Motor Neurone Disease

Consultation on draft guideline - Stakeholder comments table
01/09/2015-13/10/2015

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Association for Palliative Medicine of Great Britain & Ireland (APM)	NICE	general	general	We welcome this guideline about the assessment & management of patients with motor neurone disease.	Thank you for your comment.
Association for Palliative Medicine of Great Britain & Ireland (APM)	NICE	10	10	We welcome the recognition that specialist palliative care teams have a valuable role to play for patients with motor neurone disease	Thank you for your comment.
Association for Palliative Medicine of Great Britain & Ireland (APM)	NICE	13 14	13 14	As well as mentioning referral to specialist palliative care services in the section about “planning for end of life care”, we would suggest that referral to specialist palliative care is suggested throughout the guideline in other sections. There is a huge role for palliative care services for patients with motor neurone disease in terms of helping them manage their symptoms (which is extensively discussed in the guideline, but without mention of palliative care referral),	Thank you for your comment. We have altered the recommendations to highlight the importance of palliative care. The recommendations now state that the core MDT should include someone with palliative care skills and that the MDT should have established relationships and prompt access to specialist palliative care. Palliative care services have been added to the information we suggest people are given from diagnosis. The intention in recommendation 1.7.3 of the NICE Guideline was to emphasise

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				psychological needs and future care planning. Referral should be based on need and not because a patient has reached a particular phase of their illness. It may not be possible (nor necessary) for all patients with motor neurone disease to be referred to specialist palliative care services, but we believe there should be mention in the guideline that any patient with troublesome symptoms, psychological needs or complex future care planning needs relating to their MND should be referred to specialist palliative care services.	areas where early referral was most advantageous and we have changed the position of this recommendation to highlight this.
Association of British Neurologists	Full	General	General	We think that these new guidelines are comprehensive, and will be useful in trying to achieve local services to implement them.	Thank you for your comment.
Association of British Neurologists	Full	General	General	We think the NIV sections are very clear and will be useful in trying to achieve local delivery via commissioning.	Thank you for your comment.
Association of British	Full	General	General	We think many centres will have difficulty in complying with	Thank you for your comment. We acknowledge that access to these services

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Neurologists				statements such as (section 1.5.5) - 'The multidisciplinary team should have access to – 'Clinical Psychology and/or neuropsychology' and 'Counselling'. Centre might well have access to these services, in some of the catchment areas they cover, but not always in a timely fashion, and not always with services delivered appropriate close to the patients' homes.	is likely to vary geographically. However the Guideline development group considered it important to include these services to encourage the development of pathways and access.
Association of British Neurologists	Full	General	General	This also holds for Section 1.6.2 – 'Referral to psychological services for a speciality assessment and support' - there is such a shortage of these services. We not only need skilled assessors, but also appropriate support, once the needs have been assessed. We can refer – but sometimes there is over 6 months to wait…	Thank you for your comment and information.
Association of British Neurologists	Full	General	General	So, overall very little negative to feedback, lots of positives, and few specific suggestions for change.	Thank you for your comment.
Association	Full	Gener	Gene	We suspect we all know when we	Thank you for this insight into the

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of British Neurologists		al	ral	are fearful a patient has MND & the limitation to an ordinary Neurologist is usually how long one waits to share/confirm it with the patient/family. The skill of ones neurophysiologist is pivotal but too often there is fence sitting & reversion to El Escoriai criteria etc rather than helpful reporting. this may be different in Regional Units.	difficulties of diagnosis and informing the patient and family. We hope the guideline will improve access to specialist neurologists.
Association of British Neurologists	Full	General	General	As an incurable condition honesty & QoL is vital from the start & so early integration of care important. Because it is rare, small units can't possibly have a specialist nurse to lead on this. But one can action Gastro, Respiratory, SALT AND Palliative care but a key worker would be useful. Where I practice in an ordinary DGH, beyond occasional BTX/baclofen Neurologists could?should be 2nd place & have failed to improve patient experience compared to Palliative Care Teams & hospices, & they often have quicker access to the support that is needed. I continue to see all my patients but	Thank you for your comment. The guideline is recommending a model of clinic based multi-disciplinary care and this model includes co-ordination.

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				what I can offer is small beyond optimal transition to the support care. Across a large area it is hard to know all the different post-coded professionals someone needs to see & cc letters to. Trying to know who all these professionals involved are for any individual is challenging & I have mused upon an individual address book for patients to keep for each of us to write our names/contact etc in.	
Association of British Neurologists	Full	General	General	I always offer a 2nd opinion but <50% take that up.	Thank you for this information.
Association of British Neurologists	Full	General	General	The place of genetics in MND diagnosis and practice remains not fully defined	Thank you for this information. The genetics of MND was not prioritised at scoping.
Association of British Neurologists	Full	General	General	Our view on genetics is that it should be raised with patients if there is a clear family history of MND and/or FTD. If so, we suggest referral to an MND neurologist with interest in MND genetics OR a regional clinical genetics service - as there are huge implications for the wider family if testing is undertaken and these	Thank you for this information. We have added more detail about genetics to sections 6.6 and 8.6 of the Full guideline. Please note that the genetics of MND was not prioritised during scoping

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				should be discussed before an individual consents to testing. The clinical genetics community are now much better informed about MND genetics, and I, and others, work closely with them.	
British Dietetic Association (Neurosciences Specialist Group)	Full	14	12	Question 1: Regarding a single point of contact. This may be challenging if there is no MND specialist nurse	Thank you for your comment and for the suggestions that you give in your comment relating to question 2 below. The Guideline development group agree that different professionals can hold this role. This role may also held by different professionals at different stages of the patient journey.
British Dietetic Association (Neurosciences Specialist Group)	Full	14	12	Question 2: If there is no MND specialist nurse, an allied health professional (e.g. occupational therapy, speech and language therapy, dietitian, physiotherapist) could be allocated as a key worker.	Thank you for these suggestions.
British Dietetic Association (Neurosciences Specialist Group)	Full	16	1	Question 1: Some allied health services do not currently have funding for seeing people in their own homes, therefore if the expectation is that all members of the multidisciplinary team (MDT) can see people in their own homes this will present a challenge.	Thank you for this information. We hope that the guideline will improve access for people with MND to the services they require.

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British Dietetic Association (Neurosciences Specialist Group)	Full	16	1	Question 2: Funding could be sought for community work based on this guideline. Other members of the MDT who do currently have funding to see people in their own homes should work closely with MDT members who are hospital based in order to complete assessments and make recommendations on their behalf, with provision of sufficient training to support this process.	Thank you for this suggestion.
British Dietetic Association (Neurosciences Specialist Group)	Full	22 23	29 - 42 1 - 5	We are concerned that there is no reference to withdrawal of artificial nutritional support. There is reference to withdrawal of non-invasive ventilation (pages 30 – 31).	Thank you for your comment. This area was not included in the guideline scope. Reference to the withdrawal of artificial hydration is included in the NICE guideline on Care of the Dying Adult recommendation 1.4.10 of the NICE guideline. For people already dependent on clinically assisted hydration (enteral or parenteral) before the last days of life: • Review the risks and benefits of continuing clinically assisted hydration with the person and those important to them. • Consider whether to continue, reduce or stop clinically assisted hydration as the person nears death.

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					The published Care of the Dying Adult guideline has been added to the list of related guidelines on p.34 of the NICE guideline.
British Dietetic Association (Neurosciences Specialist Group)	Full	22 23	29 - 42 1 - 5	We are concerned that there is no reference to preferred method of gastrostomy insertion in terms of patient risk / outcomes i.e. percutaneous or radiological. This is also not covered in pages 233 – 234.	Thank you for your comment. The scope included the timing of gastrostomy but did not prioritise method of gastrostomy. More details on enteral nutrition are included in NICE Clinical guideline CG32: Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition.
British Dietetic Association (Neurosciences Specialist Group)	Full	22	29-37	We are concerned that there is no recommendation about who is best placed to initiate/undertake conversations regarding gastrostomy placement (although there is a recommendation that it should be the neurologist who assesses people with frontotemporal dementia as part of the gastrostomy placement decision-making process).	Thank you for your comment. The Guideline development group considered that this was a detail of gastrostomy placement which would require discussion with the professionals involved in this procedure. The guideline scope included timing of gastrostomy only.
British Thoracic Society	Full	General		There is no comment on follow up. Follow up should take into account adherence and	Thank you for your comment. We have added more detail to recommendations concerning the MDT assessment to include

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				symptom response, perceived patient benefit supported by control of arterial blood gases.	reference to monitoring and review of problems and their treatments
British Thoracic Society	NICE	5	15-18	Diagnosis and prognosis of Motor Neurone Disease may be given by other staff e.g. respiratory medicine, especially when there is, for example a respiratory presentation. The important comment is the person who breaks the diagnosis should have the knowledge and be able to access all of the infrastructure that is required. Whilst in some places this may be neurologists in other places respiratory physicians are the individuals who often make the diagnosis and certainly will break the bad news and discuss issues around end of life.	Thank you for your comment. The Guideline development group recognised that there are situations when the diagnosis of Motor Neurone Disease will be given by specialists other than neurologists because of clinical need. This would include a respiratory presentation where the patient has to be informed of the diagnosis so that care can be provided. The recommendation about giving the diagnosis recognises this. The evidence reviewed for the guideline and the view of the guideline group was that the person giving the diagnosis of MND needs to have extensive knowledge of MND as outlined in recommendation 1.2.1 in the NICE Guideline. This includes symptoms of MND, types of MND, treatment options, opportunities to be involved in research. The guideline group considered that consultant neurologists were the specialists who usually have this information.
British Thoracic	NICE	17	3	Not sure of the evidence of	Thank you for your comment. The Guideline development group reviewed this

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Society				nebulised bronchodilators / humidification for thick tenacious saliva. As far as we are aware there is no evidence that nebulising drugs is going to help saliva, though of course it may help some aspects of secretions. In fact some nebulised drugs e.g. Ipratropium may exacerbate thick saliva.	recommendation and agree that there is no evidence. However they also agree that clinically they do seem to benefit some patients and a trial may be useful.
British Thoracic Society	NICE	20	10	It may not be a neurologist who makes this decision "lead consultant" may be a better term, recognising the role of the MDT.	Thank you for your comment. We have added reference to the MDT and ventilation team for this decision.
British Thoracic Society	NICE	23		Offer and timing NIV should be made by a respiratory physician who may be at the MDT. This is a very surprising change that you have the MDT (or a neurologist), on the basis of physiology, deciding when NIV should be administered. Respiratory physicians are not	Thank you for your comment. The Guideline development group have reviewed the wording of the recommendation. The Guideline development group consider that the requirement for the core Guideline development group is someone who will be able to assess and monitor respiratory function and that this may not be a

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				"technicians" who will deliver NIV they are the ones who will make the judgement about its introduction and usually cessation.	respiratory physician. The Guideline development group agree that the decision to offer NIV does require involvement of relevant specialists and have altered the wording accordingly. The Guideline development group changed the wording to 'ventilation' team as this is the expertise that is required and may in some centres be provided by anaesthetic teams.
British Thoracic Society	NICE	31	16	Not always an MDT is appropriate for that decision. The individual making the decision for the introduction of NIV, usually the respiratory consultant, is the individual who is probably best placed to have the conversation about the implications of non-invasive ventilation and assess whether the patient (and family) can understand the implications thereof. The "overseeing" MDT may be too distant and certainly not timely enough to make decisions around the introduction of NIV which,	Thank you for your comment. The version of this recommendation in the NIV guideline suggested that this was a decision for the neurologist. The Guideline development group considered that this was too narrow and that it was more appropriate to include the wider multidisciplinary team as they recognised that other people include respiratory team may also be involved.

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				regrettably because of delays of referral to respiratory physicians, still has to be instituted as a matter of urgency on some occasions.	
British Thoracic Society	NICE	32	23/24	Surely it should be the team that initiated the non-invasive ventilation making the decisions. Patients may wish to stop NIV because there is no benefit, however as hopefully the NICE team appreciate, the respiratory muscle condition may progress more rapidly than other "limb" muscles and therefore as a consequence patients may find that non-invasive ventilation is not producing benefit and this is because the settings need to be changed. This sort of decision i.e. withdrawal of ventilation or "changing the settings" should be made by a respiratory physician ideally working within	Thank you for your comment. The Guideline development group have reviewed the wording of the recommendations around NIV. The Guideline development group agree that decisions related to NIV do require involvement of relevant specialists and have altered the wording accordingly. The Guideline development group changed the wording to 'ventilation' team as this is the expertise that is required and may in some centres be provided by anaesthetic teams.

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				a respiratory MDT, communicating with all parties. We note the 2010 guideline had a respiratory physician embedded with the MDT. Whilst we appreciate that this is fundamental around non-invasive ventilation hence the key role of the respiratory physician we hope the review team from NICE appreciate that the majority of deaths and complications from Motor Neurone Disease are of a respiratory nature and therefore not having respiratory input into the core of the MDT or to be making the decisions is a fundamental failing of this NICE guideline/update.	
British Thoracic Society	NICE	46		It is important to recognise that it is a combination of both symptoms and respiratory function that needs to be	Thank you for your comment. This section relates to changes from previous NIV guideline.

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				considered. Moreover there is no clear recommendation about "respiratory function". Sleep fragmentation is an important issue, as a consequence of nocturnal hypercapnoea which may not be detected by simple pulmonary function tests / mouth pressures. We do not think respiratory function tests encompass any form of sleep assessment / transcutaneous carbon dioxide monitoring and therefore symptoms, as outlined in the document such as lethargy, anorexia, malaise is an important indication for consideration of non-invasive ventilation. This should be stressed.	Specific recommendations about respiratory symptoms and functions are found in recommendations 1.14.7-1.14.14 of the NICE Guideline.
College of Occupational Therapists	Full	General		The College of Occupational Therapists welcomes this very comprehensive and well written guideline. Overall it recognises the individual contribution of	Thank you for your comment.

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				occupational therapy and within the context of the wider multi-disciplinary team.	
College of Occupational Therapists	Full	General		The COT welcomes the person-centred approach, recognising the individual needs and wishes of people with MND evident throughout this guideline	Thank you for your comment.
College of Occupational Therapists	Full	16		Could this also include podiatry and dentistry?	Thank you for your comments. The Guideline development group considered this suggestion and agreed that these were not necessary to include. The list that is included is not exhaustive but emphasises those services that are of specific relevance to people with MND.
College of Occupational Therapists	Full	57	21	The COT would like to see the inclusion of work as this is a major omission and would benefit from expansion, as it is not include anywhere any where in the document. The COT would like to see advice /support for people who want to continue working after diagnosis.	Thank you for your comment. The Guideline development group agree and have added reference to work to several recommendations.
College of Occupational Therapists	NICE	4	8	The COT welcomes the continued and integrated care of people with MND across all care settings.	Thank you for your comment.
College of	NICE	4	13	This offers a clear and	Thank you for your comment.

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Occupational Therapists				comprehensive list of symptoms which can be apparent from an early stage	
College of Occupational Therapists	NICE	5	1	The COT welcomes the inclusion of cognitive changes in people with MND	Thank you for your comment.
College of Occupational Therapists	NICE	5	16	The COT would challenge why this information needs to be provided by a neurologist as members of the MDT may be better placed regarding time to more thoroughly support people with MND to understand and respond to this	Thank you for your comment. The recommendations are intended to specify that the information is given rather than by whom and when. We have changed around the order of the recommendations to increase clarity.
College of Occupational Therapists	NICE	6	1	While the COT welcomes the inclusion of Advanced Care Planning it recommends that the MDT should contribute to this as several members of the MDT are able to discuss existential concerns of people with MND	Thank you for your comment. The recommendations do not specify who should do this and we agree that several different members of the MDT will have the skills to do this.
College of Occupational Therapists	NICE	6	2	The COT welcomes the Single Point of Contact but greater clarity is required to confirm if this is across all services or a single point of contact for each service	Thank you for your comment. We have clarified that the single point of contact should be for the MDT. However the role of the MDT is to communicate and coordinate care for the person with MND.
College of Occupational Therapists	NICE	6	22	The COT expresses some concern about this being delivered by the neurologist and suggests that this	Thank you for your comment. The recommendations specify the information that should be providedrather than by

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				should be shared within the MDT	whom and when. We have changed around the order of the recommendations to increase clarity.
College of Occupational Therapists	NICE	7	17	While the COT welcomes the specific reference to Social Services it is suggested that it is unlikely that the neurologist would make this referral as implied within the guideline	Thank you for your comment. The recommendation does not specify who should do the referral rather that it is important that it be considered and done if appropriate.
Compassion in Dying	Full	General	General	Compassion in Dying welcomes this guidance, in particular the introduction of recommendations surrounding advance care planning. We are a national charity working to inform and empower people to exercise their rights and choicesaround end-of-life care. We do this by: • providing information and support over our freephone Information Line; • supplying free Advance Decision to Refuse Treatment	Thank you very much for your comment

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				(ADRT) forms and publications which inform people how they can plan ahead for the end of their life; • delivering one-to-one support to older people through our outreach service, *My Life, My Decision*; • running information sessions and training for professionals, community groups and volunteers on a range of end-of-life topics, including accredited Continuing Professional Development (CPD) modules; • and conducting and reviewing research	

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				into end-of-life issues to inform policy makers and promote patient-centred care.	
Compassion in Dying	Full	General	General	One issue that is not addressed in the guidance is the responsibility of commissioners, policy makers and healthcare professionals' to ensure that recorded preferences can be accessed in a timely manner across all care settings. While this is something that Compassion in Dying would like to see enforced through nationwide policy and systems (for example the introduction of a formal register for ADRTs, similar in principle to the Organ Donor Register), it is something that individual professionals may be able to implement at a localised level. This could be	Thank you for your comment and information and for sharing tools you have developed. We have added the need to consider how advance care plans will be shared to recommendation 1.7.3 in the NICE guideline.

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				done for example by updating a person's summary care record to signify that an ADRT has been made or by discussing the presence and details of advance care plans with other professionals that may be involved in the person's care team, and recording those conversations on an Electronic Palliative Care Co-ordination System (EPaCCS). Research published in April 2014 revealed that 83% of Clinical Commissioning Groups in England had an EPaCCS in operation or were planning to put one in place, so being able to record a person's wishes electronically is something that most healthcare providers will have the facility to do. As is made clear in the evidence supporting this guidance, the	

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				thought that treatment wishes will not be respected at the end of life can be a major concern for people diagnosed with Motor Neurone Disease: "*Carers discussed how it was extremely distressing when advance care plans were not adhered to, and stressed the importance of all staff being aware of and adhering to advance care plans*." (page 168, lines 23-25) This is particularly important for people with Motor Neurone Disease because of the speed at which the illness can progress. Again, this is illustrated in the interviews with carers: "*Deterioration at the end of life occurred more rapidly than*	

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				expected so patients were not as prepared as they had hoped, which had good and bad points (Healthcare professionals and carers). A great deal of time and planning was involved in discussing advance care decisions or planning, but there was the need for staff with knowledge of the care plan to be available at critical points (Healthcare professionals)." (page 270, lines 8-12). This evidence echoes what callers to our Information Line tell us in follow-up monitoring. When asked what concerns them most about their treatment wishes being respected, 58% of people said their biggest fear was that healthcare professionals would not be aware of what they, as the patient, wanted. More feedback	

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				from our service users, including the evidence that shows those who plan for the end-of-life are more likely to die well can be found in our recent publication, Plan Well, Die Well. It is therefore essential that healthcare professionals are trained in all aspects of advance care planning and that there are robust systems in place so that advance care plans are available to the right people at the time when they are needed. We have published a toolkit for healthcare professionals, which explains how an advance decision can be made and implemented, this can be found here.	
Compassion in Dying	Full	18	33-41	We believe everyone should be aware of their legal rights	Thank you for your comments. We agree with your view and were not intending the recommendations to mean that some people should not be given the opportunity

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				and choices when making decisions about their treatment, including how to plan their treatment in advance in a legally binding way. This means giving people access to expert information and providing support to make choices and to make their preferences known. While the recommendations on page 18 encourages discussions around advance care planning, we feel that more stress needs to be placed on empowering people to act on their rights by supplying them with information as soon as possible. Individuals may engage with the topic or decide to come back to it later and, crucially, carers and families will be able to do the same. In the	to have an early discussion. We have changed the order of the recommendations to make that more clear. However the Guideline development group did consider that people's views differ about when they want these discussions and did want to specify situations where the doctor may need to consider action on this at earliest opportunity.

