NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Motor neurone disease.

Date of Quality Standards Advisory Committee post-consultation meeting:
27 April 2016

2 Introduction

The draft quality standard for motor neurone disease was made available on the NICE website for a 4-week public consultation period between 25 February 2016 and 24 March 2016. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 17 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been summarised within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2,

A comment 'ID' number provides a link between the summary of comments in the main body of the report and the full comments in Appendix 1. The 'ID' number is presented in square brackets, followed by an abbreviation which identifies the stakeholder that made the comment, in the main body of the report. For example,

- Core MDT team should include an orthotist and pharmacist. [1] BAPO

The first table in Appendix one shows all the full comments ordered by the 'ID' number. Below the table is a list of the full names of the stakeholders alongside the abbreviation used in the main body of the report (page 49).

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect the data for the proposed quality measures? If not, how feasible would it be for these system and structures to be put in place?

3. Do you have an example from practice of implementing the care described in this draft quality standard? If so, please submit your example to the NICE local practice collection on the NICE website.

4. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources required to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific questions:

5. For draft quality statement 2: To support measurement of this draft quality standard statement, within what timeframe from diagnosis should the person be assessed for any behavioural or cognitive changes?

6. For draft quality statement 3: Within what timeframe after diagnosis should respiratory function and symptoms be assessed?

7. For draft quality statements 3, 5 and 6: There is some overlap between draft quality statements 3, 5, and 6. Statement 5 covers regular assessments of symptoms and needs of people with motor neurone disease including respiratory function, respiratory symptoms and non-invasive ventilation; and physical function, including mobility and activities of daily living. Statements 3 and 6 also cover regular assessment of respiratory function and symptoms and mobility and daily living needs respectively. What is the key area for quality improvement: Is it that comprehensive regular assessments are not taking place (the focus of draft statement 5), or that regular assessments do take place but that respiratory function (draft statement 3) or mobility (draft statement 6) are not well-covered?

8. For draft quality statement 8: Are there clearly defined points at which offers to discuss end of life care should be made?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard. Responses to consultation questions 1 to 4 are also summarised in this section of the report. Responses to questions 5 to 8 are summarised under the section for the relevant statement. Question 7 referred to three statements. For the sake of brevity, responses to question 7 are presented only under the section that deals with statement 5.

Overarching comments

- The quality standard was explicitly welcomed by some stakeholders. [47, 56] RCGP, MNDA
- Covers many of the areas of impact for people with MND. [91] ABN
- One stakeholder commented that the quality standard needs a major rethink as it does not reflect good or current practice. [43] BTS
- There is a necessary focus of assessing needs, but less of a focus on delivering care to meet the needs. [58] MNDA

Content

- The importance of the role of specialist respiratory physician / long term ventilation service is not emphasised. A statement is needed to address this. [43] BTS
- Rigid timeframes should not be imposed by the quality standard: Care and assessments should be tailored to individuals. [47] RCGP
- The role of primary care is generally not addressed, even where GPs have expertise. A statement is needed to ensure specialists involve GPs. [47] RCGP
- Comprehensive, but statements are long and detailed making it difficult to tease out the key elements that need to be prioritised. [91] ABN
- Contextual information should be consistent with that contained in the final guideline. [57] MNDA

Comments on consultation question 1

Does this draft quality standard accurately reflect the key areas for quality improvement?

Five stakeholders responded to this question.

- Four stakeholders considered that the statements reflect key areas [13, 36, 58, 92]. ACPRC, COT, MNDA, ABN

- Stakeholders also identified some ‘key areas’ that are not addressed including:
  - specialised respiratory physiotherapy intervention [13] ACPRC
  - enteral feeding, gastronomy placement, nutrition [36, 92] COT ABN
  - palliative care services specifically for people with MND [92] ABN
- The statements are not detailed enough. [13] ACPRC

Comments on consultation question 2:

Are local systems and structures in place to collect the data for the proposed quality measures? If not, how feasible would it be for these system and structures to be put in place?

There was no clear consensus between the five respondents to this question. Comments included:

- Systems and structures are ‘probably’ in place. [14] ACPRC
- It is ‘likely’ that data is available at a local level but systems and processes will need to be developed. [37] COT
- It is ‘doubtful’ that systems and structures are in place: problems with coding and lack of consistent data set for MND. [59] MNDA
- It is ‘feasible’ for systems and structures to be put in place in MND Care Centres, but not to cover those cared for outside these centres. [93] ABN
- Systems ‘may’ be able to capture local data but collection will be reliant on collaboration between different providers such as MND centres, hospices, local hospitals, social services. [85] RCSLT

Comments on consultation question 3:

Do you have an example from practice of implementing the care described in this draft quality standard? If so, please submit your example to the NICE local practice collection on the NICE website.

