate
Aleks Radunovic	Member of the Royal College of General Practitioners MND Red Flags Steering Group.	Specific personal non-pecuniary interest	Declare and participate
Aleks Radunovic	Member of the Association of British Neurologists' Neuromuscular Section; recently developed the MND Quality Statements.	Specific personal non-pecuniary	Declare and participate

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		interest	
Aleks Radunovic	Member of the Data Monitoring and Ethics Committee for “A randomised controlled trial evaluating NeuRx/4 Diaphragm Pacing in patients with respiratory muscle weakness due to Motor Neurone Disease”.	Specific personal non-pecuniary interest	Declare and participate
Aleks Radunovic	Chair of the Palliative Care Network for Rare and Rapidly Progressing Neurodegenerative Diseases in Essex, Herts and North East London.	Specific personal non-pecuniary interest	Declare and participate
Aleks Radunovic	Member of the St Joseph’s Hospice Steering Group for Managing medication towards the end of life: local consensus guidance for professionals.	Specific personal non-pecuniary interest	Declare and participate
Aleks Radunovic	Principal Investigator, Modulation of muscle stem cell function in motor neurone disease and other neuromuscular disorders (funded by Barts and the London Charity and AR was a signatory).	Non-specific non-personal pecuniary interest	Declare and participate
Aleks Radunovic	Principal Investigator, Phase IIb Multi-national, Double-Blind, Randomized, Placebo Controlled Study to Evaluate the Safety, Tolerability and Efficacy of CK-2017357 in Patients with Amyotrophic Lateral Sclerosis (ALS), Protocol no CY 4026 (funded by Cytokinetics and AR was a signatory).	Non-specific non-personal pecuniary interest	Declare and participate
Aleks Radunovic	Principal Investigator, A prospective multi- centre evaluation of gastrostomy in patients with MND (funded by MND Association and AR was not a signatory).	Specific non-personal pecuniary interest	Declare and participate
Jennifer Rolfe	I have been working with the MNDA on the development of a prescription for a powered wheelchair specifically to meet the needs of people living with MND or other deteriorating neurological conditions. This work has been funded by DOH but has involved working with the following manufacturers: Invacare, Sunrise medical and Ottobock. Each of these manufacturers has donated powered wheelchairs to the MNDA to use with MND clients through their wheelchair services project. The manufacturers have provided funding towards lunch for 3 study days hosted by the Oxford MND Care and Research Centre which is where I work.	Specific non-personal non-pecuniary interest	Declare and participate
Jennifer	Ottobock has agreed to fund my travel	Reasonabl	Declare



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Rolfe	costs to Naidex where I am presenting the clinical aspects of the development of the Neuro powered wheelchair prescription on their stand and also at the National Wheelchair service managers forum session (same day).	e travel expenses	and participate
Jennifer Rolfe	I am presenting at the specialist interest Posture and Mobility Group national training event in April on the development of the Neuro Powered Wheelchair which will involve presenting with the three manufacturers. The manufacturers may offer to fund my day at the event if required. However, no funding was provided in the end. There may also be an article written for the OT News and PMG newsletter on the development of the Neuro Powered Wheelchair (for publication during 2014/2015) and I will submit an abstract for presentation of this project at the International Symposium on MND/ALS (Belgium, December 2014).	Specific personal non-pecuniary interest	Declare and participate
Jennifer Rolfe	I was funded by Oxford Brookes University in October 2013 to travel to Utrecht to visit the MND team there to look at the management of head drop in ALS/MND. Oxford Brookes University were funded by a private donation from Edgar Smith. This has funded the visit and time of a University Lecturer and my expenses (travel and accommodation) for a 2-day stay in Utrecht. As a result of the Utrecht visit I have been working with the orthotics department at the Oxford Universities NHS trust on the design of a customised head support currently provided by them (NHS provision). This work will also produce an article in OT News at some point. This is nearing publication in British Journal of Occupational Therapists but is a descriptive item and describes current practice in Oxford for management of head drop and that in Utrecht. There is reference made to the fact that NICE are developing guidelines for MND but not more than that and not that I am involved with this at all. I am a joint author on this article with the lecturer from Oxford Brookes University.	Specific non-personal pecuniary interest	Declare and participate
Jennifer Rolfe	Recruiting for the TONiC (Trajectories of Outcome in Neurological Conditions) study under Oxford site PI Professor Kevin Talbot (study PI is Professor C A Young – the Walton Centre). This involves me	Non-specific personal non-pecuniary	Declare and participate