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				current wording, too much emphasis is placed on the subjective view of the doctor to determine the most appropriate time to do this. While sensitivity to timing should be a factor, we believe people should be able to discuss their wishes at the earliest possible opportunity. We recommend that conversations about advance care planning take place at the diagnosis stage. This should include supplying information on the tools that are available for people to plan for the end of their lives in a legally binding way. If people are given the opportunity to create an advance care plan early in their diagnosis, then trigger points such as changes in respiratory function or gastronomic	

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				intervention provide identifiable stages for treatment preferences to be reviewed and updated. Some people find starting conversations about planning for the end of life difficult. We fear the current wording of the guidance may discourage healthcare professionals from discussing advance care planning, because they may feel unable to determine what a "sensitive time" may be. This would deny some people from being able to express their preferences for the end of life, because they may be unaware of the existence of tools that enable this. Feedback from our outreach service, *My Life, My Decision*, suggests that initially people may be reluctant to discuss their	

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				end-of-life preferences, though once these conversations are started they can act as a gateway to further consideration and reflection. Initially, preferences may be recorded in an Advance Statement, which allows a person to express what is important to them at the end of life and the values or beliefs that underpin this (for example, specifying a preference of bathing over showering, or outlining religious or spiritual views, or how they define quality of life). Over time this may lead to formally recording the specific treatment the person would like to refuse in an ADRT, or appointing someone who can make decisions on their behalf should they lose mental capacity through a Lasting Power of Attorney for Health and Welfare.	

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				We believe this process is especially applicable to people diagnosed with Motor Neurone Disease, whose treatment preferences may alter depending on the nature and severity of their symptoms as the disease progresses.	
Department of Health	Full	General		Thank you for the opportunity to comment on the draft for the above clinical guideline. **I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.**	Thank you for your comment.
Glyndwr University	Full	184	6	The interventions omits a major intervention which is "engagement in daily activity". This is primarily the form that people with MND will carry out "exercise". The wealth of evidence for occupational science and that engagement of daily function enhances well-being is key to enabling exercise for people with	Thank you for your comment. The Guideline development group acknowledge that engagement in daily activity would be good for the physical and mental health of people with MND. We were specifically looking in this question at treatment interventionsthat the Guideline committee prioritised..

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				MND. I am willing to provide studies which provide such evidence.	
Glyndwr University	Full	185	15	There are two studies which should be considered within the evidence: 1: Mezzani A et al (2012) Reduced exercise capacity in early-stage amyotrophic lateral sclerosis: Role of skeletal muscle. Amyotrophic Lateral Sclerosis. 13; 87-94. This shows that deconditioning is in main cause of impaired exercise capacity in MND and hence provides a form of evidence that exercise should be enabled and guided by therapists from diagnosis. 2: Pinto S et al (2012) Respiratory exercise in amyotrophic lateral sclerosis. Amyotrophic Lateral Sclerosis. 13: 33-43. This states that a minor positive effect of aerobic exercise can not be ruled out.	Thank you for your comment. These studies did not meet the inclusion criteria for this review (please refer to appendix C for more details). Mezzani (2012) was not a randomised controlled trial and where we had RCTs we would not include other types of study design in the evidence review; Pinto (2012) involves respiratory exercise and the Guideline development group did not include respiratory related programmes but were concerned with muscle cramps and fasciculation, increased tone (including spasticity, muscle spasm or stiffness) and muscle stiffness, wasting or atrophy**.**
Glyndwr University	Full	192	28	Given the above studies and the commentators clinical experience with MND, point 47 should include: "the programme might be *an aerobic programme*, a resistance	Thank you for your comment. Please see response above, unfortunately we cannot include an aerobic programme in this recommendation as we have no evidence of its effect on: muscle cramps and

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				programme" etc.	fasciculation, increased tone (including spasticity, muscle spasm or stiffness) and muscle stiffness, wasting or atrophy.
Glyndwr University	Full	193	28	There is a study with emerging findings (to be presented in work in progress poster form at International MND Symposium, Orlando 2015) that therapy provision is key to appropriately challenging the system in MND at a productive level: the effect is not continued when family members/carers deliver in absence of direct therapy involvement.	Thank you for this information. We look forward to the findings from this work being available when this guideline is reviewed for update.
Glyndwr University	Full	213	15	There is concern that occupational therapists prescribe equipment and adaptations to make ease of accomplishment of activities of daily living when the person with MND has the potential to be engaged in activity and therefore achieve the task without the aid. The adaptations and aids therefore have capacity to further disable the person. The recommendation should include provision of equipment when need is omnipresent rather than when need	Thank you for your comment. The Guideline development group did not think it appropriate to add such a recommendation. They considered that the timing of provision of equipment and adaptations will be dependent on multiple factors. While equipment and adaptations may disable a person there is also concern that people should be given equipment and adaptations in a timely manner particularly in a progressive disease.

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				is envisaged in future.	
Glyndwr University	Full	213	15	A large role of occupational therapy within MND is to empower and enable achievement in purposeful occupation; this document translates that occupational therapists purely provide a compensational frame of reference rather than a rehabilitative frame of reference. There is much qualitative information that people with MND achieve a higher quality of life when empowered and enabled to achieve rather than preoccupation on fatigue management and equipment/adaptation provision. This will be discussed within a study with emerging findings (to be presented in work in progress poster form at International MND Symposium, Orlando 2015).	Thank you for your comment. Unfortunately the publication of this study will be after our date cut-off for inclusion of studies into the Guideline. This issue will be flagged for consideration when the guideline is reviewed for update.
Hywel Dda University Health Board	NICE	6	6	Information should be provided to GPs on the condition and should recommend that patients are added to the GP palliative care register.	Thank you for your comment. We have added information about likely prognosis to this recommendation and included detail about palliative care register to the Full guideline.
Hywel Dda University	NICE	6	6	At diagnosis patients should be referred to the MDT for	Thank you for your comment. The guideline recommends that people with

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Health Board				assessment.	MND be cared for by a MDT team and the Guideline development group did not think an additional recommendation was required.
Hywel Dda University Health Board	NICE	9	5	We feel the words shown in red should be added: 1.5.3 The multidisciplinary team should assess the following: Weight, weight history, height, body mass index, diet, hydration, nutritional and fluid intake and requirements, feeding, drinking and swallowing (see recommendations 1.10.1–1.10.10).	Thank you for your comment. We have added reference to hydration and drinking to recommendations where appropriate. The Guideline development group preferred not to mention BMI in recommendations regarding nutrition. The Guideline development group considered that measurements of weight and height can be difficult in people with MND and preferred to mention weight only and not want to mandate measurement of height.
Hywel Dda University Health Board	NICE	17	24-25	Fluid intake needs to be taken into account with sialorrhoea - i.e avoid dehydration	Thank you for your comment. The recommendation includes attention to hydration.
Hywel Dda University Health Board	NICE	18	17-22	We feel the words shown in red should be added: 1.10.1 At diagnosis and at multidisciplinary team assessments, or if there are any concerns about weight, nutrition, hydration or swallowing, assess the person's weight, weight history, height, body mass index, diet,	Thank you for your comment. We have included 'fluid intake' and 'drinking' in this section. The Guideline development group preferred not to mention BMI in recommendations regarding nutrition. The Guideline development group considered that measurements of weight and height can be difficult in people with MND and preferred to mention weight only and not t to mandate measurement of height.

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				nutritional and fluid intake and requirements, oral health, feeding, drinking and swallowing, and offer support, advice and interventions as needed (see recommendations 1.10.2–1.10.10). See the NICE guideline on nutrition support in adults. [new 2016]	
Hywel Dda University Health Board	NICE	18	23	We feel the words shown in red should be added: 1.10.2 Assess the person's diet, hydration, nutritional and fluid intake by taking into account:	Thank you for your comment. We agree and have changed the wording to include these suggestions.
Hywel Dda University Health Board	NICE	18	25	We feel the words shown in red should be added: ☐ oral intake versus nutritional and hydration needs of both solids and liquids	Thank you for your comment. We agree and have changed the wording to include these suggestions.
Hywel Dda University Health Board	NICE	18	27	We feel the words shown in red should be added: ☐ appetite, thirst	Thank you for your comment. We agree and have changed the wording to include these suggestions.
Hywel Dda University	NICE	18	18/19	Along with weight, should be assessed at diagnosis along with %	Thank you for your comment. The Guideline development group reviewed the

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Health Board				weight loss. This should be repeated at regular intervals. There needs to further emphasis on the assessment of nutritional status along with assessment of dietary intake and mechanical/environmental problems that may affect eating and drinking.	wording and considered that these aspects are included in the recommendation in this section or in NICE guideline CG32 Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition
Hywel Dda University Health Board	NICE	18	16	We feel the words shown in red should be added: 1.10 Nutrition, hydration and artificial nutrition and hydration including gastrostomy	Thank you for your comment. We have changed the wording to include hydration but felt the longer title was unnecessary.
Hywel Dda University Health Board	NICE	19	4	We feel the words shown in red should be added: 1.10.3 Assess the person's ability to feed and drink by taking into account:	Thank you for your comment. We have changed the wording to include 'and drink'.
Hywel Dda University Health Board	NICE	19	21	We feel the words shown in red should be added: fear of choking and psychological considerations (for example wanting to eat and drink normally in social situations). **[new 2016]**	Thank you for your comment. We have changed the wording to include 'and drink'.

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Hywel Dda University Health Board	NICE	19	22	We feel the words shown in red should be added: 1.10.6 Pay particular attention to the nutritional and hydration needs of people with MND who have frontotemporal dementia and who lack mental capacity. The multidisciplinary team assessment should include the support they need from carers, and their ability to understand the risks of swallowing difficulties. **[new 2016]**	Thank you for your comment. We have changed the wording to as suggested.
Hywel Dda University Health Board	NICE	19	29	We feel the words shown in red should be added: 1.10.7 Discuss gastrostomy at an early stage, and at regular intervals as MND progresses, taking into account the person's preferences and issues, such as ability to swallow, weight loss, respiratory function, urea and electrolyte levels,	Thank you for your comment. This area is included in more detail in CG32 Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition. CG32 does not include urea and electrolyte levels.
Hywel Dda University Health Board	NICE	19	5	☐ the need for feeding and drinking aids and altered utensils to help them take food from the plate to	Thank you for your comment. We have changed the wording as you suggested.

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				their mouth	
Hywel Dda University Health Board	NICE	19	7	☐ the need for help with food and drink preparation	Thank you for your comment. We have changed the wording as you suggested.
Hywel Dda University Health Board	NICE	19	9	☐ advice and aids for positioning, seating and posture while feeding and drinking	Thank you for your comment. We have changed the wording as you suggested.
Hywel Dda University Health Board	NICE	20	1	We feel the words shown in red should be added: effort of feeding and drinking and risk of choking. Be aware that some people will not wish to have a gastrostomy. **[new 2016]**	Thank you for your comment. We agree and have changed the wording to include 'and drinking'.
King's College Hospital	NICE	5	6	"Specify the suspected diagnosis in the referral letter". Not always appropriate if just suspected.	Thank you for your comment. The Guideline development group considered that if the referrer had reason to suspect MND it would be helpful to the neurology department to know this as this information might allow the hospital department to triage the referral more effectively.
King's College Hospital	NICE	8	9	1.4.1 "Estimate survival time on an individual basis". Should be clarified. If survival is estimated, should be done on an individual basis. Otherwise sounds like you must always estimate survival time,	Thank you for your comment. We have altered the wording of the recommendation to indicate that these are the issues to consider when planning care.

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				but it can be difficult, is often inaccurate, and is not always wanted. Other factors such as cognitive impairment, genetic status and biomarkers may also impact the prognosis.	
King's College Hospital	NICE	9	4	1.5.3 MDT assessment. Should include end of life needs.	Thank you for your comment. We have updated the section to include this.
King's College Hospital	NICE	9	24	1.5.4 Core MDT. Should include a palliative care physician and clinical specialist coordinator. It is extremely concerning that there is no mention of the widely recognised and accepted role in the UK of clinical specialist coordinator (see recently published MND Association Outcomes standards document) as part of the Core MDT. None of the papers cited in the full guideline as evidence for this decision specifically look at whether there is additional benefit from the role of specialist coordinator or indeed the specific impact of any other individual disciplines cited in the make up of the Core MDT. We strongly	Thank you for your comment. We have added skills in palliative care to the description of the core MDT. We have clarified that we do consider co-ordination an important part of the role of the MDT but have not specified who within the MDT should be responsible for this.Regarding the interpretation of the papers we did not analyse the Republic of Ireland general neurology clinic compared to the northern Irish ALS care network coordinator, as these did not, as you say, examine any individual component of the MDT. We only analysed the 2 groups together compared to the multidisciplinary team, as we know that the other 2 groups did not include multidisciplinary care. Therefore we did not use this study to

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				disagree with the interpretation of the paper comparing Ireland with Northern Ireland (Rooney 2015). That study did not examine any individual component of the MDT and no conclusion can therefore be drawn regarding care coordinators. We also think there has been confusion between the roles of a Case Manager (Creemers 2014) and a Care Coordinator. They are not the same. You also cite a low quality paper that apparently supports a Care Coordinator, but the reference is not given. This is a crucial part of current care in the UK. Lack of evidence to support a role is not the same as evidence against the role, but at the moment the guideline is worded as if the evidence is against the benefits of a care coordinator.	make the recommendations regarding co-ordination of MDT. The following sentence has been removed from the LETR 'however, the studies in Ireland indicated that the addition of a coordinator per se was not as beneficial as the coordinated MDT approach.' The paper you refer to is Cordesse 2015, a before-and-after study, which we have not cited within the quality of evidence part of the LETR.
King's College Hospital	NICE	9	24	Despite the lack of evidence it is a real shame that the Motor neurone disease co-ordinator is not identified as a key member of the team, both as a support	Thank you for your comment. The guideline does recommend that care be co-ordinated but does not specify a specific role/position by which this can be achieved. The Guideline development group were aware of the MND care co-ordinator role

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				for the patients and for the organisation of the clinic.	and the intention was not to devalue their role. However the evidence for improved outcomes comes from a clinic based model where co-ordination is part of the role of the MDT. We have altered the recommendations to highlight this aspect of care which was not emphasised adequately in the draft guideline. Who in the MDT co-ordinates care is not prescribed and we agree that this may be a specialist nurse or other AHPs.
King's College Hospital	NICE	15	7	1.8.3 Consider use of word "spasms" in symptom list. Physiotherapy can also be effective.	Thank you for your comment. The Guideline development group felt the wording 'increased tone' covered spasticity, muscle spasm or stiffness'.
King's College Hospital	NICE	16	8	No mention of radiotherapy which can be successful as a last resort	Thank you for your comment. No evidence was identified regarding radiotherapy for destruction of salivary glands. The position of radiotherapy is discussed in the Full guideline in section 14.
King's College Hospital	NICE	16	23	The wording of saliva should be replaced with 'secretions' as this description of thick and tenacious usually demonstrates	Thank you for your comment. The Guideline development group reviewed the wording of the recommendations and did not agree that thick and tenacious secretions indicate a chest infection.

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				a chest infection.	
King's College Hospital	NICE	17	1	Advice on secretion clearance and cough augmentation techniques should be added as a treatment option as this section of the guideline is implying that the patient has a chest infection.	Thank you for your comment. The Guideline development group reviewed the recommendation but do not agree that thick and tenacious secretions are indicative of a chest infection and have therefore not added to this recommendation.
King's College Hospital	NICE	20	19	No mention of voice banking	Thank you for your comment.Voice banking was not prioritised during scoping.
King's College Hospital	NICE	21	21	Giving an example of 'manual assisted cough' as a cough augmentation technique may make it clearer for clinicians who are not familiar with the techniques.	Thank you for your comment. We have changed recommendation 1.13.2 of the NICE Guideline in line with your suggestion and have updated the glossary with an explanation of manual assisted cough.
King's College Hospital	NICE	21	27	Use of the lung recruitment bag may be unavailable due to manufacture changes.	Thank you for your comment. We are aware that a manufacturer has withdrawn supply but consider that this is still a valid treatment option with an evidence base which needs to be included in the guideline..
King's College Hospital	NICE	26	7	There should be a point about using a face mask instead of a mouth piece to complete the	Thank you for your comment. These recommendations are from CG105 and were not updated in this guideline

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				Forced Vital Capacity/Vital Capacity respiratory tests if the patient has bulbar weakness.	
King's College Hospital	NICE	27	21	1.14.15 and Table 2. What is the suggested reference for the predicted FVC? There are several different ones available with greatly differing predictions.	Thank you for your comment. These recommendations are from CG105 and were not updated in this guideline
King's College Hospital	NICE	33	16	The forms of MND listed are not logical (although widely used) as three of them are based on the neuronal type involved and one on the site of disease burden or onset. I would suggest omitting progressive bulbar palsy from the list. The guideline already states that the bulbar region can be affected. If that is needed to be stated more clearly, then an additional line can be added to say that MND may affect swallowing and speaking, the limbs or the breathing muscles first.	Thank you for your comment. We have rewritten this section.
King's College Hospital	NICE	34	16	Might be useful to state that about 1 in 300 people dies of MND. Also, the statement there is "increasing evidence" of a genetic basis is not correct. There is a genetic	Thank you for your comment. We have rewritten this section.

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				component to MND. This is beyond doubt as the evidence is overwhelming. Ref: Johnston CA et al J Neuro 2006 253:1642-3	
King's College Hospital	NICE	35	8	Recommendations for research are a bit limited and too specific. For example, ALS prognostic index is just one of many prognostic tools. What about biomarkers, genetics, molecular models, understanding survival, understanding environmental risks etc etc. Either expand massively or make more general.	Thank you for your comment. The research recommendations in the guideline are not intended to be a comprehensive list of possible research on MND but areprioritised from the key uncertainties identified during guideline development. The systematic reviews included in the guideline examined only those areas identified during the scoping process.
Marie Curie	NICE	General	General	Marie Curie provides care and support for people living with a terminal illness, such as MND, and for their families and carers. We are also the largest charitable funder of research into palliative and end of life care in the UK. We welcome the opportunity to comment on the updated guidance on MND. In particular we are very supportive of the inclusion of the new section 1.7 'Planning for end of life care'.	Thank you for your comment and this information.

