



ROYAL COLLEGE OF  
PHYSICIANS AND  
SURGEONS OF GLASGOW

<b>CONSULTATION:</b>	Draft quality standard on Motor neurone disease
<b>ORIGINATING SOURCE:</b>	National Institute for Health and Care Excellence (NICE)
<b>CONTRIBUTORS:</b>	Professor Hazel Scott, Honorary Secretary, RCPSG Dr David Raeside, Consultant GIM/Respiratory Dr George Gorrie, Consultant Neurologist
<b>SUBMITTED:</b>	24 March 2016

**Consultation on draft quality standard – deadline for comments** 17.00 on 24/03/2016 **email:** [QSconsultations@nice.org.uk](mailto:QSconsultations@nice.org.uk)

	<p>Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none"> <li>1. Does this draft quality standard accurately reflect the key areas for quality improvement? If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures? Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the <a href="#">NICE local practice collection</a> on the NICE website. Examples of using NICE quality standards can also be submitted.</li> </ol>
<p><b>Organisation name – stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p>Royal College of Physicians and Surgeons of Glasgow</p>
<p><b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.</p>	<p>Nothing to disclose</p>
<p><b>Name of commentator person completing form:</b></p>	<p>Prof H R Scott, Honorary Secretary, in consultation with neurological and respiratory experts</p>
<p><b>Supporting the quality standard</b> - Would your organisation like to express an interest in formally supporting this quality standard? <a href="#">More information.</a></p>	<p>[no]</p>

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Type		[office use only]	
Comment number	Section	Statement number	Comments
Insert each comment in a new row. Do not paste other tables into this table because your comments could get lost – type directly into this table.			
1		1	We are concerned that the application of this standard depends on how many neurologists specialising in MND are in any one centre and is not practical where there is only one or a limited number. All Neurologists should be able to deliver the diagnosis in a sensitive fashion. Follow up by a specialist MND Neurologist could then take place.
2		2	This is reasonable however there should be mechanisms in place to deal with the consequences of a super added diagnosis of dementia.
3		3	<p>Limited data collection is likely to be the norm. Respiratory data collection should include referral source, measurement of respiratory function (of all types) and the nature and frequency of follow up and clinical interactions e.g. outpatient clinic, nurse led services, day unit visit, home visit etc. While this will be done on an ad hoc basis in most cases more extensive and sophisticated data collection would require funded support. Who will interpret data is also not defined and an interest in respiratory ventilation would be advantageous. Early integration of the respiratory team into the care pathway will enhance quality.</p> <p>Assessment should be carried out at diagnosis and at frequent intervals thereafter. The accepted frequency of respiratory review would be at a minimum of 4 months with the option to do so more frequently and on demand by patient, carers or other members of the MDT. Respiratory function may be determined by local availability but should include measurements of muscle function and regular capillary blood gases to record resting daytime CO<sub>2</sub>. Overnight transcutaneous measurement of CO<sub>2</sub> is also an essential component of the assessment and will often be prompted by symptoms. Measurement of respiratory function in a wider sense should include symptom assessment and prompt interventions as appropriate; e.g. weak or ineffective cough leading to specialist physiotherapy assessment and the use of cough augmentation / assist techniques.</p> <p>This respiratory monitoring should be carried out in the context of specialist respiratory review to allow interpretation of the tests in parallel with an assessment of the patient's symptom burden. Development of local expertise in a dedicated regional neuromuscular respiratory service would be ideal, integrating into the regional MND clinic.</p>



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4		4	<p>The utility, benefits and disadvantages of NIV should be discussed at the earliest opportunity, consistent with the wishes of the patient. Such discussions when held before NIV is considered to be a necessary and urgent intervention and when communication is likely to be easier, are less burdensome to the patient and carers. In these circumstances they are less likely to find these discussions distressing and are afforded more time to consider NIV as an option and to discuss this with the MDT with whom they will also be developing a relationship with regular clinical review.</p> <p>For tertiary respiratory services these should not be difficult to measure and will routinely be recorded in the clinic communication the GP and wider MDT.</p> <p>It will not infrequently be the case that a patient and / or their carer will prefer not to have these discussions at an early stage in the disease process; this should be recorded and it made clear to the patient that this conversation can take place at any time of their choosing. This will require clear lines of communication to be established.</p> <p>It would be very difficult for local services to provide the breadth of services required to provide respiratory services in the context of a multidisciplinary service. Furthermore the relative rarity of MND would suggest that tertiary services would offer the potential for more specialist services to be developed. Providing services locally would require substantial investment in staff (including medical, specialist ventilation nurses and respiratory physiotherapy) as well as monitoring equipment set against the highly specialised clinical challenges of a relatively low volume patient population.</p>
5		5	<p>It requires significant organisational focus and interdisciplinary and cross specialty cooperation to provide a patient centred service. Even in tertiary centres which host all components of the relevant specialist services, this may prove to be a challenge. Nonetheless this is an extremely important aspect of the guidelines, which emphasise the importance of minimising multiple hospital visits for a patient group with significant physical and psychological issues. The development of the MDT should be a central objective and specialist teams should prioritise the provision of such MD services in job planning and service development discussions.</p> <p>Measurement will require agreed definitions of the minimum components of a quorate MDT and a clear MDT record to be kept of every clinical interaction with patients and their carers.</p> <p>Unplanned admissions are a crude measure of failed multidisciplinary care. What about speed of post diagnostic support? Quality of life measures would be better e.g. achieving the place of death that they have chosen in advance care planning.</p>
6		6	The pressing issue is that while the majority of the components of a full assessment are available they are not

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			coordinated and delivered in a patient centred manner. Further some of these components may not be funded specifically to meet the needs of MND patients and their carers with consequent gaps and inconsistencies in their delivery. In addition, speed of access to support and equipment is not covered in this quality document. Individuals can often wait too long to have what is recommended put in place. Individuals with MND/ALS do not have the time to wait six months for their adaptations. Quality assessments should not only assess access but speed of implementation and uptake
7		7	Please see response to 6
8		8	<p>Patients should have advance care planning in the last year of life as defined by palliative care tools eg SPICT. A member of the care team well known to the patient should perform this. Continuity of care will enhance such a discussion. The average survival with MND/ALS is 2.5 years from symptom onset with patients taking a year to be diagnosed; many patients when they are diagnosed will have less than a year to live. Involvement of local palliative care early in patient care may also enhance quality especially in those patients who have less than a year to live.</p> <p>From a respiratory perspective discussions about the future provision of NIV may in themselves be considered to be a component of end of life discussion or indeed Advanced Care Planning and as discussed above will often take place at the first contact with respiratory services. Further end of life discussions would be precipitated by measured changes in respiratory function and / or progression of symptoms indicative of worsening respiratory muscle function. Discussions about the initiation of breathing support should certainly prompt end of life discussions.</p>
Other			Assessment of nutrition and decisions regarding provision of artificial nutrition are not in the quality standards. Nor is there mention of the 10% of cases that have a familial basis to their condition: should there be quality measures applied to the provision of genetic counselling and availability of genetic tests?

Insert extra rows as needed

### Checklist for submitting comments

- Use this comment form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include section number of the text each comment is about eg. introduction; quality statement 1; quality statement 2 (measure).
- If commenting on a specific quality statement, please indicate the particular sub-section (for example, statement, measure or audience descriptor).
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.

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- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- For copyright reasons, comment forms do not include attachments such as research articles, letters or leaflets (for copyright reasons). We return comment forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.

You can see any guidance and quality standards that we have produced on topics related to this quality standard by checking [NICE Pathways](#).

**Note:** We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.