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	gaining consent form participants to give them a questionnaire to complete and provide this information and completed questionnaire back to TONiC study staff (commenced recruiting on 23 July 2014).	interest	
Jennifer Rolfe	MND Association are reviewing their published advice to NHS wheelchair services on the provision of wheelchairs for people living with MND which I am contributing to (commenced August 2014). This is clinical advice and I am not responsible for writing the document but giving my clinical opinion on its clinical accuracy. This forms part of my job and as such is not something I am able to withdraw from. The document is a detailed clinical support tool not a guideline.	Specific personal non-pecuniary interest	Declare and participate
Jennifer Rolfe	MND Association are sitting on the NHS England Wheelchair Summit and they discuss work they are undertaking and ask my clinical opinion which they may feed back to that meeting. I am not directly involved with the summit or giving any written/formal feedback.	Specific personal non-pecuniary interest	Declare and participate
Jennifer Rolfe	Interviewed by Wendy Grey from NHS Improving Quality for the NHS England wheelchair summit. I was asked about my clinical experiences of wheelchair services and the current model of service delivery I give in my clinical practice.	Non-specific personal non-pecuniary interest	Declare and participate
Jennifer Rolfe	Attended the International Symposium on MND/ALS and presented a poster on my work with the MNDA on development of Neuro Wheelchair.	Specific personal non-pecuniary interest	Declare and participate
Jennifer Rolfe	Have been a professional reviewer for a research vignette submitted to National Institute for Health Research – which was for a vignette titled: “Intervention to improve the psychological health of people living with MND and their carers”.	Specific personal non-pecuniary interest	Declare and participate
Jennifer Rolfe	The MNDA have been shortlisted for a Health Service Journal Award for Value and Improvement in Specialist Services category for the Powered Neuro Wheelchair project I have been involved with them. There is no personal financial gain from this award. I do not know if there is any prize monies paid to the Association if they are successful in winning this award.	Specific personal non-pecuniary interest	Declare and participate
Ian Smith	There has been an offer of an unconditional educational grant to fund a	Non-specific	Declare and

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	fellow under his supervision from B and D Electromedical Ltd who manufacture ventilatory support devices. This is not linked to any particular study as yet and is likely to fund work relating to sleep apnoea.	non-personal pecuniary interest	participate
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Sandra Smith	Trustee of the MNDA and member of the Trustee Care Committee and Chair of Engagement Committee.	Specific personal non-pecuniary interest	Declare and participate
Sandra Smith	One of 14 Campaign contacts for MNDA (Chair of the Merseyside branch of MNDA. Association Visitor for MNDA (all voluntary capacity).	Specific personal non-pecuniary interest	Declare and participate
Sandra Smith	Gave a presentation at Manchester University for student nurses on 'being a carer for someone living with MND and FTD'. No payment or expenses were received.	Specific personal non-pecuniary interest	Declare and participate
Sandra Smith	I am involved with MND Association renewing and updating information literature with regards to MND and cognitive impairment and FTD.	Specific personal non-pecuniary interest	Declare and participate
Rachel Starer	I will be talking to a group of healthcare professionals about integrated care between primary and secondary services with reference to MND organised by the Oxford MND Centre on 18 March 2015. There is no payment for the event.	Specific personal non-pecuniary interest	Declare and participate
Jean Waters	I chair the Gloucestershire branch of the MND Association and External member MND Association care committee.	Non-specific personal non-pecuniary interest	Declare and participate
Jean Waters	Speaking at GlaxoSmithKline on 08 October 2014 at an ALS seminar on personal experience of living with MND. An honorarium will be paid.	Non-specific personal pecuniary interest	Declare and participate
Jean Waters	Patient representative for NHS England Wheelchair Action Plan – Better Commissioning & Procurement.	Non-specific personal non-pecuniary interest	Declare and participate
Jean Waters	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.	Non-specific personal non-pecuniary interest	Declare and participate

## DRAFT FOR CONSULTATION

Christine Strohmeier (MNDa peer reviewer)	I am employed by the Motor Neurone Disease Association as a Regional Care Development Adviser in South London.	Specific personal financial pecuniary interest	Declare and participate