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				Our response is informed by what we know about the palliative and end of life care needs of people with MND through our services and research. Our research activity has included working with the James Lind Alliance on the Palliative and End of Life Care Priority Setting Partnership, a public engagement exercise which identified key unanswered research questions about the care and support needs of people approaching the end of life. Many of these were raised in the context of or apply to the needs of people who are living with MND. We believe that this guideline does provide some helpful guidance on the priority areas identified through this exercise, although there is clearly a need for further research.	
Marie Curie	NICE	General	General	We believe it would be helpful for palliative care to be mentioned earlier in the guidelines. Although the 'Planning for end of life' section (1.7) does suggest that palliative care may be appropriate from	Thank you for your comment and links to reports. The section is called 'planning for end of life' and as you say suggests this can be discussed from diagnosis. We have added reference to potential involvement of palliative care to recommendation 1.7.3 in

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				diagnosis, the inclusion of the bulk of information about palliative care in this 'end of life' section may mean it is not properly considered for people who are not felt to be in their final year (as this is a common interpretation of end of life), and gives the impression that it is not normally integrated into a package of care. Evidence shows that a referral to specialist palliative care at diagnosis or as soon as sensitively possible can have a substantial impact on a person's psychological and spiritual wellbeing when they are living with MND, strengthens support for their family, and supports disease management in the later stages (See Marie Curie's Triggers for Palliative Care report; also APPG on MND 2011 Inquiry into Access to Specialist Palliative Care). The following comments contain suggestions for including palliative care earlier in the guideline as part of some of the new	the NICE Guideline as well.

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				recommendations. We believe this could impact on practice by encouraging all professionals to consider a referral to specialist palliative care as a routine part of treatment following a diagnosis of MND. The variable availability of specialist palliative services to people with MND will be a key challenge to implementing this.	
Marie Curie	NICE	6	1	Suggest including another point in list: 'Knowledge about appropriate referral to specialist palliative care'	Thank you for your comment. The Guideline development group discussed this and have added reference to palliative care in list of items people should be informed about rather than in this recommendation.
Marie Curie	NICE	6	26	Suggest including '… and palliative care' in parentheses, as well as social care	Thank you – we have added this as you suggest.
Marie Curie	NICE	10	10	We welcome the inclusion of specialist palliative care in the list of services the MDT should have access to. We are however concerned that this recommendation replaces the section of the 2010 guidelines which says 'The team should include… a specialist in palliative	Thank you for your comment. The previous guideline covered NIV only while this guideline makes recommendations for all people with MND. We have added that the MDT should include a professional with palliative skills.

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				care' (p39). As MND is a condition for which specialist palliative care is very appropriate and should typically be available as soon after diagnosis as is appropriate, we hope that this change from MDT inclusion to access is based on evidence which supports that this will not impact on the care available to people with MND.	
Marie Curie	NICE	13	2	We are very supportive of the trigger point approach to planning for end of life care set out here and the inclusion of diagnosis as a trigger. We believe it would help to emphasise that earlier referral to specialist palliative can have a substantial impact on a person with MND's psychological wellbeing and supports disease management in the later stages. The wording of 1.7.3 suggests that early referral should only be considered for those with the most complex needs.	Thank you for your comment. The Guideline development group have altered the recommendations to highlight the importance of palliative care. The recommendations now state that the core MDT should include someone with palliative care skills and that the MDT should have established relationships and prompt access to specialist palliative care. Palliative care services have been added to the information we suggest people are given from diagnosis. The intention in recommendation 1.7.3 of the NICE Guideline was to emphasise areas where early referral was most advantageous and we have changed the position of this recommendation to highlight this.

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Marie Curie	NICE	13	21	'…including use of Just in Case kits/boxes'. These are widely used in palliative care settings and therefore warrant mention in this guideline. More information on the MNDA Just in Case kit here. (This comment is also relevant to pg. 14, line 17).	Thank you for your comment. We have used the term 'anticipatory prescribing' in line with NICE guideline on Care of the Dying Adult.
Marie Curie	NICE	35	8 onwards	We support the inclusion of recommendations for research. The research topics identified here fit well with some of the topics identified as needing further research through the Palliative and End of Life Care Priority Setting Partnership work previously mentioned, in particular: managing symptoms relating to drooling and salivation; managing symptoms relating to nutrition (in relation to weight loss and difficulty swallowing), and delivering appropriate care (including pain relief, palliative and end of life care) to people when their cognition and communication is affected. One of the 'top ten' unanswered	Thank you for this information.

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				questions identified through the Priority Setting Partnership relates to the best ways to begin and deliver palliative care to people with non-cancer conditions, such as MND. We feel that better evidence-based guidance on when and how to begin palliative care for people with MND would strengthen this guideline. As per comments 2 and 6 of this response, this guideline is not completely clear on this issue, which may perhaps be a consequence of the need for greater research in this area. A lack of clear guidelines is likely to impact on whether people receive the care they need when they need it. We therefore hope that this and the other findings of the Priority Setting Partnership will be considered when finalising the research recommendations. For more information, please contact Natasha.wynne@mariecurie.org.uk.	
Motor	All	genera	Gene	The MND Association welcomes	Thank you for your support and comment.

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Neurone Disease Association		l	ral	this draft guideline. We are confident that it will be a highly useful tool in raising standards of MND care, and intend it to be a central element in our work with statutory services and other stakeholders from 2016 onwards. We feel that the draft guideline is predominantly a helpful statement of best practice, and there is far more of it that we are happy with than we would wish to see changed. Inevitably, this response will focus mainly on aspects we would like to see improved, but we would not want this to disguise our general satisfaction with the draft. We are grateful to NICE and the members of the Guideline development group for producing it.	
Motor Neurone Disease Association	All	general	general	In some instances, we feel that the summary guideline has omitted helpful content from the full guideline that it would be better for it to include. We appreciate the tension between the need for	Thank you for your suggestions which we will respond to individually. The short version is intended to make clear the actions required by professionals rather than provide the rationale.

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				brevity and the need to offer full and rounded guidance, but we will highlight a few respects in which we strongly believe the summary guideline – as the version to which health and social care professionals will turn most frequently – should be expanded.	
Motor Neurone Disease Association	All	general	general	People living with and affected by MND are not permitted to respond directly to this consultation; instead, we are the stakeholder with whom they are required to register their views in England, Wales, Northern Ireland, the Channel Islands and the Isle of Man. In order to facilitate this, we constructed an online survey which went live on September 8th and closed on September 30th. There were 390 respondents, among whom were people with MND, carers, former carers, and some health and social care professionals (although generally we expect their professional bodies to represent their views). A representative	Thank you for your work in representing people with MND and their families and carers and for providing an overview of the responses. For your information individuals can comment on draft guidelines but we do not respond to their comments or publish them online.

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				selection of free text answers to this survey is included at appropriate points in this response. This response is informed by the evidence gathered through that survey, and also by comment from expert staff within the MND Association, who have considerable experience of working with people with MND.	
Motor Neurone Disease Association	All	general	general	Additionally, this response is informed by a piece of research commissioned by the MND Association to investigate different configurations of MND care. The Models of Care project is being run by the independent consultancy OPM, and will deliver its final report by the end of 2015. An interim report, which outlines findings to date from a literature review, an online call for evidence and telephone interviews with clinicians and other practitioners, has already been delivered. We will be happy to share the interim report, and full	Thank you for your comment and this information. Unfortunately we are not able to include any further evidence in this review. However it will be considered when reviewing the need to update the guideline. The Guideline development group are aware that care is organised in a multiplicity of ways and that that care can be of high standard. The recommendation was not intended to specify that the MDT clinic based care had to be conducted in a hospital and the recommendation has been altered to make that clear.

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				report if time permits, with NICE on request. The findings to date of the Models of Care work confirm that MND care is arranged in a multiplicity of ways. Identifying or generalising about individual models and their effectiveness is an extremely challenging task, but it can be safely observed that multidisciplinary care is often delivered to a high standard by community-based services. The emphasis placed by the draft guideline on multidisciplinary care is extremely welcome, as are the findings regarding its cost-effectiveness. We are concerned, however, that the characterisation of multidisciplinary care in the draft guideline is not representative of how at least some, and probably much, care occurs in the real world. While formally organised teams based in hospital clinics are undeniably an important part of the MND care mix, multidisciplinary	We are aware that health professionals work in ways such as in networks which may not meet the multidisciplinary care model as we have described it. The evidence for outcomes does come from a clinic based model and the Guideline development group considered it important to emphasis this model because there is evidence which supports the recommendation. The Guideline development group agree that other models of care may be similarly effective and have therefore developed an additional research recommendation to promote research to assess the effectiveness of alternative models.

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				care can be, and often is, delivered in the community, by professionals working in sometimes much looser arrangements. These latter instances are almost entirely absent from the draft guideline. This is therefore the single biggest aspect of the draft guideline about which we have concerns, and we strongly urge the Guideline development group to look again at this area, very carefully. If the final version does not address this issue, there is a significant risk that many health and social care professionals may simply not recognise the world it describes, and accordingly not understand how to apply its recommendations to their work, or even not feel any obligation to. We outline this concern in more detail, with specific reference to the draft guideline, in our comments 31 to 39 below.	

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Motor Neurone Disease Association	All	general	general	Timeliness of delivery is a key theme that runs through the guideline, and we welcome its prominence. In our survey, 96% of respondents agreed this is important. We recommend, however, that the wording used in the guideline be reconsidered. Phrases such as 'without delay' or 'without unnecessary delay' were felt by many respondents not to capture the urgency required when addressing a rapidly progressing illness. Some respondents suggested that timescales should be specified, often in terms - at most - of a small number of weeks. We would support this approach being introduced at appropriate points in the guideline. Respondents commonly reported that provision of home adaptations, wheelchairs and other equipment was notably slow. A further theme that emerged from responses was services or equipment being delivered so slowly that they were	Thank you for your comment. The Guideline development group reviewed the recommendations following stakeholder comments and have added further comments about anticipation of needs and delivery of services. The Guideline development group decided against specifying precise time periods as these decisions need to be individual to the needs of the person with MND and their circumstances and what may be appropriate for one person could be too quick or too slow for another.

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				no longer appropriate for the person's needs: - *New services were often delivered well after they were needed by my father as the disease progressed rapidly in the final 18 months.* - *My mum passed away within 8 months of diagnosis, and many assessments were done too late for equipment and facilities that would be beneficial to be put into place due to rapidly changing needs.*	
Motor Neurone Disease Association	All	general	general	While the guideline's emphasis on timeliness is welcome, albeit that it would benefit from being made sharper, we feel that greater emphasis could usefully be placed on the need to assess and provide in an anticipatory manner. In our survey, 71% of respondents felt the guideline could give more prominence to anticipatory assessment. A further 26% gave free text answers, which provide	Thank you for your comment. The examples you provide indicate the difficulty in being prescriptive in a national guideline about what timeliness means and the potential different trajectories people with MND are on.

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				powerful insight into both the importance of informed anticipation of progression, and some of the complexities that arise from it. Numerous respondents effectively summarised the importance of anticipation, and how things can go wrong without it. - *Things happen and then it's thought about. It should be the other way round.* - *Dad went through a horrendous phase without proper communication devices, which meant his other care suffered as he couldn't explain what he needed. He also had difficulty getting on top of a saliva issue which meant he would spasm and then not be able communicate or swallow, this then led to more issues. Speed is everything when getting on top of a new development in the disease.* - *I don't think any normal*	

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				practitioner would understand that 'urgent' means 'before symptoms arise'. Every practitioner dealing with MND should be considering what will happen next and get that step in place even if it's slightly early. If you are dealing with something urgently then really you are too late because the patient will already be suffering. The day my dad was diagnosed he applied for planning permission to build a carer's wing. When the first carer was needed the extension wasn't ready. When he got a hospital bed he was already sleeping downstairs, when he got a wheelchair he was already using a borrowed scooter, when he got eye gaze he was already using software he had found himself. Other respondents provided examples of effective good	

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				practice, which usually rely on at least one of the patient and a care professional being alert to the need for anticipation. - *Failure to plan ahead has not really affected me so far because I am fairly clued up on what I need, what is available and where and from whom I can get it. My neurologist always comments that I am ahead of the game.* - *We have been fortunate that our OT has anticipated our needs. There is often no time to jump through bureaucratic hoops when aids are urgently required.* However, some respondents highlighted that if done insensitively or inappropriately, anticipatory assessment and provision can cause distress to the person with MND, by alerting them to the likely future course of the disease. Individual preferences about how much they wish to know in advance	

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				vary from person to person. - *My concern in anticipatory assessment is the worry in waiting for awful symptoms to occur. I was asked five years ago what hospice I wanted to go in - this is not helpful. My solution would be to give someone a pack on diagnosis with sealed envelopes with specific symptoms that MAY occur written on the front - when ready (at the first onset of the symptom) they open the package and see the help / advice / equipment is available.* - *Needs must be met quickly when they arise but too much anticipation is frightening. I don't know how my mother would have got through it if she had known everything that might happen.*	
Motor Neurone Disease	All	general	general	The use of riluzole to treat MND is covered by a separate technology appraisal (NICE TA20). While it is	Thank you for your comment. NICE pathways will include NICE TA20 alongside the guideline so that those using the

Stakeholder	**Document**	**Page No**	**Line No**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
Association				right that the technology appraisal remains separate from this guideline and is therefore outside its scope, we would like to see signposting from the short version in particular to TA20. Given that riluzole is the only drug known to slow progression of MND and currently licensed for use in the NHS, some signposting to it would be appropriate. In our survey, 90% of respondents felt a statement about riluzole should be including; only 3% felt it unnecessary, and the remainder had no opinion or were unsure.	website will see these areas of guidance together. We have also added reference to TA20 to the short guideline.
Motor Neurone Disease Association	All	general	general	As the guideline is intended to provide guidance on health and social care, it is right that it does not go into detail about matters such as welfare benefits and the financial implications of a diagnosis of MND. Nonetheless, the financial implications can be significant, and an individual's or family's economic circumstances can have an enormous bearing on their day-to-	Thank you for your comment and suggestions. We have added details about the need for rapid response to information for items such as benefits applications and the issue you describe in relation to DS1500 forms to the Full guideline in section 6.6. but consider this information is too detailed to be included in the short version of the guideline.

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				day experience of the disease (for instance, some may be able to self-fund equipment; others may be unable to move home or adapt their existing one; others still may struggle to make ends meet and suffer from anxiety arising from this). One point at which clinical practice and financial considerations meet is in the provision of evidence to support welfare benefit claims. We recommend that a statement be included advising clinicians to provide evidence in a timely manner when requested, and to support their patients to access fast-track claims processes whenever possible. It may not be appropriate to go into details about specific mechanisms such as DS1500 forms, not least because they are liable to change by the Government, but it may be worth reassuring clinicians that there is no prospect of any professional sanction in the event that, for	

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				instance, a person with MND lives somewhat longer than a clinician had judged that they might, earlier in their illness and at the time of a welfare benefits application. This statement should be included in both versions of the guideline.	
Motor Neurone Disease Association	All	General	General	Dry mouth can be a troubling symptom of MND; we recommend that the guideline offer some guidance on it.	Thank you for your comment. The guideline is not intended to be exhaustive and provide guidance on all possible symptoms people with MND may suffer from. Dry mouth was not specifically included as an area for guidance when the guideline was scoped. Oral health is included as an area to be reviewed in assessments.
Motor Neurone Disease Association	All	General	General	A few respondents to our survey made reference to their wish, or the wish of the person they cared for, to leave their bodies or specified organs and tissues to medical research. Advice on this appears not to be offered routinely by clinicians; we recommend the Guideline development group considers whether to include advice on this.	Thank you for your comment. This area of concern is not specific to MND and is outside the scope of the guideline.

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				- *I feel organ donation, brain and spine should be talked about as I only found out through an MND Thumb Print [magazine] as my consultant isn't allowed to mention the subject. It seemed to me a worthwhile thing to do from a research point of view so something good might come out of this most inconvenient of diseases.* - *My mother has recently died, nearly five years since diagnosis. She regularly updated her advance directive (ADRT) with the help of the MND nurse. But when the time came, much of it was ignored. She also wanted to leave her body or 'tissue' for research but, again, was not properly advised. The university research team told me that the MND clinicians did not think this was a suitable subject to raise with their patients. I have since*	

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				spoken to the consultant and he has written to say they will look at amending their practices in future.	
Motor Neurone Disease Association	All	General	General	There is no reference in the guideline to genetic testing for MND, or to genetic counselling. Although, as the guideline notes, genetic influences are only part of the explanation for MND and the full range of mutations involved has not yet been identified (notwithstanding that 5-10% of cases involve the clear transmission of the disease down the generations), there may still be some diagnostic benefit in genetic testing, and there may more often be a benefit in terms of informing family members about possible risks to future generations. For people with MND who are considering starting a family this may influence their decisions; when possible, they may wish to access pre-implantation genetic screening in order to ensure that any children	Thank you for your comment. We have added detail about genetic issues to the Full guideline in sections 6.6 and 8.6. The Guideline development group did not consider this level of detail appropriate in the recommendations themselves. Genetic testing for MND was not identified as a priority area during scoping.

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				are born without a specific mutation. We recommend that these points are addressed in both versions of the guideline.	
Motor Neurone Disease Association	Appendices	389	24-28	We welcome this observation that the measures of quality of life in EQ-5D may not be adequate for capturing the experiences of people with MND. It accords with our own research, for instance on attitudes towards the end of life, which indicate that people with MND can become accustomed to, and value, a quality of life that they might previously have felt would be unacceptable. We will be happy to supply this research on request. One respondent to our survey captured how views of what constitutes an acceptable quality of life can change as someone adapts to living with MND: - *Patients choices may change during the course of the illness. After becoming accustomed to living with MND I rescinded my Do Not*	Thank you for your comment. The NICE reference case prefers us to use EQ-5D in health economic analyses. Although the Guideline development group recognised the pitfalls with this method in a motor neurone disease population, this limitation was taken into account and a positive cost-effective recommendation was made. Therefore any further information or clarity on the subject will not influence the conclusions drawn from the analysis.

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				Resuscitate [Order].	
Motor Neurone Disease Association	Appendices	393	6-9	In stating that 'palliative care costs are only occurred once in the last phase of the individual's life' we believe that the guideline is confusing palliative care with end of life care. Palliative care can be delivered at any phase of the person's illness.	Thank you for your comment. It is worth noting that the table of costs to which this comment refers, was not used in the economic analysis. Rather it was used as a reference to show that the costs used in the economic analysis were not too dissimilar to other published sources. However we recognise the importance of distinguishing palliative care from end of life care and this has now been made clearer.
Motor Neurone Disease Association	Appendices	393	19-21	The inability to factor costs and benefits associated with equipment into an analysis of multidisciplinary care is a significant problem, and this must be factored in to any future research. Qualitative evidence submitted to the inquiry into communication support run by the All Party Parliamentary Group on MND in 2014-15 indicated that the scope for communication devices to improve quality of life is, in some cases, enormous. The benefits and costs associated with this must be factored in to any	Thank you for your comment. As with a lot of limitations of the economic analysis they biased against the use of MDT care. This means that our conclusion that MDT care is cost-effective is a conservative one and in reality it is likely to be more cost-effective than our analysis shows. This consideration was taken into account when making a strong recommendation concerning the use of MDT care.

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				authoritative analysis of the value of MND care.	
Motor Neurone Disease Association	Appendices	404 412	general	We welcome the recommendations for research, and would be grateful for clarification from NICE of whether it will take any steps to instigate these research projects, or if that will be a matter for stakeholders such as ourselves. Our most substantial recommendation for a further research priority is multidisciplinary care, specifically how it is arranged and the cost-effectiveness of different models. Our Models of Care report will provide a start in answering this question, but as the issue is a highly complex one, and changing as the NHS develops, we anticipate that further research may be necessary.	Thank you for your comment. NICE do not fund research projects directly but it is hoped that research funding bodies will take these forward. NICE research recommendations are noted by NIHR and other funding bodies when considering future research funding. Following stakeholder comment the Guideline development group has decided to include a research recommendation on Models of Care and this is included in the Full guideline 9.6 and appendix N.1.
Motor Neurone Disease Association	Appendices	409	Table	The study design for this research recommendation proposes to collect information from the existing AAC hubs in England in order to	Thank you for your comment. The 'spoke elements' referred to in the recommendation are the local services to which your comment refers. We have

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				identify a baseline of AAC use among people with MND. This approach will not, however, capture the full MND population: before a person's needs become 'complex' (see comment 59) they will be met by local speech and language therapy services, not the specialised hubs. Most people with MND in England can expect to be referred to a hub at some point in their illness, but at any one time a substantial portion of the MND population using AAC will not be on the hubs' caseloads. The current proposed study therefore cannot meet its stated objectives using the proposed methodology; we recommend this be revisited. Additionally, we recommend that the scope of the study specifically include the use of high tech AAC, notably eye gaze, at or near the end of life. Evidence to the APPG inquiry on communication support exhibited a divide among professionals: palliative and end of	added the following information to capture non-hub AAC-MND activity – '**and incorporating local service provision to capture non-hub AAC-MND activity**' - and ensure it is inclusive of the full MND population. Thank you for your comment. The Guideline development group considered that we need to start with collecting information about patterns of provision and use as opposed to looking at best practice, and that the current research question adequately achieves this.

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				life care professionals tended to promote advance care planning and argue that communication at the end of life when the person has speech problems is often unsuccessful; SLTs expert in AAC, by contrast, reported seeing eye gaze and other approaches used to good effect at the end of life. More robust research on this topic is required in order to identify best practice.	
Motor Neurone Disease Association	Short	5	1-5	We believe that the wording in this section unhelpfully conflates emotional lability with FTD, which risks misleading the reader. Emotional lability is a motor response symptom and often temporary, and therefore quite distinct from cognitive change. At worst, an inexpert clinician or practitioner might currently take emotional lability to mean that there has been cognitive change and the individual lacks mental capacity, even though this may not be the case at all; as it stands, the	Thank you for your comment. We have altered the wording of the recommendation (1.1.3 in the NICE guideline) to specify cognitive 'features' as opposed to changes.

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				guideline will not save the reader from such an error. We recommend that emotional lability is addressed separately, and at greater length, in the guideline: for those who develop it, it can be one of the most distressing symptoms of MND, and should be given greater consideration. If evidence to support more extensive coverage in the guideline does not exist, a new research recommendation should be added. There is however one respect in which the guideline could say more on cognitive change: it does not say anything on the risk of a person with FTD becoming aggressive or undergoing other serious behavioural change. This may generate a need for greater support for the carer, or even put the safety of children in the household at risk. We recommend that these aspects should be addressed, or a research recommendation made if there is	The scope of the guideline did not include management of emotional lability and we cannot therefore make a research recommendation in this area. However, we have flagged this as an issue to consider when reviewing the need to update the guideline In respect of FTD, the NICE guideline CG42 Dementia: supporting people with dementia and their carers in health and social care includes recommendations for care of people with behaviour problems and care for carers. CG42 includes people with frontotemporal dementia.

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				insufficient evidence.	
Motor Neurone Disease Association	Full	8	21-28, 1-2	Assumptions about the nature of a multidisciplinary team hinder this section somewhat. To avoid this problem without exploring the nature of MDTs at inappropriate length for the summary document (and bearing in mind the relative lack of evidence), the use of the phrase 'coordinated multidisciplinary care', which avoids assumptions about the nature of teams, may be more appropriate.	Thank you for your comment. The reference to the section in the full guideline does not seem correct. We are recommending specific ways of working for the multi-disciplinary teams and "co-ordinated multi-disciplinary care" would not adequately explain this.
Motor Neurone Disease Association	Full	32	1-11	We recommend that the figures given for the proportions of MND cases made up of different sub-types are presented more clearly. The figures given in the guideline appear to be prevalence figures, but the differing rates of progression among the sub-types of the disease mean that the equivalent incidence figures may look very different: if 25% of people living with MND at any one time have progressive bulbar palsy, for	Thank you for your comment. We have altered this section to improve clarity.

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				instance, the proportion of diagnoses with this type must necessarily be somewhat higher than 25%, as survival times are shorter than the average for MND as a whole. The guideline should clarify that the figures presented are indeed prevalence (if that is the case), and set out the contrast with incidence clearly, in order to ensure that clinicians and practitioners have accurate expectations of the proportions of different types they may encounter.	
Motor Neurone Disease Association	Full	32	17-21	This text is the same as page 34 of the short guideline, and presents incorrect statistics as per our comment 27 above. It should be corrected.	Thank you for your comment. We have altered this section to improve clarity.
Motor Neurone Disease Association	Full	32	31-32	We question the use of the term 'care centres' in the guideline. While the term is in common use among professionals familiar with MND, its meaning is not self-evident. The 'care centres' established and funded by the MND	Thank you for your comment. We have altered the wording of this section.

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				Association's care centre programme, which we believe is what the guideline intends to refer to, might more formally be described as specialist multidisciplinary MND outpatient clinics – for instance, in the relevant NHS England specialised service specification. Those unfamiliar with their operation may infer that the 'centres' are more extensive in their offering than is the case; their status as services not currently formally commissioned within the NHS, or fully funded by the NHS, complicates matters further. In some regions, networks rather than single centres have been established, which makes the term even more difficult. We therefore recommend that the informal term 'care centres' is avoided in this formal guidance, or alternatively is referenced and a definition given (the term currently goes undefined), and more formal terminology used thereafter.	

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Motor Neurone Disease Association	Full	32	23	The guideline cites figures of 'about 5,000' people living with MND in the UK at any one time, and around 1,100 people diagnosed per year. We would be interested to see the source of the 'about 5,000' figure as, although we believe it is plausible, we have only been able to identify firm evidence for a population of up to about 4,500. The diagnosis figure by contrast seems low: death certificate figures for MND from 2004-8 ranged between 1,361 and 1,508 per year. Given that the MND population is not appreciably shrinking, the rate of diagnosis must be approximately the same as the rate of deaths; indeed, we believe that the ageing demographic profile of the population as a whole may be causing the MND population to grow somewhat, in which case the diagnosis rate should be slightly higher than the death rate. An authoritative exploration of these issues by NICE would be welcome; at the very least, the number of	Thank you for your comment. As you indicate there is some uncertainty about this statistical information. We do not have more robust information so have altered this section to avoid providing misleading information.

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				diagnoses should be re-examined, or a comparable figure for deaths presented. If the 1,100 figure is a reference to cases in England only, this should be clarified, as the context suggests very strongly it is intended to refer to the UK as a whole.	
Motor Neurone Disease Association	Full	33	17-23, 1-3	These lines also use the slightly ambiguous figures for different types of MND.	Thank you for your comment. As you indicate there is some uncertainty about this statistical information. We do not have more robust information so have altered this section to avoid providing misleading information.
Motor Neurone Disease Association	Full	60	Table	The discussion of possible costs arising from the practices in respect of referral outlined here suggests that no additional costs would arise from them compared to other current practice. In England, we do not believe this is strictly true: under identification rules for specialised commissioning, neurology services only count as specialised, and therefore only attract an uplift in tariff, if the referral is made from one neurologist to another. Referral	Thank you for your comment. When we consider costs in our analyses we refer to the actual cost to the NHS as opposed to how much is reimbursed, which represents the tariff. In terms of the resources used by the NHS, after the assessment is made and it is decided a referral to a specialist is needed, these are the same whether a GP refers to a specialist or a neurologist refers to a specialist.

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				direct from a GP, for instance, to a specialist in a designated neuroscience centre would not be classified as specialised; it can of course still happen, but could generate a reduced level of income for the hospital. These identification rules may in future be revised: if the coding of NHS activity can be made more accurate in respect of neurology, specialised activity can be identified by code and not referral route. We await confirmation from NHS England of when this might prove possible.	
Motor Neurone Disease Association	Full	61	Table	The same point applies to the discussion of referral pathways in the table on page 61 as in comment 14 above: diagnosis by a neurologist expert in MND would generally fall under NHS England's specialised commissioning regime, but the design of that system does not intersect well at present with the recommendation to refer directly to	Thank you for this information.

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				a specialist neurologist. We welcome the reference to the Association's Red Flags tool.	Thank you for this comment.
Motor Neurone Disease Association	Full	65	general	This review of evidence suggests that there is an absence of evidence on multidisciplinary care outside hospital clinics. This supports the case for a research recommendation on the topic.	Thank you for your comment. The Guideline development group considered this and we have added a research recommendation regarding models of care.
Motor Neurone Disease Association	Full	68	15	References to the Association throughout the guideline variously use the terms 'MND Association' and 'MNDA'. We would be grateful if the term 'MND Association' could be used consistently; we do not refer to ourselves as 'MNDA'.	Thank you and we apologise if we have used incorrect terminology to describe your organisation. We have amended all references to the MND Association.
Motor Neurone Disease Association	Full	70	40	References to the Association throughout the guideline variously use the terms 'MND Association' and 'MNDA'. We would be grateful if the term 'MND Association' could be used consistently; we do not refer to ourselves as 'MNDA'.	Thank you and we apologise if we have used incorrect terminology to describe your organisation. We have amended all references to the MND Association.

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Motor Neurone Disease Association	Full	71	Table	We agree that the diagnosis and information on prognosis and management should be given by a neurologist with current expertise in MND. In our survey, 98% of respondents agreed that diagnosis should be given by a neurologist expert in MND whenever possible	Thank you for this information.
Motor Neurone Disease Association	Full	71	4-8	We agree with the suggestion that it is important to connect a person with MND to a palliative care centre, to provide a framework for proactive care planning, tailored to the individual's care needs. However, it is not clearly made in the guideline's recommendations, and indeed is slightly cut across by the suggestion that early referral to palliative care should be reserved for complex cases (see our comment 53). We recommend that this advice be clearly added to the guideline's recommendations.	Thank you for your comment. Our intention was to highlight areas where early referral should be considered and not that early referral was reserved for people with these problems. We have altered the order of the recommendations and added reference to palliative care in other recommendations to highlight the potential role of palliative care.
Motor Neurone Disease	Full	74	Table	We note that in the short version of the guideline, the advice in guideline CG138 is not signposted.	Thank you for your comment and for the powerful examples of good and bad care that you have provided.

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Association				The result is that certainly in the short guideline, and also in the full version if the reader is not familiar with CG138, numerous crucial considerations in how to give a diagnosis of MND, which have a significant bearing on the experience of the patient, are not addressed. In particular, we strongly recommend that the following are expressly included, along with reference to CG138 if appropriate, but not using the reference as a substitute: – The diagnosis must be given in a private place (as in CG138) – The patient should be given the opportunity to bring someone with them (as in CG138); ideally, to avoid this invitation causing anxiety by alerting the patient to the likelihood of bad news, the invitation to have a friend or relative present should be	We have added specific reference to Patient Experience guideline CG138 to signpost this to people who may not be aware of it.

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				extended for all appointments from the start of any investigation into suspected MND (not covered in CG138) – After the diagnosis has been given and the appointment is over, the person with MND and whoever is with them should have time in a private room in order to compose themselves (not covered in CG138). In our survey, 79% of respondents felt it should specify that diagnosis should be given in a private place, and the person should be invited to bring someone with them; a further 20% felt this was so obvious as not to need stating. The qualitative evidence generated by our survey on this issue was among the most powerful we received, and strongly suggests that these recommendations are indeed not too obvious to need stating, and should be spelled out.	

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				Numerous respondents reported that they or their relative were given the news alone, without the opportunity to bring someone with them. – *My father was given his diagnosis alone and had to drive himself home afterwards. I was surprised at the time that this was considered appropriate.* – *We had no idea that my husband was going to be given life changing news - I dropped him off at the hospital and he was given no support once he'd been told, nor was I contacted to pick him up. He then had to find his way home on the bus in a state of shock and find the words to tell me. I think this was extremely cruel and could have been handled a lot better.* – *My mum was given the diagnosis on her own and it distressed her terribly, if a*	

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				phone call had been made prior to the appointment somebody would have gone with her. One respondent noted that even those who might not feel inclined to bring someone with them could come to feel it was a mistake – people should not be obliged to bring someone, but it should perhaps be recommended, even if only gently. – *In my case, because I am so independent I chose to go alone, however that was not the wisest move I have made.* Some respondents gave examples of the diagnosis not being given in private, which often seem to go hand-in-hand with a delivery lacking compassion and empathy. - *My sister's diagnosis was done on the ward for everyone to see and hear, after confusion about whether we could have a room or not –*	

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				the left hand in the ward didn't know what the right hand was doing. Some of the distress caused that day could have been [avoided if things had been] better planned and managed between doctors and the ward sister. - *My husband was given his diagnosis in an open ward by a consultant who had several students with him. No compassion was shown and my husband was lucky I was with him.* - *The consultant who gave me the definitive diagnosis at Morriston Hospital did so on the ward and in a very downbeat way. He would have made a good undertaker.* A failure to provide adequate information about the significance of the diagnosis was another theme among the responses. - *I hear from patients about their diagnosis being given in*	

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				private but without family members or any support / information at the consultation. The most recent case I'm thinking of was on a Friday afternoon, the gentleman had never heard of MND but was told he would die from it, and soon... He was advised to 'go home' and talk to his wife about it. Not having any knowledge of MND he did not know what he was supposed to be talking with his wife about! They spent entire weekend without support / advice, didn't sleep or eat, literally 'worried sick'. - *As an allied health professional I recently found myself in a home visit realising that my patient's diagnosis had amounted to medical jargon in a copy letter and neither she nor her husband understood what she had or what MND is. It fell to me to try to inform, which was*	

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				similar to giving the diagnosis, something which is not part of my job and for which I was not prepared. - *My dad was given his diagnosis by his doctor who then just gave him some leaflets and left him to it. My dad was handed an agonising death sentence by someone who couldn't answer his questions.* Many respondents reported that after being given the diagnosis they would have benefited from some time in a quiet and private place to gather their thoughts and compose themselves before beginning the journey home, but that this was not an option for them. This added to the trauma of receiving the diagnosis, and was sometimes compounded by professionals beginning care planning procedures with insensitivity and inappropriate haste. - *My mum was told and then we*	

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				were asked to sit back in a corridor and wait to see MND nurses and fill in a questionnaire which indicated how the illness would progress. We were shell shocked by the news and time would have been appreciated in a private room to recover from the shock. The questionnaire etc and meeting the support team was inappropriate at the time. I will never forget wanting to burst into tears in a busy corridor. - *My late husband and I had just been told the devastating news that he had MND; we were then sent into a crowded waiting room to wait to book another appointment, my husband was sobbing and the whole room went quiet with everyone staring at us. It was a very difficult moment.* - *My diagnosis was given to me at the end of the consultation,*	

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				when my husband and I were sitting at opposite sides of the room. We were clearly expected just to get up and go, which we did. Both of us were in tears we walked the length of the corridor, as staff just stared at us, no one offered comfort or a private corner. It was the most horrendous experience. - *Total shock when diagnosis given - we had a horrific experience by a physio who outlined all we would require, this was within ten minutes of being told the devastating news. We were in shock and speechless.* A further recurring theme was people having to drive home after receiving such a devastating piece of news. – *Our experience was far from ideal, my husband was given his diagnosis and then asked to leave. He was given no*	

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				chance to sit and recover from the shock and was not asked how he intended to get home. He had a 45 min drive along busy A-roads whilst in a distressed state - hardly the best time to be in charge of a car. – *When I was told I had MND I was alone, drove home alone and the house was empty. I was a danger to myself and other road users as all I knew about MND was that it was bad.* Numerous examples of good practice also emerged from the survey, but even in these the devastating nature of the news is clear. - *My father was shocked when he received the news and very grateful I was there with him, to discuss with the neurologist and to drive him home. It is important to have someone with them. I was asked to pass*	

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				the news on to family as my dad was so shocked after. - *I believe my brother was given the weekend to think about it and then return with any questions. At that time I thought this was very generous and caring. The shock would have meant he wasn't listening so a weekend with family and friends gave him a short moment to catch his breath and return to receive more information.* - *I accompanied my mum to every appointment, including pre diagnosis. It is such a devastating moment, it's very challenging to retain much information at all in such circumstances and patients absolutely need support of family / friends, both emotional and practical.*	
Motor Neurone Disease	Full	101	10-18	This point addresses a characterisation of multidisciplinary care that runs through the	Thank you for your comment. With regards to the economic analysis, the

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Association				guideline, and a contrasting characterisation of 'general care'. We will use this comment to set out our broad concerns in relation to this issue, and recommendations for how the guideline might better address it. Subsequent comments will address the same issue in relation to specific items in the guideline. We must emphasise that we strongly support the guideline's emphasis on multidisciplinary care and welcome its findings in relation to cost-effectiveness – our concerns relate only to the detail, albeit crucial, of how this care is characterised. The contrast between 'general care' and 'MDT care' presented in both the guideline and the assessment of economic evidence is an overly simplistic binary divide that does not represent the complex and varied reality of MND care in the UK. The 'general care' comparator describes a situation that is probably not terribly representative:	question the guideline sought to answer was whether an MDT approach was cost-effective relative to no MDT which we defined as '*general care'*. This was what the evidence obtained from this guideline assessed. We found no evidence that compared MDT to a different composition of care. Therefore the economic analysis was bounded by what '*general care'* was defined by in the studies. The Guideline development group felt that in fact this level of care was still being implemented in some areas of the country so confirming the cost-effectiveness of MDTs was important to ensure that MDT care should be considered the minimum level of care that individuals with MND should receive. We appreciate that there are different ways the MDT could be delivered, all with different costs associated. To account for this in the economic analysis we re-ran the model assuming that MDT care would cost 50% more. We found that this did not impact the conclusions we obtained from the model. Of course if the MDT costs less than we calculated in the economic analysis this would not change our current

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				how many people are really diagnosed with no input from an MND specialist, and their care then managed in a general clinic with two reviews per year? Surely a small and shrinking number, if only because of the MND Association's care centre programme. The description also fails to take any account of the involvement of community services in this 'general' model, which could themselves supply a substantial element of multidisciplinary care for some people. The description of multidisciplinary care is also problematic, as it assumes that the care is delivered by a formally constituted team, based in a hospital. Community-based services, network models and less formal arrangements are considered only seldom, for instance in reference to 'an extended outreach team' clearly envisaged as 'on top of' the costs of the clinic-based MDT. Again, this	stance of MDT care being cost-effective. Although the Guideline development group considered that a clinic based approach was necessary, the location of the meetings could take place in either a hospital or community setting. The recommendations have now been made clearer to reflect this. Further exploration of the MDT structure has also been considered and the Guideline development group have also now made a research recommendation that will look into comparing a network based MDT to a clinic based approach.

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				risks making the comparator unrepresentative of MND care as it occurs in the real world. A further risk is that developments in health policy will make this approach seem increasingly remote from real-world practice: the NHS in England, and to an extent elsewhere, is embarking on a clear shift of focus out of hospital and into the community, for instance with the development of new care models following NHS England's Five Year Forward View. The guideline should therefore take full account of community services and care network models, without which some health professionals may read it and find it describes a world that simply does not correspond with the one they work in. It will be harder to incorporate them into the economic analysis, as the necessary evidence appears not to exist. For this reason, we suggest adding a research recommendation on this subject.	

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				Additionally, while it is often implicit that effective multidisciplinary care must be well coordinated, this is not consistently stated in the guideline, and the nature of coordinator roles is not explored. At times there even seems to be an inference that a coordinator is a specialist nurse, when the two roles are distinct: providing nursing care to a person is not the same as coordinating their care, and while the latter might ideally entail a fully resourced role in its own right, professionals from a range of disciplines can in principle take that role on. From the discussion and evidence below it will be clear that coordination can take place within the community or in hospital, but that there must be clarity among all professionals about who is responsible for it, and that there must be effective coordination when necessary between services in different settings.	

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				Input from people living with MND supports the view that multidisciplinary care is highly desirable, but that the reality is more complicated than the guideline suggests. In our survey, 97% of respondents approved of the strong advocacy of multidisciplinary care, but only a minority of respondents recognised multidisciplinary care as involving a formal, clinic-based team: - 29% said their care was organised exactly like that - 56% said their care was partly or very different - 15% weren't sure. Differences observed between real life care and the description in the guideline were as follows: - 20% of respondents said there doesn't seem to be a formal team - 17% of respondents	

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				said the professionals who support them are based in the community, not a hospital clinic - 67% of respondents said the professionals who support them are based in a mix of the community and a hospital clinic - 14% of respondents said they don't receive support from professionals from a wide range of disciplines - 30% of respondents said the professionals who help them aren't well coordinated with each other. When we asked respondents to indicate their satisfaction with the care they received, those who received multidisciplinary care of whatever sort were more likely to express satisfaction; those who	

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				expressed dissatisfaction were more likely to note that care was not multidisciplinary or well coordinated. These responses did not, however, reveal any clear relationship between satisfaction with care and different types of multidisciplinary care (hospital or community-based, or in formal or informal teams). More research is needed to show some different models of multidisciplinary care are more effective than others. Respondents to our survey, ranging from people living with MND to carers and to health an social care professionals, outlined an array of multidisciplinary care arrangements with involvement by, variously, hospitals, hospices and community services. - *In the absence of a care centre in West Dorset, coordinated care is offered via Joseph Weld Hospice where all the professionals have an MDT each month and*	

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				there are joint clinics attended by a neurologist every three months. - *The core multi-disciplinary team were based in the hospital, there was some evidence of them working as a team - but it was by no means always evident Counselling was never offered to my husband. Social care was arranged by me in the first instance, I never managed to get a formal carer's assessment. It was only through the MNDA* [sic] *that I knew of Continuing Healthcare, and it was only because I asked for my husband to be assessed for CHC that it eventually happened[. ...] It worries me that if I had not spoken with our RCDA and hassled the professionals this might not have been offered.* - *Not everybody will be fit enough to continue to travel to*	

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				clinics. Care centres may be difficult to access and parking can be a nightmare. We have had to arrange taxis to take people to and from clinic appointments at care centres due to the lack of parking and arduous journey. Ultimately all of the patients I see can't make it to the care centre. Some patients prefer to stay with local neuro hosts. In my area our MDT is community based and includes the palliative care team. - *We are quite geographically isolated so care was often coordinated by our GP, and district nurses.* - *MDT is hospice based under palliative care plus the option of hospital MND care centre clinic. This works really well.* - *None of the MDTs in NE London are attended by a neurologist - they are fundamentally community based with input from the*	

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				Care Centre Coordinator. - *My husband's care was originally clinic based but as he deteriorated it was an ordeal to get to the clinic and wait approx 3 hours, so care was passed to the neurological community care team.* Some respondents highlighted problems with coordination of care. - *The MND coordinator is excellent and always fully informed. Other members of the virtual team don't seem to be aware of each other's involvement.* - *The multidisciplinary team meets but never asks for updates prior to discussing my husband. Key individuals leave without us knowing. As my husband has a more slowly progressive form we notice these things getting worse over time.*	

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				It was common for respondents to note that community-based professionals were key to their care. - *Because I live at a distance from my main hospital clinic it is a great help to have some support nearer at hand. This includes speech and occupational therapists and physiotherapist. They all keep in close touch with my co-ordinator.* - *Before the local MDT was formed 5 years ago my care was haphazard. Now it is excellent.* - *Worked wonderfully for us. One foot in the hospital system and one foot in the community where most care actually took place. Couldn't fault it.* The interim Models of Care report reinforces this picture of a varied landscape of multidisciplinary care – and in some cases, less	

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				obviously multidisciplinary, more general care. A common situation identified by the Models of Care work is of a community-based multidisciplinary team (MDT) with which a specialised MND clinic has strong links. Respondents to the call for evidence outlined this scenario: - *In between clinic appointments there is often frequent discussion with the local health community as issues/problems arise. We do also have regular MND MDTs in each area so information can be discussed and shared then* (Bristol) - *The MND Coordinator attends local MND MDT's where possible and links in with the [MND Association] Regional Care Development Advisers to help facilitate seamless care over into the community and good communication.* (London)	

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				One neurologist indicated that the central clinic is actively building this local, community-based capacity: - *We are building a network of local teams - I think the time for large (often distant) 'Centres' is passing and Networks linking local teams is the way forward.* (Neurologist who specialises in MND) Many of the in-depth interviews generated evidence of the importance of delivering care in the community, and in the homes of people with MND. It was not uncommon for interviewees to articulate that MND care should lean towards community services as opposed to acute care, and that the majority of care occurs in the community. Among these responses, the value of MND clinics, including care centres organised along the	

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				traditional Association model, was still recognised: they provide access to procedures that cannot be performed in the community, and they are a valuable source of advice and support for those in the community. Outreach clinics organised from the central clinic can avoid patients travelling long distances. Differing attitudes and preferences on this issue were observed among different clinicians and practitioners: some neurologists and other hospital-based staff were characterised by respondents as firm advocates of hospital-based clinics, perhaps at the expense of looking beyond the acute setting and being willing to get advice or support from community services. Equally, general neurologists were sometimes characterised as reluctant to refer 'their' patients to a specialist clinic, or as being unaware of the full range of MND services available. A further	

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				reported observation was that MND Association staff appeared more likely to be invited to clinics and meetings in hospices and the community than in the acute sector. While the draft guideline advocates that coordinated assessments should be undertaken at the multidisciplinary clinic, and implies that the team should therefore meet, in hospital, in the presence of the person with MND, evidence of current practice and views on best practice identified by the Models of Care project do not entirely support this. Among respondents to the call for evidence, 46% said the MDT meets as a group without the patients, 19% said the MDT initially meets as a group with the patient, and 12% said the MDT subsequently meets with the patient. One respondent questioned the value of large meetings with the patient present:	

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				All multidisciplinary team members may not be required from the outset. Many professionals seeing together may be frightening for the patient. Additionally, it would be waste of time and resources of the professionals if they are not needed. A tailored approach of seeing patients in the community with quick response time is most suitable for this group of patients. A respondent to our September 2015 survey voiced similar reservations about large meetings with patients present, drawing on experience in Scotland: - *A monthly or bimonthly 'clinic' based in Aberdeen where patients are 'rolled out' in front of a group who then 'observe' and then debate each others opinions in front of the patient. MND nurse not in attendance (neurologist did*	

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				not work with MND Scotland nurse at all). There was also evidence of considerable variation in MDT arrangements, in respect of the size and composition of the team, and frequency and nature of meetings. Many have good input and attendance from community teams, hospitals, and hospices; however a few reported little input from hospitals or, in some cases, neurologists. Others were noted as having excellent input from, and close working with, MND clinics including care centres. Another variation apparent in the evidence was the presence or absence of neurological care coordinators based in the community. Some were noted, for instance in Greenwich, Hertfordshire and Milton Keynes. In other areas, such dedicated roles appear to be absent.	

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				It can also be noted that multidisciplinary teams and clinics are seldom, if ever, formally commissioned or planned by the NHS in any territory covered by the Association.	
Motor Neurone Disease Association	Full	103	16-18	This description of an outreach team arising from the hospital-based MDT is an example of the hospital-oriented focus of the guideline; it appears not to take into account the possibility of support from community-based multidisciplinary care.	Thank you for your comment. The recommendation was not meant to only refer to hospital-based MDTs and we have clarified in the recommendation that the MDT can be hospital or community based. We have also added the importance of access to community based neurology teams.
Motor Neurone Disease Association	Full	104	1-4	We feel this is a problematic characterisation of 'general' care. If someone is assessed only twice a year, it seems unlikely that needs such as for communication support will be reliably or promptly picked up as assumed here.	Thank you for your comment. We based our modelling on the clinical papers that were identified in the systematic reviews and the definitions they gave to 'general care'. The clinical evidence does show a survival benefit for MDT care and this may be because the needs you refer to are not being picked up.
Motor Neurone Disease Association	Full	109	Table	The lack of evidence in respect of community-based services and additional coordinators is a substantial problem, and	Thank you for your comment. The Guideline development group have considered this and following stakeholder comments have included a research

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				contributes to the guideline's relative weakness on community-based care. The nature and value of coordinator roles in different settings must be included in any new research recommendation.	recommendation regarding models of care. The guideline does recommend co-ordination as an important part of organisation of care but does not specify who should carry out this role.
Motor Neurone Disease Association	Full	112	Table	We particularly welcome this recommendation against inappropriate case closure, which is often reported to us as a problem. A similar conclusion is drawn in the Models of Care interim report.	Thank you for your comment.
Motor Neurone Disease Association	Full	157	Table	The wording in this paragraph is unclear, or possibly problematic: as written, it states that social services provide assistance with motoring, the blue badge scheme, Motability and car adaptations, home adaptations, wheelchairs and AAC. It may be the intended meaning that social services provide assistance with applying for these services; but they are not, themselves, social services (the blue badge scheme and some provision for home adaptations are	Thank you for your comment. We have amended the section in light of your comments to reflect the organisation and delivery of services.

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				administered by local authorities, but do not count as social care; wheelchairs and AAC are NHS responsibilities).	
Motor Neurone Disease Association	Full	157	Table	We agree that the advice given here about case closure is particularly relevant for social care, and welcome its inclusion. Discussion in the same table also notes that assumptions should not be made about the ability or willingness of family members to undertake caring responsibilities; we agree.	Thank you for your comment.
Motor Neurone Disease Association	Full	170-1	Table	The helpful discussion in this table about having conversations at key junctures about legal mechanisms and control later in the illness could be sharpened and included in the short version of the guideline. In particular, we would like to see clearer guidance about making counselling available prior to starting NIV, to alert people to the possibility that it might give them a measure of control over the timing	Thank you for your comment. We have reviewed the recommendations and consider that the issues outlined are covered in the recommendations on NIV.

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				of the end of life. In our survey, 80% felt that the guideline should specify that counselling be available when NIV is being considered, to ensure the possible implications for end of life are understood; 9% felt the current approach sufficient. Respondents gave examples of how early discussion of end of life considerations before commencing NIV can be important, but also difficult. We would be happy to see the guideline include a statement clarifying that withdrawal of a treatment is legally distinct from euthanasia, as this seems to be a common area of confusion and uncertainty for some professionals. - *There was an out of the blue end of life discussion at the initial consultation about the NIV machine which was horrific. We were told that when he was dying the NIV machine would have to be taken off. This sounded to me,*	

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				the carer, almost like euthanasia. Very shocking at a fairly early stage of his illness. - *I think an additional statement should be included regarding discussions and counselling at the start and end of treatment. Professionals working in respiratory teams frequently have differing opinions on when or if NIV withdrawal should be discussed.* - *Would it be appropriate to include a statement which clarifies the distinction between the withdrawal of an intervention such as non-invasive ventilation and assisted suicide? For a number of healthcare professionals I have come across who have been involved in the process of withdrawal of ventilation, this has been difficult to resolve.* - *This happened to us my husband he had been using a*	

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				Bipap for 6 years. When my husband became very ill in hospital he became totally dependent on his Bipap, Whereas before he only used it at night, he was very anxious because he knew he didn't want to live if he had to have ventilation 24 hours a day. I raised this concern with the respiratory nurse and she said you have choices – we can gradually take it away and give medication enough to relax you through it. My husband took great comfort from this as he didn't realise this could be done as no one had mentioned it before. This ended up being the decision he made. So most definitely this should be explained at the beginning. - *People are not always aware of implications when started on NIV.* Respondents identified instances	

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				both where people with MND did not wish to consider the issue, and where this reluctance caused difficulties later. - *Difficult this one. I accept the final outcome. I do not want to be given all this information at the outset. Let me have a bit of peace and quiet, gather my own thoughts.* - *With reservations - my husband did not want to know what the future held - he very much wanted to live for the day. At one point one of the doctors did speak to him about a DNACPR order - he was adamant that he should never be subject to one - though did say he didn't know how he might feel at the time one became necessary, yet when the FTD had developed to the point where he could not communicate a DNACPR was put in place. My husband did not want to think about*	

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				Lasting Power of Attorney when we updated our wills and he was still able to understand what was involved - I wish I had known of the possibility of FTD developing. It was expensive, time consuming (at a difficult time) and distressing to have to apply to the Court of Protection just to enable me to file his tax return and sign on his behalf! Somewhere there needs to be a relaxed discussion at least with the partner, where one exists as to the possible problems that might occur. Advice must also be given on potential problems that can arise with the use of NIV. - *Constant explanation of what non invasive therapy can mean. Ultimately my partner commenced and became reliant on the respiratory machine and the deterioration*	

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				was rapid and additional problems with facial abrasion, nose and mouth discomfort through dryness occurred which was unexpected and very distressing.	
Motor Neurone Disease Association	Full	171	Table	The evidence in this table about misunderstanding of when palliative care might be available suggests that referral to specialist palliative care at a reasonably early stage should be a matter of routine.	Thank you for your comment. Following stakeholder comments we have added additional references to the place of palliative care in the recommendations. Please see the following recommendations: 1.2.3; 1.5.4; 1.5.11; 1.7.3 in the NICE Guideline.
Motor Neurone Disease Association	Full	173	4-11	We would like to see a greater prominence given to pain in its own right, rather than being bundled in with other symptoms. In the full version of the guideline it is mentioned in the context of muscle problems (as here, although often only in parentheses) and end of life. It is also included in the list of things an MDT should review, although in the short version of the guideline it attracts no mention beyond this. Although the development of MND – that is, the	Thank you for your comment. Pain was not an area included in the scope, however it was included as a patient-reported outcome for the review on pharmacological interventions for muscle problems and no evidence was identified. As you note we have included pain in the list of issues to be reviewed by the multidisciplinary team We have now strengthened this recommendation, therefore pain would be an issue to be assessed, managed and reviewed by the multidisciplinary team (see recommendation 1.5.3 in the NICE Guideline).

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				process of the motor neurones dying within the body – is not itself painful, pain is in practice a major element of the problems presented by MND for those who develop it, whether from muscle problems such as cramps or posture-related issues. The notion of 'painless progression', while technically accurate, is one that gets challenged by people with MND at Association events. If insufficient evidence can be found to expand the guideline's content on pain, a research recommendation should be added.	
Motor Neurone Disease Association	Full	194	Table	While clear guidance on exercise is very welcome, we recommend that there should also be guidance on fatigue. While the aim of exercise is to maintain function and quality of life, over-exercise or competitive exercise may be ill-advised, and lead to fatigue that outweighs any other benefit. Without guidance on this subject, less experienced professionals may recommend	Thank you for your comment, this is covered in the exercise recommendations (recommendation 1.8.6 in the NICE Guideline) which states 'Choose a programme that is appropriate to the person's level of function and tailored to their needs, abilities and preferences. Take into account factors such as postural needs and fatigue. The programme might be a resistance programme, an active-assisted programme or a passive programme).

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				inappropriately intensive rehab-style exercises.	We have added your comments regarding over-exercise or competitive exercise to section 13.11 of the Full guideline.
Motor Neurone Disease Association	Full	239	table	The content on AAC in this table is mostly a good match with NHS England's service specification, although it does not directly address the funding divide between communication support (AAC) and computer access for those who can still speak (the responsibility of EC services). Addressing the importance of maintaining social interaction and a role in society is helpful. However, the service specification makes very clear that referral for AAC assessment can be made on an anticipatory basis; we would like to see the guideline offer similar clarity, in order to be consistent. In our survey, 78% of respondents wanted to see a separate statement making clear that referral for AAC could be on an anticipatory basis; 22% felt the current approach	Thank you for your comments. We have changed the wording of the recommendations to make it clear that people can be referred if a need is anticipated.

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				sufficient. One respondent to our survey highlighted that early understanding and anticipation of cognitive change can also be crucial to securing effective ongoing communication, as well as avoiding the pitfall of concentrating on swallowing function at the expense of speech. - *My husband developed FTD, by this stage it was too late for him to learn how to use a communication device suitable for his physical abilities at that stage. I had signposted spelling difficulties that had not been present before the onset of MND, and changes in empathy - yet although the neurologist tested for FTD this information did not feed through to the SaLT - who when she did come really didn't seem to have an up to date grasp of what equipment was available. Her*	

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				appointments were always too long and too distressing for my husband with a concentration on swallowing rather than communicating - this led him to express what I assume to have been extreme frustration - a wordless howl that I can still hear three and a half years after his death.	
Motor Neurone Disease Association	Full	272	Table	This discussion further supports our recommendation that there should be early discussion of the possible issues around withdrawing NIV at the end of life.	Thank you for your comment and support.
Motor Neurone Disease Association	Full	281	Table	This discussion further supports our recommendation that there should be early discussion of the possible issues around withdrawing NIV at the end of life.	Thank you for your comment
Motor Neurone Disease Association	NICE	5	6-8	It is not clear which clinicians this paragraph is addressing; it could apply equally to a GP or to a non-specialist neurologist, but the wording in its second sentence	Thank you for your comment; we have removed the word specialist to clarify the meaning of the recommendation.

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				seems to rule out the latter. We recommend clarifying that this is sound advice for both groups of clinician.	
Motor Neurone Disease Association	NICE	6	8-12	As part of this process to ascertain the preferences of people with MND for receiving information and involving their family members in their care, it should be recommended that these preferences be included in all letters of referral to other agencies. This will help to avoid the inappropriate omission, or inclusion, of carers and other family members at later stages.	Thank you for your comment. The Guideline development group considered that this would not necessarily be good practice as people may differ in what information they are happy to have shared with different members of their families for example they might differ in their view about sharing of medical and financial information.
Motor Neurone Disease Association	NICE	6	2-4	We support the recommendation for a clearly named coordinator of care, and single point of contact that a person with MND can contact in an emergency. However, we recommend that more thought is given to, and guidance offered on, how this works in practice. In particular, is the single point of contact intended to be a care	Thank you for your comment. The Guideline development group did not wish to specify who should carry out this role. The evidence indicated better outcomes for people cared for by a clinic based multi-disciplinary team and the role of that team included communication and co-ordination. This model does not need to be based in a hospital and we have clarified this in the recommendation.

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				coordinator? The nature of the care coordinator role is discussed further in point 31. In context, this wording in the draft guideline appears to imply, but not explicitly state, that this single point of contact should be in the hospital where the person was diagnosed. This may or may not be the intended meaning, but it is not representative of how MND care is arranged in practice. We asked about this in our survey, and respondents fed back as follows: - 24% have a single point of contact in the hospital where they were diagnosed - 10% have a single point of contact in another hospital - 18% have a single point of contact not based in a hospital - 21% do not have one and feel it has been a problem for their	

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				care - 7% do not have one and feel it has not been a problem for their care. We also asked respondents to indicate how satisfied they were with their care overall: those who had a single point of contact, in whatever setting, were more likely to indicate that they were satisfied. The Models of Care project also sheds some light on this aspect of care. Among respondents to its call for evidence, fewer than half identified a key worker or coordinator for people with MND in their area (although this is not quite the same role); some noted that the first member of the multidisciplinary team (however constituted) to make contact with the patient assumes the key worker role, which in the majority of cases is maintained throughout the patients' disease progression.	

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				Overall therefore, we support the recommendation for a single point of contact, but believe that how it should work in practice requires further exploration.	
Motor Neurone Disease Association	NICE	7	17-23	We recommend that the guideline suggest a follow-up appointment be offered for a couple of weeks after diagnosis, to allow for questions to be asked and care planning to be developed once the person with MND has had a chance to take in the news.	Thank you for the information. We have added a new recommendation to offer follow up within 4 weeks from time of diagnosis.
Motor Neurone Disease Association	NICE	7	17-19	The formulation 'many people with MND may not have informal care available' is potentially somewhat misleading. While it is certainly possible for someone to have no informal care available, for instance if they live alone or are themselves caring for a spouse or other relative with their own care needs, it is probably a step too far to describe this group as 'many'. The same wording occurs in the table on page 74 of the full guideline.	Thank you for your comment. We have changed this to 'some' people. Thank you for this information. We are not

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				The current wording could also be taken to mean that this phenomenon is distinct to MND, although there is no reason to believe it is. That said, our recent survey of carers benchmarked the experience of caring for someone with MND against the National Carers Survey, and found that the burden on an MND carer, in terms of the time commitment required of them, is greater than the average in the carer population as a whole. The guideline may wish to take this into account when discussing issues pertaining to carers; we will be happy to supply the MND Carers Survey to NICE on request.	intending to indicate that this situation is distinct to Motor Neurone Disease; however since it is a guideline for people with Motor Neurone Disease it seems important to recognise the issue here.
Motor Neurone Disease Association	NICE	7	25-27	This text rightly states that someone with FTD may lack capacity. However, there is no balancing statement to emphasise that people with milder cognitive change may still be able to reason: although they may struggle to take new information on board, with	Thank you for your comment. We have reviewed the wording of the recommendation and consider it covers this point. Readers are directed to the Mental Capacity Act 2005 which provides further advice in this area.

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				appropriate help and support to do so they may still be able to process it rationally. In short, reasoning may still be intact even if the ability to take information on board has become impaired. Discussion in the table on page 77 of the full guideline ventures into this territory; it would be desirable to reflect some of this content in the summary version,	
Motor Neurone Disease Association	NICE	7	25-26	This section notes the possible implications of frontotemporal dementia (FTD) for the individual's mental capacity. Overall, we feel the guideline does a good job of recognising the significance of FTD, and welcome the emphasis placed on it throughout. In our survey, 77% of respondents agreed that recognising FTD in the guideline was important; 21% were unsure, and 2% felt it wasn't important. It is possible, however, that when MND occurs in older people in particular, they may also already	Thank you for your comment. We recognise that people with MND may have other morbidities including other forms of Dementia. The suspicion of and management of other morbidities is outside the scope of the guideline.

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				have, or go on to develop, another type of dementia such as Alzheimer's instead of, or even as well as, FTD. This too will have implications for mental capacity and consent, similar to those identified throughout the guideline in respect of FTD. The possibility should be included in both versions of the guideline – an inexpert reader might otherwise draw the conclusion that non-FTD dementias do not occur in people with MND.	
Motor Neurone Disease Association	NICE	9	24-30, 1-10	We recommend that an MDT – whether based in hospital or the community – should involve the GP of the person with MND. Ideally this would be as a core member, although bearing in mind practicalities such as the need to attend MDT meetings, strong communication and information sharing between MDT and GP is perhaps the best recommendation. In our survey, 82% of respondents felt GPs should be included in the core team. Respondents reported	Thank you for your comment. The Guideline development group recognise that frequent and good quality communication with GPs is essential. The model of care for which we had evidence is a clinic based model and we have described the professionals specific to the needs to people with MND. We acknowledge that many other healthcare professionals such as GPs will be involved in the care of people with MND.

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				that their GP's involvement in their care varied: - 18% said their GP was heavily involved - 27% said their GP was somewhat involved - 40% said their GP was only very occasionally involved - 15% said their GP was not involved. GP involvement correlated positively with the respondent's satisfaction with their care, which suggests that more research may be needed to test the proposition that GP involvement in MND care has a beneficial effect. We also recommend that palliative care should be in the core team: in our survey, 95% of respondents believed that specialist palliative care should be part of the core team. Speech and language therapy should be available on an	We have added skills in palliative care to the description of the MDT. The Guideline development group acknowledged that some MND teams provide palliative care without involvement of specialist palliative care as a core member of the team. The core MDT constitution was developed from the evidence. The studies informing the MDT had specialist nurses and we have added comment on the make up of the MDT to the Full guideline. Co-ordination is also added as a fundamental aspect of what the MDT should provide and we acknowledge that this was not as

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				'access' basis at least, and benefits advice should be available as well – 96% of respondents wanted to see benefits advice added to the list. Although the draft guideline recommends that a specialist nurse should be a core member of the team, this role is not defined or explored. In different settings, such a role might be dedicated to MND, or might cover a range of rarer neurological conditions. The Models of Care interim report identified a variety of views about to what extent, and how, specialism should be brought into multidisciplinary teams: some saw great benefit in having an MND specialist nurse, both in terms of care provided and the ability to up-skill other members of the team; others saw more need for specialism in care coordination, and even argued that this would be more valuable than a specialist	prominent as it should have been in the draft version.

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				nurse as such. See point 31 above for further discussion of coordinator roles.	
Motor Neurone Disease Association	NICE	12	9-25	Social care can be a difficult aspect of MND care if not delivered to a high standard; it would be helpful for the guideline to include advice to address the potential problems associated with it. Care workers can lack expertise in MND, and can also rotate very quickly, providing little continuity; the resulting care can feel like a parade of strangers visiting someone's home. Some respondents to our survey identified this as a significant problem in their care. - *Untrained, unskilled carers, with no knowledge or understanding of MND, caused more problems than they solved.* - *My main bone of contention is the carers. I appreciate they*	Thank you for your comment. The Guideline development group acknowledged this issue and therefore included recommendations 1.5.10 and 1.6.5 in the NICE Guideline about continuity of care.

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				are on zero hours and minimum wage (and that until caring becomes a profession alongside nursing things probably won't change). But an awful lot of heartache and misunderstanding could have been prevented if they had some understanding of the condition. I often ask them if they know anything about MND, and to go and google it - especially the emotional side effects including anxiety.	
Motor Neurone Disease Association	NICE	12	20-30	This section does not address the substantial impact of isolation and shrinking social networks as a result of MND, for both the person living with MND and their carer or carers. We are, however, pleased to see the value of wider communication such as email, as well as face-to-face communication, acknowledged: this engagement with the wider world can be hugely important to a person with MND.	Thank you for your comment. We have tried to cover this within the recommendation 1.6.5 of the NICE Guideline 'support to engage in social activities and hobbies, such as access to social media and physical access to activities outside their home'.

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Motor Neurone Disease Association	NICE	13	2-12	This section should be clarified, to emphasise that all health and social care professionals in an MDT should be prepared to have conversations about end of life issues, and should not close them down when the person with MND initiates them – this could be at any time, not necessarily when a professional might expect it, and people with MND tell us that they place importance on being able to discuss this when they feel ready. This responsibility should not be assumed to rest only with palliative care teams. Many respondents identified the need for such discussions, and even expressed annoyance at some professionals' apparent reluctance to engage in them. - *Depends on the person...in our case my wife happened to be very open and exploratory...eg she wanted to give her remains for study...the clinician always*	Thank you for your comment and this information. The Guideline development group considered this issue and have added a recommendation to suggest that professionals be prepared to discuss end of life issues whenever the person with MND wishes to.

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				had difficulty in dealing with such strident honesty - *We were caught out by the speed of the disease. So end of life discussions were left to family members. Wills and power of attorney were discussed early on but not considered at that point and therefore not completed before respiratory and physical condition deteriorated to such a debilitating extent. It should be insisted upon early with a knowledgeable professional to avoid problems later.* - *Even professionals from the specialist team at the MND Centre shy away from discussion about end of life issues. It would not be considered 'up beat' enough!!* - *What are clinicians waiting for. Why are they waiting? Until that conversation can't be had with a voice. It's barbaric.*	

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				- *I made it quite clear that if I had lost my mental capacity or was for other reasons not able to communicate I did not want to be resuscitated. Once I had done this I was able to get on with my life without worrying so much about the assumed progression of my illness* - *The ability to discuss end of life is often more difficult for the carers / family of the sufferer and medical staff should be sensitive to that and allow discussion when raised.* - *We would have both welcomed counselling at the beginning and at the end. We didn't know the end was so close when it did come.* - *I think there should also be a sentence emphasising that people can change their mind at any time.* The consequences of failing to address wishes about the end of	

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				life early enough were recounted by some respondents. - *An advance care plan is so important. It wasn't done in our case and led to all sorts of problems in trying to fulfil end of life wishes. For example, being in a hospice instead of dying in hospital - the question was never asked by professionals until it was too late and the death was in hospital, not the preferred place which was hospice.* - *My husband couldn't discuss his end of life choices, he'd lost his voice and couldn't type, it was too late for him.* There are however obvious problems with raising end of life issues insensitively, as numerous respondents identified. - *I have been quite blown away by how an MND nurse brings up an end of life plan - like it's just another treatment. Even receiving a phone call 'out of*	

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				the blue' asking me if I want one. I do believe the patient should be the one to instigate it, I object to having it rammed down my throat! - *On one visit to the neurologist my husband was asked, 'where would you like to die?' There was no preamble, no explanation that his condition had not suddenly deteriorated and that he was simply being asked about his wishes in line with guidelines that seemed to have been updated just prior to the consultation. My husband was unable to respond, he was by then too slow with the Lightwriter - and was distressed by the question - this should have been delegated to the neurological nurse specialist as a question to be asked in the home setting, or at the very least there should have been some explanation of why he was being asked.*	

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				- *It should not be discussed though at diagnosis! This is a devastating time and patients and family need time to digest this first, not try and talk end of life care. Totally wrong timing and insensitive.* - *This in particular is a very private and personal business, done too quickly it would be very distressing. Left too late especially if the bulbar issues become especially challenging and psychological factors develop and it is essentially too late. Very tricky one.*	
Motor Neurone Disease Association	NICE	13	10-12	This recommendation could usefully be strengthened: nearly all people with MND will find one or more of their communication ability, cognitive ability or mental capacity impaired during their illness, so this should simply be a recommendation to start advance care planning at an early stage, once the person with MND is ready to face it (which will vary	Thank you for your comment. The recommendations aim to strike a balance between ensuring end of life issues and advance care planning are discussed early in a patient's journey and making specific mention about situations where this might have to be done as soon as possible. We have changed the order of the recommendations to make this intention clear.

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				considerably). In our survey, 88% of respondents agreed that the guideline should recommend that advance care planning be started early in a person's illness, to ensure it is not hindered by, say, communication difficulties later on; 4% disagreed. We also recommend that lasting power of attorney (LPA) should be added here; to discuss it under circumstances of 1.7.5 (when considering NIV or gastrostomy) is too late.	
Motor Neurone Disease Association	NICE	13	13-14	We recommend that early referral to specialist palliative care should be routine for all people with MND, not just complex cases. The analysis in the full guideline and views expressed by people with MND as discussed in our points 46 and 51 above bear this out. In our survey, 82% of respondents felt there should be early referral to specialist palliative care for everyone; 16% felt the guideline was correct to reserve this for people with significant or complex	Thank you for your comment. The Guideline development group have altered the recommendations to highlight the importance of palliative care. We have added that the core MDT should include someone with palliative care expertise and that the MDT should have established relationships and prompt access to specialist palliative care. The guideline group have also added palliative care services to the information we suggest people are given from diagnosis.The intention in recommendation 1.7.3 of the NICE Guideline was to

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				needs.	emphasise areas where early referral was most advantageous and we have changed the position of this recommendation to highlight this.
Motor Neurone Disease Association	NICE	14	3-5	Although tracheostomy is out of scope of this guideline, similar considerations may pertain to it as to gastrostomy and NIV, as referenced here. Given that this discussion is focused on planning for the end of life, there is a case for referring to tracheostomy – if it is not covered in an ADRT or other legal instrument, there is the possibility of it being introduced in an emergency situation.	Thank you for your comment. We have clarified in the introduction to the NIV section that these were outside the scope of the guideline. The Guideline development group reviewed the recommendations and preferred not to include these specifics in the list but we have added them to the Full guideline.
Motor Neurone Disease Association	NICE	14	20-21	This stipulation regarding bereavement support is welcome, but could offer more specifics about what this support should involve, and what is meant by 'as appropriate'. The full guideline offers no further detail, although the finding in the evidence review that support from health and care services seems to carers to 'disappear' immediately after	Thank you for your comment. The specifics of bereavement support are outside the scope of this guideline.

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				bereavement rings true.	
Motor Neurone Disease Association	NICE	16	9-14	Reference to neck control and support should be included in these paragraphs on saliva management.	Thank you for your comment. The Guideline development group considered that this was covered in 'posture'.
Motor Neurone Disease Association	NICE	17	7-16	Daily living needs such as shopping, housework and food preparation should be added here; these are all within scope of social care as defined in England by the Care Act 2014.	Thank you for your suggestion. We have added these to the list. .
Motor Neurone Disease Association	NICE	17	24-25	We recommend that more detail be provided on the characteristics of wheelchairs for people with MND, such as the need for wider arms, a head support, a tilt function and so on. In our survey, 81% of respondents felt the wording should be expanded to give more details of the MND specifics of appropriate wheelchairs; 19% felt the current approach to be sufficient.	Thank you for your comment. The Guideline development group reviewed the wording of the recommendation and preferred to alter the wording to emphasis the potential need for manual and/or powered chairs and not to specify the detail of the chairs themselves. This was considered to be too detailed for a recommendation.
Motor Neurone Disease	NICE	17	15	We would like to see the references to assistive technology expanded to include computer access, to ensure	Thank you for your comment. The Guideline development group reviewed the wording of the recommendations. Assistive

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Association				that people are still able to use online services and communication channels as outlined earlier on page 12. In England and some other territories, computer access is dealt with by environmental control services, but this is not always widely understood by professionals or service users; a clear statement would help set appropriate expectations on all sides. In particular, the ability to communicate should be preserved, rather than assistive technology being restricted to specific purposes such as environmental control. In our survey, 86% felt that there should be a statement that the person's ability to communicate should be maintained for its own sake; 14% felt the current approach sufficient	technology is used as an example here only and the Guideline development group did not consider it would be useful to provide multiple examples as the list could not be comprehensive. The section on communication (section 1.11 of the Full guideline) provides more detailed examples and does include reference to computers.
Motor Neurone Disease Association	NICE	18	17-22	We recommend the inclusion of advice on training and support for carers, both on technical matters such as feeding using a tube and keeping the tube clean, and on	Thank you for your comment. NICE has a guideline Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition NICE guidelines [CG32] which covers this area in more detail.

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				issues such as addressing potential awkwardness or more complex issues, such as feelings of guilt if eating solid food in front of someone who is tube fed.	
Motor Neurone Disease Association	NICE	19	20	We advise against the use of the word 'normally' here; in this context, it may appear to have a loaded meaning. Neutral language such as 'without assistance' should be used.	Thank you for your comment. We agree and have changed the wording to include 'without assistance'.
Motor Neurone Disease Association	NICE	20	1-2	This text notes that some people choose not to have a gastrostomy, but no further guidance is offered on what the implications of this might be, or what support should be made available to them. We recommend that the guideline offers further clarity on this point.	Thank you for your comment. The guideline scope includes timing of gastrostomy only.
Motor Neurone Disease Association	NICE	20	8	This stipulation should offer greater clarity about what is meant by 'unnecessary delay' (for instance, waiting until a patient is clinically able to undergo the procedure might be a necessary delay, but	Thank you for your comment. The Guideline development group discussed this at length but were concerned that providing clear timeframes would not be appropriate in all cases.

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				having to wait because a hospital cannot roster an anaesthetist would not be), or alternatively use more direct wording such as 'urgently'.	
Motor Neurone Disease Association	NICE	20	23-4	We recommend that this provision should specify that the speech and language therapist should have appropriate knowledge of MND.	Thank you for your comment. The recommendations state that 'the core multidisciplinary team should consist of healthcare professionals and other professionals with expertise in MND' with speech and language therapists listed under this, therefore it is specified there rather than in the individual communication recommendations.
Motor Neurone Disease Association	NICE	21	6-8	As with the equivalent section in the full guideline, this should specify that referral for assessment can be anticipatory, in line with NHS England's service specification. It should also clarify the meaning of 'complex' in this instance, which is quite specific: here, 'complex' need means that in addition to impairment of the voice, the person is also losing hand function (and therefore cannot use more basic text-to-speech communication aids). Accordingly, the guideline	Thank you for your comment. We have changed wording to indicate that this can be anticipatory. We have also added this meaning of complex to the glossary and to the Full guideline section. The recommendations do specify where referral to hub is required.

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				should also clarify that in non-complex cases, assuming no anticipatory referral, local speech and language services should meet the person's needs, not an AAC hub (in England). In some areas of the country, a timeframe for anticipatory assessment of 18 weeks is starting to be used: so, if the person might be expected to develop 'complex' needs within 18 weeks, an anticipatory referral is appropriate, even if the need is only just starting to develop. This will ensure that by the time the need is clear-cut, provision should be in place. We would be content to see this timescale proposed (though this does not mean we would support a general timescale of 18 weeks from referral to provision for any MND service – for too many people, this would be unacceptably slow).	
Motor Neurone	NICE	22	17-22	These paragraphs are arguably unclear in what decisions they are	Thank you for your comment. All recommendations include some

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Disease Association				asking clinicians to make: what conclusions should they draw in respect of the route of administration and cost of the medicine? Although part of the role of NICE guidance is to evaluate cost-effectiveness, this is the only point in the guideline at which the reader is advised to make a judgement on cost. We recommend that this text should either be much clearer about what it expects from clinicians, or remove reference to cost in particular. In our survey, 80% of respondents felt these paragraphs were clear, but 68% felt they should not advise clinicians to consider cost.	consideration of cost and cost effectiveness. This is standard NICE wording when drugs are available in several formulations at potentially different costs.
Motor Neurone Disease Association	NICE	22	1-3	When mechanical cough support is used, ongoing professional support must be in place. This has been known to cause difficulties for people with MND, so it should be stipulated in the guideline.	Thank you for your comment. We have added reference to ongoing management in the description of role of MDT rather than in individual recommendations.
Motor Neurone	NICE	22	14-15	While it may be strictly true that the decision to offer a treatment rests	Thank you for your comment. We agree that patient preferences are important and

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Disease Association				with clinicians, we would prefer to see a reference here to the person with MND, to acknowledge that this decision will be made with knowledge of their circumstances and, when possible, preferences.	have altered the wording and order of the recommendations to highlight this. The detail of discussions with patients is outlined later in this section.
Motor Neurone Disease Association	NICE	24	6-12	This recommendation should be expanded to stipulate that the person with MND must understand the possible interaction between NIV and other equipment – in particular, that it can sometimes be incompatible with eye gaze devices.	Thank you for your comment. We have made this change.
Motor Neurone Disease Association	NICE	24	13-15	This discussion further supports our recommendation that there should be early discussion of the possible issues around withdrawing NIV at the end of life.	Thank you for your comment.
Motor Neurone Disease Association	NICE	33	10-11	The MND Association has a range of information and support available for professionals caring for people with MND, which in many cases go into greater detail than the short guideline, and in some cases than	Thank you for this information.

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				the full one. We also suggest that the MND Association Red Flags tool, already mentioned in the guideline, and Outcomes Standards framework as tools that might assist users of the guideline. Our award-winning Guide to End of Life, although written primarily for people with MND, is directly relevant to the guideline's content on planning ahead and is already used by professionals. We will be happy to supply these to NICE, and discuss whether and how they can be promoted alongside the guideline.	
Motor Neurone Disease Association	NICE	34	9-12	This paragraph contains a mistake in presenting the statistics on dementia and cognitive change: it refers to 10-15% of people with MND developing FTD, and a further 50% showing signs of mild cognitive change. This suggests a total of up to 65%. Page 75, line 3 of the full guideline states that up to 50% of people with MND experience cognitive change,	Thank you for your comment. We have rewritten this section.

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				and that this includes those who develop FTD. We believe the latter to be correct, and recommend that the wording on page 34 of the short guideline be corrected.	
Motor Neurone Disease Association	NICE	34	29-29	These lines use the problematic generalisation about 'care centres' versus 'general care' already discussed. We recommend that they are amended to reflect the variety and complexity of MND care available.	Thank you for your comment. We have altered the description of current care.
Motor Neurone Disease Association	NICE	34	16	We feel it is misleading to state that MND 'mainly affects people aged 50 to 65 years'. While this may be the age group in which incidence is highest, MND can affect any adult. The current wording may create misleading expectations among clinicians and professionals not already familiar with MND. We recommend that the guideline states that MND can affect any adult, but is most common between the ages of 50 and 65.	Thank you for your comment. We have rewritten this section.

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NHS England	NICE	13	13	Much of this section is devoted to communication and advance care planning. This is appropriate but I would suggest that the point made in this line (para 1.7.3) is moved to the top of this whole section, so that it does not get lost.	Thank you for your comment. We have moved this recommendation to an earlier part of the guideline as we agree it was not well placed in this section.
NHS England	NICE	14	6	The reference to the potential need for additional nursing and social care is important. But at an earlier point and at this stage, the role of occupational therapists and physiotherapists should be more strongly emphasised as they have a great deal to offer in terms of direct interventions to improve quality of life, symptom management and maintaining wellbeing and social participation, but also in terms of indirect intervention through education and support of family and lay carers.	Thank you for your comment. The recommendation indicates nursing and social care as examples only. Occupational therapists and physiotherapists are already included in recommendations about multi-disciplinary care and about equipment and adaptations.
NHS England	NICE	20	10	These discussions should also include the future scenario – anticipating situations when it might be appropriate to consider stopping feeds through a gastrostomy, e.g. patient choice, etc. and what that	Thank you for your comment. Recommendations about stopping assisted hydration are included in NICE Guideline Care of the Dying Adult

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				might look like. Rehearsing these possibilities beforehand enables informed decision making by the patient.	
NHS England	NICE	23	11	Discussion about when and how decisions to withdraw NIV should be considered at this point for the same reasons as set out re. gastrostomy above.	Thank you for your comment. We think this is covered in the recommendations.
NICE medicines and prescribing centre	NICE	general		There are a lot of examples given within the recommendation; I am not sure all of these are needed. The length of the document could be reduced with some editing of these examples, without affecting the messages contained within the guideline	Thank you for your comment. We are unclear which recommendation your comment refers to. We acknowledge that there are many examples in some recommendations but the Guideline development group considered these important.
NICE medicines and prescribing centre	NICE	16	15	Rec 1.8.12 Anticholinergics are now known as 'antimuscarinics' (in BNF, SPC and MHRA literature) please update term	Thank you for your comment. We have changed the term.
NICE medicines and prescribing centre	NICE	16	22	Rec 1.8.14 Botulinum toxin a is not licensed for this indication	Thank you for your comment; we have added a footnote to clarify this.
NICE	NICE	19	22	When talking about mental	Thank you for your comment. We have

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medicines and prescribing centre				capacity, should the act be footnoted here?	added this.
NICE medicines and prescribing centre	NICE	21	23	Rec 1.12.2 Should this recommendation clarify this refers to unassisted breath stacking (as opposed to assisted in next rec)?	Thank you for your comment. We have changed this in line with your suggestion.
NICE medicines and prescribing centre	NICE	31	28	Rec 1.14.26 Opiods are not licensed for breathlessness. Benzodiazepines are licensed for anxiety (which may exacerbate breathlessness), see recs 1.13.5, 1.13.6	Thank you for your comment.
NICE medicines and prescribing centre	NICE	33		The context secion of the implementation section has allot of figures (e.g. 10-15% of people with MND will show signs of FTD), these should be referenced.	Thank you for your comment. As you indicate there is some uncertainty about this statistical information. We do not have more robust information so have altered this section to avoid providing misleading information.
NICE medicines and prescribing centre	NICE	35	18	Please reference figure quoted	Thank you for your comment. We have altered the context section as there is some uncertainty regarding statistics.
NICE medicines	NICE	36	25	Please reference figures quoted	Thank you for your comment. We have altered the context section as there is

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and prescribing centre					some uncertainty regarding statistics.
NICE medicines and prescribing centre	NICE	36	28, 29	Anticholinergics are now known as 'antimuscarinics' (in BNF, SPC and MHRA literature) please update term	Thank you for alerting us to this change. We have changed the term.
NICE medicines and prescribing centre	NICE	37	11	Please reference study quoted	Thank you for your comment. We have altered the context section as there is some uncertainty regarding statistics.
NICE medicines and prescribing centre	NICE	37	13	Please reference study quoted	Thank you for your comment. We have altered the context section as there is some uncertainty regarding statistics.
North Bristol NHS Trust	Full	16	31	I am very concerned that there is no mention of the MND care coordinator role in these guidelines which is a well-established role amongst the MND care centre and networks across England, Wales & Northern Ireland. As well as some Clinical Commissioning Groups fund MND coordinator posts (separate from the MND care	Thank you for your comment. The guideline does recommend that care be co-ordinated but does not specify a specific role/position by which this can be achieved. The Guideline development group were aware of the MND care co-ordinator role and the intention was not to devalue their role. However the evidence for improved

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				centre/network model). With regards to this role many coordinators are either from a nursing or allied health professional (AHP) background which has long been supported by the MND Association. I do not agree there has to be a specialist nurse for people with MND as the AHPs in such roles are well skilled to manage the needs of people with MND and can provide advice and support to a wide range of professionals who support people with MND. I am very disheartened to see them not mentioned at all in these guidelines and I am sure the coordinators feel devalued this important role has been omitted. We strongly feel that the coordinator role has aided our service in supporting the person with MND form diagnosis to end of life, through excellent communication with the various professionals involved in their care to ensure coordinated and timely interventions, as well as for	outcomes comes from a clinic based model where co-ordination is part of the role of the MDT. We have altered the recommendations to highlight this aspect of care which was not emphasised adequately in the draft guideline. Who in the MDT co-ordinates care is not prescribed and we agree that this may be a specialist nurse or other AHPs.

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				education and raising the profile of MND and its management.	
North Bristol NHS Trust	Full	17	2	I strongly feel palliative care is part of the core multidisciplinary team – we have access to palliative care in our clinic and often refer at diagnosis if the person with MND is agreeable, and we very much view them as part of the core team due to the nature of MND.	Thank you for your comment. The Guideline development group agreed that the core team needs to include someone with specialist palliative care skills and have added this to the description of core members of MDT.
North Bristol NHS Trust	Full	18	41	It would be helpful to mention MND care centres and networks in the guidelines– I am aware not everyone may have a centre/network local to them which they can easily access and often people with MND attend their local district general hospital for neurology review. MND care centres and networks are a useful resource in particular for second opinions or for people wishing to visit only once to see professionals with an expertise in MND. Also though in some areas it is helpful to have a multidisciplinary team approach in clinic, in our own	Thank you for your comment. We have added mention of care centres and networks to the discussion of organisation of care. The Guideline development group recognise that there are different models of care. However the evidence for improved outcomes comes from a clinic based model where co-ordination is part of the role of the MDT. The Guideline development group agree that community based teams are important and have clarified that MDT can be hospital or community based in recommendation 1.5.1 of the NICE guideline and that all MDTs need prompt access to community neurology teams in recommendation 1.5.5 of the NICE guideline.

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				service though we have access to a multi-disciplinary team in clinic we rely more on the expertise of the Specialist Community Neurology Services (community Allied Health Professional teams often consisting of Physiotherapists, Occupational Therapists, Speech & Language Therapists & Psychologists) as in our experience they provide regular, ongoing review and often are proactive in assessing the needs of the person with MND. As well as it is imperative people are assessed in their home environment, as seeing someone in clinic does not highlight some of the problems a person may be experiencing and what techniques, equipment etc. may be beneficial. I feel an essential part of our work supporting people with MND is through such services as the Specialist Community Neuro Therapy teams, though I am aware not all parts of the country have such services and this varies regionally depending on what each	

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				Clinical Commissioning Group has commissioned. In areas where there are more locality therapy based teams often they will discharge the person with MND, often they don't have much experience of seeing the person with MND and may also discharge people with MND though they have a progressive condition which needs regular monitoring. I feel it is more imperative that the community services are well resourced as often these are the services supporting people at home, preventing unnecessary hospital admission and have helped our service, along with the MND care coordinator role, to reduce our hospital admission rate for people with MND. This is also alongside the AHPs working very closely with Community Matrons and District Nurses too who play a vital role in patient monitoring, symptom management, supporting people with long term conditions, and end of life care & support etc. We are	

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				more than happy to share our experiences with this.	
Nutrition and Diet resources UK	NICE	18	General	Once the decision to instigate nutrition support, either oral or via an enteral tube, it is important that concise, clear written information is provided to augment the verbal advice offered by the dietitian and other members of the clinical care team.	Thank you for your comment. NICE has a guideline Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition NICE guidelines [CG32] which covers this area in more detail.
Royal College of General Practitioners	Full	General	General	We do not have any comments on this guideline at the current time.	Thank you.
Royal College of Nursing	Full	General	~General	Our members consider that the document seems very focused on the neurologist role. In many areas people are carried for by generalist neurologists, who do not have many of these skills, but this is provided by other team members especially Motor Neurone Disease (MND) co-ordinators.	Thank you for your comment. The Guideline development group were clear that a neurologist with the required information was the best person to give the diagnosis to the patient. It is not intended that the neurologist is the only person who provides information and we have changed the order of the recommendations to make this clear.
Royal College of Nursing	Full	General	General	The Royal College of Nursing (RCN) welcomes proposals to develop the guideline for the assessment and management of motor neurone disease (MND).	Thank you for your comments.

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				The invited members who care for people with motor neurone disease and neurological conditions reviewed this draft document on behalf of the RCN. The comments below are based on feedback from our members. The comments below reflect the views of our members.	
Royal College of Nursing	Full	General	General	The whole document feels very focused on hospital care, when the aim of care should be primary care focused	Thank you for your comment. The actions included in the recommendations are not intended to be hospital based and can take place in hospital or community depending on what an individual patient needs and what is available locally. We have clarified this in the recommendations about organisation of care.
Royal College of Nursing	Full	General	General	Our members consider that the word "anticipatory" care should be used throughout and avoidance of the "crisis" concept must be made throughout all documentation It is considered that there is no excuse for crisis in the care of people with motor neurone disease (MND).	Thank you for your comment. The Guideline development group have reviewed the recommendations and added more emphasis to anticipation and delivery of services without delay. We accept that anticipation is important but do not agree that all crisis can be avoided.
Royal College of	Full	General	General	There seems to be little emphasis on adaptation and/or capability to	Thank you for your comment. We have added reference to work to

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Nursing				continue in meaningful activity, be it work or home based for as long as possible.	recommendations 1.6.1 and 1.6.5 in the NICE guideline.
Royal College of Nursing	NICE	5	16	There is a concern that neurologists are not going to be able to fully provide the information and support needed at diagnosis to deal with all these issues in a general neurology clinic slot of twenty minutes.	Thank you for your comment. The recommendations are intended to specify that the information is given rather than by whom and when. We have changed around the order of the recommendations to increase clarity.
Royal College of Nursing	NICE	6	11	Our members have stated that in some areas this happens in patients own home, with visits from a MND co-ordinator.	Thank you for your comment and this information. The recommendations do not specify where this should take place.
Royal College of Nursing	NICE	9	24	Our members consider that the MDT clinics can become so big that patients could become exhausted after seeing everyone at their appointments. The physiotherapists and occupational therapists are better placed to visit people in their own homes, where assessments can be made bearing in mind the actual home setting/limitations. Also we need to take into consideration moving care out of	Thank you for your comment. The description of the MDT includes seeing people in their own homes and the need for relationships with community neurology teams.

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				hospitals and into people's homes where people with MND spend 95% of their time through the disease.	
Royal College of Nursing	NICE	9	28	Why a specialist nurse? Many of the co-ordinators in MND care centres/Networks are very skilled Allied Health Care Personnel such as occupational therapists, physiotherapists and speech and language therapists. We would suggest that this should also include and MND Coordinator role not just a specialist nurse role.	Thank you for your comment. The studies informing the MDT had specialist nurses and we have added comment on the make up of the MDT to the Full guideline. Co-ordination is also added as a fundamental aspect of what the MDT should provide and we acknowledge that this was not as prominent as it should have been in the draft version. The Guideline development group did not wish to designate an individual heal professional to be responsible for co-ordination.
Royal College of Nursing	NICE	10	3	Our members wonder if the speech and language therapy should be offered in a clinical setting as mentioned earlier. How does one assess eating a meal in an outpatient setting? Home visit would be much more useful.	Thank you for your comment. We have reworded this to clarify the issue.
Royal College of Nursing	NICE	10	6	Will funding be made available for neuropsychology service? Our members have indicated that in current clinical practice, many neuropsychologists do not have the capacity to work with MND patients.	Thank you for your comment. Theprovision of funding is outside the scope of the guideline. We hope that the guideline will improve access for people with MND to services.

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Royal College of Nursing	NICE	12	13	In areas where there is inadequate carer recruitment, continuity of care presents a big challenge. Our members have indicated that in rural areas they are often unable to access any carers, resulting to difficulty in ensuring continuity of care.	Thank you for this information.
Royal College of Nursing	NICE	13	13	Often palliative care teams only take patients on for a short period, then discharge.	Thank you for your comment. We recognise that this may occur. We have a recommendation suggesting that all healthcare professionals consider the nature of MND and not close cases.
Royal College of Nursing	NICE	22	1	Our members welcome this recommendation if it will lead to the provision of this equipment, in certain areas some clinics are unable to access mechanical cough assists as commissioners will not fund it.	Thank you for your comment. We hope that inclusion in the guideline will increase access to treatments.
Royal College of Nursing	NICE	23	1	Our members have stated that in certain areas respiratory clinical nurse specialists are unable to visit MND patients in their own homes, so as they deteriorate and need more respiratory support, they are unable to access this service.	Thank you for this information. We hope that variability of service might be addressed through the implementation of this guideline
Royal	FULL	Gener		The RCSLT query that the role of	Thank you for your comment. We

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College of Speech and Language Therapists		al		the care coordinator is not recommended in the guidance, whilst acknowledging the lack of evidence for this.	acknowledge that the draft guideline did not give appropriate emphasis to co-ordination of care. We have added a reference to co-ordination of care in the recommendations on MDT and organisation of care. The Guideline development group did not wish to specify who should take the co-ordinator role as this may vary by area and according to patient need.
Royal College of Speech and Language Therapists	Full	General	General	The RCSLT believe it is excellent to see swallowing, saliva management and cough being more overtly included	Thank you for your comment.
Royal College of Speech and Language Therapists	Full	General	General	Does the early identification of MND / diagnosis have a clear ideal pathway? Is there scope to include a clinical nurse specialist (CNS) as standard, during the consultation diagnosis that is given? RCSLT members suggest that there would then be an immediate opportunity to share info with the Motor Neurone Disease Association (MNDA).	Thank you for your comment. The Guideline development group considered that it would not be helpful to outline a specific ideal pathway or individual professionals with specific roles. The Guideline development group considered that a neurologist with appropriate knowledge and skills is required for diagnosis but that roles that you describe for a CNS can be fulfilled by other healthcare professionals and that arrangements for this vary around the country.

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Royal College of Speech and Language Therapists	Full	General	General	Have patients and families with MND been consulted in the process of updating these guidelines? If this is yet to happen, the RCSLT suggest that, if possible, this is included and the detail made available to the reader.	Thank you for your comment. We can confirm that, consistent with the process for developing all NICE guidance, people with MND and their families have been involved in the development of these guidelines and consulted on the draft version. The Guideline committee includes patient and carer members and registered stakeholders include patient organisations.
Royal College of Speech and Language Therapists	Full	General	General	Could the recommendations state more strongly the benefit of a well-coordinated community based team, in all localities, with access to specialist acute based support as required? Our members' comments are based on recent clinical experience in areas interfacing with several community teams – each with quite different services available (or not) for this particular client group.	Thank you for your comment. The recommendations have been altered to indicate that clinic based care does not need to be hospital based and that prompt access to community based neurology teams is important. The recommendations for the model of care are based on clinical and cost effectiveness evidence.
Royal College of Speech and Language Therapists	FULL	16	41	The RCSLT suggest it may be helpful here to add specialist services such as: environmental controls (with knowledge, expertise and a specific remit for computer adaptations), Specialist AAC Hub and home enteral nutrition team.	Thank you for your comment. We have expanded the list of services in this recommendation. It is not however intended to be exhaustive.

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Royal College of Speech and Language Therapists	FULL	17	14,15,16	The RCSLT would like to highlight the importance of seeking patient's consent, prior to information sharing	Thank you for your comment. This section does not specifically relate to information sharing and it is the view of the Guideline development group the addition of patient consent does not seem appropriate here.
Royal College of Speech and Language Therapists	FULL	20	28	Within the section on 'saliva problems' – the RCSLT suggest altering the wording to reflect 'secretion management options'. Education on suctioning is mentioned and pharmaceutical recommendations are considered as the first-line option, but the RCSLT query whether this is always the case? We would suggest anecdotally that for some points oral suction may be preferred as a first option to try. We appreciate this does not address the issues where pooling of secretions is experienced in the pharynx, and thus pharmacy is a sensible option.	Thank you for your comment. This section provides recommendation on saliva problems rather than management of secretions associated with inadequate cough.While the Guideline development group recognise that therapists may use suction as a means of managing secretions they do not agree that suction is appropriate first line treatment. Anti-muscarinic medication may provide on-going reduction in saliva secretion and training is required for family or carers to use suction.
Royal College of Speech and Language Therapists	FULL	20	55	If botulinum toxin injections are not successful (or tolerated) then perhaps a trial of parotid irradiation is included here? *Journal of the Neurological Sciences 308 (2011)*	Thank you for your comment. We did search for RCTs for radiotherapy but as this study is a case series we would not include it in the review. The Guideline development group consider that use of

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				155–157 Kasarskis et al 'Unilateral parotid electron beam radiotherapy as palliative treatment for dialorrhea'	radiotherapy is a rare occurrence and did not wish to make a recommendation. We have included reference to radiotherapy in the Full guideline in section 15.
Royal College of Speech and Language Therapists	FULL	21	1,2,3	The RCSLT suggests adding: 'ensure adequate hydration' as an extra bullet point here as MND patients often do not drink enough and this exacerbates thick secretions. This may not just be due to swallowing problems. Reduced hydration may be purposeful due to the patient's anxiety over mobility difficulties restricting toileting ability.	Thank you for your comment. Hydration is already included in the recommendation.
Royal College of Speech and Language Therapists	FULL	21	20	Include computer adaptations at the point, as they are often forgotten for those without augmentative and alternative communication (AAC) needs and should be included with environmental controls.	Thank you for your comment. The Guideline development group discussed your suggestion and did not consider it appropriate to include computer adaptations at this point. We have added reference to computers and tablets when discussing integration of equipment for communication as the Guideline development group considered it was more appropriate in that section.
Royal College of Speech and	FULL	22	15,16	The RCSLT would like to query what is meant by 'formal' swallowing assessment? Is a	Thank you for your comment. We have changed recommendation 1.10.4 in the NICE guideline to clarify that this is a

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Language Therapists				'clinical' swallowing assessment adequate or does this refer to an instrumental examination?	'clinical' assessment.
Royal College of Speech and Language Therapists	FULL	22	15,16	We believe it would be helpful to include here management as well as assessment, i.e. speech and language therapy to advise on suitable swallowing management strategies, to enhance safety and efficiency of swallowing based on the results of the swallowing assessment, and again, i.e., chin tuck to aid airway protection if beneficial, thickened fluids, food texture modifications.	Thank you for your comment. We have added 'and manage' to recommendation1.10.5 in the NICE guideline) .
Royal College of Speech and Language Therapists	FULL	23	23	RCSLT suggest including interaction with 'computers/tablets', as well as environmental controls as these may not always be deemed as AAC.	Thank you for your comment. We have added 'personal computers and/or tablets' to recommendation 1.11.4 of the NICE guideline.
Royal College of Speech and Language Therapists	FULL	31 (1.2)	16	The RCSLT question whether a research question could perhaps be added around swallowing assessment, such as 'when is an instrumental swallowing examination, of benefit in the management of swallowing difficulties, for people with MND?'	Thank you for your comment. The Guideline development group recognised that there are many possible research recommendations and based the included research recommendations on a prioritisation by the Guideline Group. Furthermore we did not look for qualitative data and instead looked for RCTs. We can

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				This could be done through qualitative research, interviewing expert and non-expert speech and language therapists as well benchmarking current practice through quantitative research; looking at percentage of patients managed with use of instrumental examinations to supplement clinical findings.	only include research recommendations requiring certain types of study design when we have examined those study designs to ensure there is no available evidence.
Royal College of Speech and Language Therapists	FULL	32	4-12	'There are several forms of MND'. This section is a little confusing as it mixes location of onset and description of the disease i.e. progressive bulbar palsy with neurophysiological diagnosis i.e. ALS vs PLS. One or the other should be used and if location is used as a descriptor then flail arm and flail leg subtypes ought to be included.	Thank you for your comment. We have altered this section to improve clarity.
South Wales Motor Neurone Disease Care Network	Full	16	31	In many regional Motor Neurone Disease (MND) Care Centres/Networks, MND Care Co-ordinators (who are registered professionals –	Thank you for your comment. The evidence for improved outcomes comes from a clinic based model where co-ordination is part of the role of the MDT. We have altered the recommendations to highlight this aspect of care which was not

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				nurses, Speech and language Therapists Physiotherapists, Occupational Therapists or Dieticians) are employed to co-ordinate services (as opposed to MND nurses).The role of these MND experts is missing from the document and should be included to reflect current service provision. The MND Association's new Outcome Standards make particular reference under Domain 2 of the importance of Coordinated Health and social care and the Indicator that people with MND should have access to a Specialist Clinical Coordinator.	emphasised adequately in the draft guideline. The guideline does not specify who should co-ordinate care for the person with MDT but all members of the MDT are expected to have expertise in MND.
South Wales Motor	Full	32	31	We suggest saying 'MND care centres and networks.' Newer	Thank you for your comment. We have changed to 'multidisciplinary team clinics

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Neurone Disease Care Network				network approaches may be the right fit to local need in some areas of England and Wales. If any expansion on this point is needed, we would be very willing to share experience and evidence in the form of reports and user feedback.	and networks'.
South Wales Motor Neurone Disease Care Network	NICE	General	General	1. Patients with significant arm weakness cannot remove their ventilator mask should be setup with a nasal mask. This reduces the risk of aspiration I they vomit whilst using the full face mask, 2. Cough should be considered and addressed at respiratory assessment. Cough peak flow should be measured and	Thank you for your comment and this information.

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				addressed according to protocol. Trained HCP should be available to deal with implementation of mechanical cough devices. 3. Feeding tube placements should be managed according to protocol. Close coordination with respiratory medicine is necessary to reduce the risk of PEG placement in a patient with respiratory compromise.	
South Wales Motor Neurone Disease Care Network	NICE	9	1-3	The point about the need for regular clinic review is important, but the guideline should also cover the need to have systems for review of	Thank you for your comment. We have included recommendation about care for people unable to get to clinic. We agree that clinics close to home may also be a useful model of providing care.

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				patients who are not able to attend the clinic as well as those who are. This includes but is not limited to those nearing the end of life. Organising clinics well (close to home, no time wasted) may make it easier for patients to attend but nonetheless some patients who need continuing access to expertise will remain unable to.	
South Wales Motor Neurone Disease Care Network	NICE	10	19-21	The point in comment 8 about assessment outside the clinic setting could be made instead, or in addition, by adding something to this later section.	Thank you for your comment. We have added the importance of care for people who are unable to attend the clinic to the recommendation about MDT.
South Wales Motor Neurone Disease Care	NICE	10	6	We suggest that there should be access to both clinical psychology (for expert assessment of psychological	Thank you for your comment. We have altered the recommendation as our intention was not to indicate either/or.

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Network				problems and if necessary for level 4 intervention) and neuropsychology (for expert assessment of cognitive impairment), rather than saying '&/or'.	
South Wales Motor Neurone Disease Care Network	NICE	10	29	Repeated assessment is important but we suggest adding that the assessment, combined with expert knowledge of the disease, should where appropriate drive anticipatory decisions rather than merely reactive ones.	Thank you for your comment. We have included reference to anticipation of needs to other recommendations and the Guideline development group preferred not to include this here.
South Wales Motor Neurone Disease Care Network	NICE Full	10 18	7 & 25 10 & 26	Inpatient or residential respite is not always available. There is anecdotal evidence that it is not always helpful in that the dislocation from the person's usual place of care may, given the exquisite dependence on very finely	Thank you for your comment. This aspect of respite care is included in the Full guideline in section 11.6

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				calibrated details of care, be so disruptive as to outweigh the benefits. We would therefore suggest making specific mention of options for respite in situ as opposed to respite in an alternative place of care.	
South Wales Motor Neurone Disease Care Network	NICE	13	6	We suggest adding 'or at any other contact if the patient wishes' to the list of points when this opportunity should be offered. The complex and evolving nature of people's information support and communication needs makes it important to offer opportunities at times other than those when we expect them to be taken up. Services should be structured in a way that makes this opportunistic 'striking while	Thank you for your comment. The Guideline development group have added an additional recommendation to this effect.

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				the iron is hot' discussion possible.	
South Wales Motor Neurone Disease Care Network	NICE	13	11	We suggest rewording this in favour of an assumption of early offers of advance care planning rather than doing so only if problems are expected. We should expect some deterioration in a person's ability to participate in decision-making; the majority of pwMND will have failing communication at some point and a large majority will experience progressive fatigue which alone can make complex reflexive decision-making harder.	Thank you for your comment. The Guideline development group have re-organised the order of these recommendations and added an additional recommendation (1.7.2 in the NICE Guideline) to make it clear that while we are suggesting specific trigger points people should be open to this discussion at any time.
South Wales Motor Neurone Disease Care	NICE	13	13	We suggest strengthening this recommendation. Where these needs are complex, referral to specialist palliative	Thank you for your comment. The recommendations have been altered and now state that the core MDT should include someone with palliative care skills and that the MDT should have established

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Network				care should not be merely considered – it should be offered without delay. And it should be considered even if there is no current overwhelming need, for instance if the MND team's instinct is that problems risk becoming harder to control.	relationships and prompt access to specialist palliative care. Palliative care services have been added to the information we suggest people are given from diagnosis. The intention in recommendation 1.7.3 of the NICE Guideline was to emphasise areas where early referral was most advantageous and we have changed the position of this recommendation to highlight this and also altered the wording to reflect likelihood of future problems.
South Wales Motor Neurone Disease Care Network	NICE	13	18	We suggest adding to this sentence something to reflect the patient's willingness to discuss each point and the value in discussing other points even if some are left aside. For instance, even in a patient who does not (yet) want to talk about how death may occur there is value in discussing anticipatory medicines.	Thank you for your comment. We have changed 'should' in the stem to say 'may' to reflect that this is a list of possible discussion points rather than a list of mandatory topics.

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South Wales Motor Neurone Disease Care Network	NICE	14	6-9	We would mention continuing health care specifically. Many people with more rapidly progressive MND meet the criteria. Often the team wait until the person clearly does so, and opportunities for important early changes in care are then missed.	Thank you for your comment. We would rather not specify the mechanism by which this is done as this may change.
South Wales Motor Neurone Disease Care Network	NICE	14	20-21	In line with other guidance we suggest mentioning the need, in some cases, for bereavement support to start before death where anticipatory grief is a significant problem.	Thank you for your comment. Recommendations 1.6.3 and 1.6.4 in the NICE Guideline include attention to psychological and emotional needs of families and carers of people with MND.
South Wales Motor Neurone Disease Care Network	NICE	14 14-16	22ff General	At the start and throughout this section on selected symptom control needs we strongly suggest reinforcing the need for MND teams to offer referral to the specialist	Thank you for your comment. We have altered the recommendations to highlight the importance of palliative care. We have added that the core MDT should include someone with palliative care skills and that the MDT should have established relationships and prompt access to specialist palliative care services. We have

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				palliative care team without delay where there are more complex problems with symptom assessment or symptom control or a failure to respond to first line measures.	also added palliative care services to the information we suggest people are given from diagnosis.
South Wales Motor Neurone Disease Care Network	NICE	15	12-15	We would add that the response to treatment may need to be reviewed sooner than the next planned clinic review, and that the MND team should consider all the options for this including involving the primary care team or if appropriate the specialist palliative care team. 2-3 monthly clinic reviews give too long an interval for review of response to measures for symptom control.	Thank you for your comment. We recognise that appropriate review of interventions will vary according to the nature of the problem and the intervention and the Guideline development group considered that this was a matter for clinical judgement.
South Wales Motor	NICE	15	10	We would strengthen this to	Thank you for your comment. NICE wording is to use 'consider' when the

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Neurone Disease Care Network				say 'offer referral' rather than merely consider it. Where there is severe spasticity and the treatments mentioned are not suitable we see no justification for not offering that.	evidence is of poor quality.
South Wales Motor Neurone Disease Care Network	NICE	18	3-6	We suggest strengthening the wording to reflect the need for that monitoring to drive anticipatory, not merely reactive, planning for adaptations and care needs.	Thank you for your comment. We have added reference to anticipating future need in the first recommendation in this section (recommendation 1.9.1 in the NICE Guideline)
South Wales Motor Neurone Disease Care Network	NICE	23	General	Assuming that invasive ventilation is not generally recommended in MND, we suggest finding an opportunity to say so somewhere in these sections rather than leaving the point implicit by not mentioning it at all.	Thank you for your commnet. This was not included in the scope and we have clarified this in the Full guideline section on NIV.
South Wales Motor	NICE	25	13	Oxygen saturations are not a	Thank you for your comment. These recommendations are from CG105 and

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Neurone Disease Care Network				good screening tool. When the oxygen saturations have dropped due to hypercapnea, they should already be on NIV. Overnight oximetry is more helpful, but should not be an initial screening tool.	were not updated in this guideline
South Wales Motor Neurone Disease Care Network	NICE	26	18	Patients referred to respiratory assessment should have capillary, arterial or venous gas (capillary is most acceptable) as a routine.	Thank you for your comment. These recommendations are from CG105 and were not updated in this guideline
South Wales Motor Neurone Disease Care Network	NICE	27	6-20	The HCO3 level is a better measure of likely ventilatory failure than a point raised PC02 alone and should be considered.	Thank you for your comment. These recommendations are from CG105 and were not updated in this guideline
South Wales Motor Neurone Disease Care Network	NICE	28	1	FVC and SNIP are better screening tools (SNIP is better than MIP – evidence based). Agree if FVC <50% or SNIP <40cm then should	Thank you for your comment. These recommendations are from CG105 and were not updated in this guideline

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				refer on for respiratory testing, or if respiratory symptoms such as dyspnoea on lying flat, increasing sleepiness at higher FVC levels.	
South Wales Motor Neurone Disease Care Network	NICE	28	15 – 5(page 29)	Sleep studies (oximetry, limited channel studies and TCCo2 measurement are all more sensitive than daytime blood gases at predicting impeding ventilatory failure and requirement for NIV, but establishing a patient on NIV who is not yet in ventilatory failure runs a significant risk of producing a respiratory alkalosis. In view of this, regular access to capillary blood gas testing is probably the safest means to determine the optimum time to establish NIV, and	Thank you for your comment. These recommendations are from CG105 and were not updated in this guideline

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				practically this means easy access to a trained healthcare professional (respiratory nurse specialist usually), with discussion at ventilatory 'MDT' with a consultant.	
The British Association of Prosthetists and Orthotists (BAPO)	NICE	9		The orthotist is not named as a member of the multidisciplinary team in sections 1.5.4 or 1.5.5. Considering the updated guidance of 1.8.9 where the provision of orthoses is strongly supported BAPO believe that the orthotist be named as a member of the multidisciplinary team. BAPO place the orthotist as the principle health professional in assessment and provision of orthoses. Whilst many professionals may try and help with use of readily available orthoses, the orthotist will be the one who best understands the underlying principles and can recommend the most appropriate provision along with any modifications to customise a device to give best results	Thank you for your comment. We have included relationships with and prompt access to orthotic services to the description of the multi-disciplinary team.

The following stakeholders were invited to comment but did not:

5 Boroughs Partnership NHS Foundation Trust
Addenbrookes Hospital
Aintree University Hospital NHS Foundation Trust
Allocate Software PLC
Alzheimer's Society
anglia community leisure
Aspire Pharma
Association for Respiratory Technology and Physiology
Association of Ambulance Chief Executives
Association of Anaesthetists of Great Britain and Ireland
Association of British Insurers
Association of Chartered Physiotherapists in Neurology
Association of Chartered Physiotherapists in Oncology and Palliative Care
Association of Chartered Physiotherapists in Respiratory Care
Association of Educational Psychologists
Barts Health NHS Trust
Belfast Health and Social Care Trust
BOC Healthcare
Boehringer Ingelheim
Brighton and Sussex University Hospital NHS Trust
British Association for Music Therapy
British Association of Neuroscience Nurses
British Association of Prosthetists & Orthotists
British Association of Psychodrama and Sociodrama

British Medical Journal
British National Formulary
British Nuclear Cardiology Society
British Psychological Society
British Red Cross
Caplond Services
Care and Social Services Inspectorate Wales
Care Not Killing Alliance
Care Quality Commission
Central London Community Health Care NHS Trust
Chartered Society of Physiotherapy
CLEAR Cannabis Law Reform
Covidien Ltd.
Croydon Council
Croydon University Hospital
CSH Surrey
Cumbria Partnership NHS Foundation Trust
CWHHE Collaborative CCGs
Department for Communities and Local Government
Department of Health, Social Services and Public Safety - Northern Ireland
Ealing Hospital NHS Trust
East and North Hertfordshire NHS Trust
East London NHS Foundation Trust
Epilepsy Society
Essex Centre for Neurological Sciences
Ethical Medicines Industry Group
Faculty of Intensive Care Medicine
Four Seasons Health Care
GP update / Red Whale
Greenwich & Bexley Community Hospice
Guidelines and Audit Implementation Network

Health and Care Professions Council
Health and Social Care Information Centre
Healthcare Improvement Scotland
Healthcare Infection Society
Healthcare Quality Improvement Partnership
Healthwatch East Sussex
Healthwatch Halton
Healthwatch Portsmouth
Helen and Douglas House
Herts Valleys Clinical Commissioning Group
Home Care Direct
Hull and East Yorkshire Hospitals NHS Trust
Isabel Hospice
James Paget Hospital
Lambeth Community Health
Leeds Motor Neurone Disease Care Centre
Leeds Teaching Hospitals NHS Trust
Liverpool PCT Provider Services
Local Government Association
London North West Healthcare NHS Trust
MacGregor Healthcare
Mastercall Healthcare
Medicines and Healthcare Products Regulatory Agency
Ministry of Defence
Motor Neurone Disease Association Care Centre Directors
Muslim Doctors and Dentists Association
National Clinical Guideline Centre
National Collaborating Centre for Cancer
National Collaborating Centre for Mental Health
National Collaborating Centre for Women's and Children's Health
National Council for Palliative Care

National Deaf Children's Society
National Hospital for Neurology & Neurosurgery
National Institute for Health Research Health Technology Assessment Programme
National Institute for Health Research
National Patient Safety Agency
National Public Health Service for Wales
NeuroImmune Science
Newcastle Regional MND Centre & Regional Domiciliary NIV Service
Newcastle upon Tyne Hospitals NHS Foundation Trust
NHS Barnsley Clinical Commissioning Group
NHS Choices
NHS Chorley and South Ribble CCG
NHS Clinical Knowledge Summaries
NHS Connecting for Health
NHS Cumbria Clinical Commissioning Group
NHS Devon
NHS Hardwick CCG
NHS Health at Work
NHS Improvement
NHS North East Lincolnshire CCG
NHS Plus
NHS Plymouth
NHS Sheffield
NHS Sheffield CCG
NHS Somerset CCG
NHS South Cheshire CCG
NHS Wakefield CCG
NHS West Cheshire CCG
NHS West Hampshire CCG
NIHR CCRN ENT Specialty Group
Norfolk Community Health and Care NHS Trust

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North East London Foundation Trust
North of England Commissioning Support
Northern Health and Social Care Trust
Northern Ireland Hospice Care
Nottingham City Council
Nursing and Midwifery Council
Nutricia Advanced Medical Nutrition
Nutrition and Diet Resources UK
Oxfordshire Clinical Commissioning Group
Papworth Hospital NHS Foundation Trust
Pathfinders Specialist and Complex Care
Peacocks Medical Group
Peninsula MND Network
PERIGON Healthcare Ltd
philip parkinson homecare
Philips Healthcare
Public Health Agency for Northern Ireland
Public Health England
Public Health Wales
Public Health Wales
Quality Institute for Self Management Education and Training
Queen Elizabeth Hospital
Queen's Medical Centre Nottingham University Hospitals NHS Trust
ResMed
Rotherham Doncaster and South Humber NHS Foundation Trust
Royal Brompton Hospital & Harefield NHS Trust
Royal College of Anaesthetists
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health

Royal College of Pathologists
Royal College of Physicians
Royal College of Physicians and Surgeons of Glasgow
Royal College of Psychiatrists
Royal College of Radiologists
Royal College of Surgeons of England
Royal Cornwall Hospitals NHS Trust
Royal Free London NHS Foundation Trust
Royal Pharmaceutical Society
Royal Society of Medicine
Sandoz Ltd
Scottish Intercollegiate Guidelines Network
Sense
Serious Hazards of Transfusion
Sheffield Teaching Hospitals NHS Foundation Trust
Social Care Institute for Excellence
South Eastern Health and Social Care Trust
South Gloucestershire Council
South London & Maudsley NHSFT
South Tees Hospitals NHS Trust
South West Yorkshire Partnership NHS Foundation Trust
Southern Health & Social Care Trust
Speakability
St Andrew's Hospital
St Christopher's Hospice
St Josephs Hospice
St Michaels Hospice
Staffordshire and Stoke on Trent Partnership NHS Trust
States of Jersey
Stockport Clinical Commissioning Group
Sue Ryder

TB Action Group
The London Centre for Children with Cerebral Palsy
The Neurological Alliance
The Walton Centre for Neurology and Neurosurgery
The Walton Centre NHS Foundation Trust
Therapy in Praxis
UK Clinical Pharmacy Association
University College London Hospital NHS Foundation Trust
University Hospital Birmingham NHS Foundation Trust
University Hospital of North Staffordshire NHS Trust
University Hospital Of South Manchester NHS Foundation Trust
University of Sheffield
Welsh Government
Welsh Scientific Advisory Committee
West Suffolk Hospital NHS Trust
Western Health and Social Care Trust
Western Sussex Hospitals NHS Trust
Wigan Borough Clinical Commissioning Group
York Hospitals NHS Foundation Trust
Yorkshire and Humber Strategic Clinical Network