Comments received included:

- The King's College Hospital Motor Nerve Clinic provides the necessary specialist services to fulfil statements 1, 2, 3, 4, 5, 6, & 8 but not 7. [86] RCSLT

- Several MND Care and Research Centres will have data on implementation of the care described as part of their regular monitoring of their service, as requested by the MND Association. [94] ABN

Comments on consultation question 4:

Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources required to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Five stakeholders responded to this question with contrasting views:

- Statements are achievable and there is evidence that some services are already achieving the standard. [38] COT
- It is likely that most patients with MND are diagnosed and cared for in a setting in which most of these quality statements could be achieved, but additional resources would be needed (even in large centres delivering excellent care for people with MND). [95] ABN
- Statements are not achievable, as more detail is required to allow commissioners to plan accordingly. [15] ACPRC
- Resource requirements identified included:
  - Development of occupational therapists with specialist knowledge and skills to manage MND (as condition is rare). [38] COT
  - Local services may need support of tertiary services / specialist centres to achieve statements. [87] RCSLT
- Cost savings:
  - Timely assessments and interventions and end of life care planning would lead to fewer hospital admissions and unnecessary treatments. [11, 15] CiD, ACPRC

    - No clear potential for cost savings or opportunities for disinvestment other than there may be fewer inappropriate acute hospital admissions. [95] ABN

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Adults diagnosed with motor neurone disease (MND) are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Consultation comments

Stakeholder comments on draft statement 1 are summarised below.

Focus of statement

- Extend statement to include referral to key worker (who coordinates care and assessments). [31] NHS Eng
- Amend statement to allow specialty trainee under the consultant's supervision to give information (to allow experience to be gained). [51] SWMNDCN
- All neurologists should be able to deliver the diagnosis in a sensitive fashion with follow up by a specialist MND Neurologist. [75] RCPSG
- Knowledge and expertise of consultant should include support groups (MNDA groups are invaluable and highly used). [19] ACPRC

Implementation / achievability / resources

- Who identifies the consultant with expertise and does it mean that neurologists in rural areas have to refer to specialist centres for a diagnosis to be communicated? [3] RCN
- There may not be enough neurologists with MND expertise in England to achieve statement, and there is a low number of neurologists relative to the size of the population. [60] MNDA

- Achievement depends on how many neurologists specialising in MND there are in a specific centre. [75] RCPSG
- Commissioners may lack the 'detailed level of oversight necessary' to be aware of the MND services available. [62] MNDA

Measurement

- Routine data collection may not be possible - existing data collection will not identify neurologists who are MND specialists. [61] MNDA
- Use patient survey to measure statement? Triangulate with MNDA 'Improving MND Care' survey?[61] MNDA

Audience descriptors

- Commissioning is more complex than statement suggests. NHS England commission MND specialists, but some will work in local hospitals. Locally commissioned services will also play a role, such as identifying people with MND and referring to specialists. [62] MNDA
- Some expert MND neurologists are employed by universities and are not commissioned by the NHS. [62] MNDA

5.2 Draft statement 2

Adults newly diagnosed with motor neurone disease (MND) are assessed to identify any cognitive or behavioural changes.

Consultation comments

Stakeholder comments in relation to draft statement 2 are summarised below.

Focus of statement

- Statement welcome as service provision is patchy across the country in relation to assessment of cognitive and behavioural changes. [92] ABN
- Nature of the assessment is unclear: Is it part of the neurological assessment or a formal assessment? [4, 47] RCN, RCGP
- All professionals have a role to play in recognising cognitive change, not just neurologists and those in specialist MDTs. [64] MNDA

- Need to include mechanisms to deal with the consequences of a super added diagnosis of dementia. [76] RCPSG

Implementation / achievability / resources

- Would every clinic have resource to use a formal tool for assessment? [4] RCN
- Administration of cognitive assessment scales, e.g. Edinburgh Cognitive and Behavioural ALS Screen, can be undertaken by Clinical Nurse Specialists, i.e. do not need to be done by a Neuropsychologist. [96] ABN
- Professionals need further and improved training to achieve the statement. [64] MNDA

Measurement

- Unless a formal tool is used for assessment, measurement will be difficult. [4] RCN

Audience descriptors

- Wording "assessed… as soon as they are 'comfortable' to do so" challenged – it can be hard for a person to recognise that they have undergone change. [63] MNDA

Timescales (consultation question 5)

To support measurement of this draft quality standard statement, within what timeframe from diagnosis should the person be assessed for any behavioural or cognitive changes?

No stakeholder suggested the same timescale for this statement. Suggestions were:

- No timescale - Professional judgement and discussions with those close to the person with MND might be more important. [63] MNDA
- At diagnosis, or within a few weeks of diagnosis. [96] ABN
- Some MND services are achieving this within 2 months of diagnosis (where there is neuropsychological support). [39] COT

- Within 3 months of diagnosis (allows for contacts and relationships to be established). [4] RCN
- Within 4 months of diagnosis – Timeframe is needed; should be early but if done immediately after diagnosis it may be compromised by the emotion of dealing with the diagnosis and immediate assessment is not always wanted. [52] SWMNDCN
- As soon as possible after diagnosis, and within 6 months. [88] RCSLT

5.3 Draft statement 3

Adults with motor neurone disease (MND) have their respiratory function and symptoms assessed at diagnosis and then monitored in multidisciplinary team assessments.

Consultation comments

Stakeholder comments for draft statement 3 are summarised below.

Focus of statement

- Statement is necessary - respiratory weakness often present at diagnosis but not fully assessed. [5, 27] RCN, ACPRC
- Cough effectiveness, measurement of Peak Cough Flow and cough augmentation need including. [21, 26, 27] ACPRC, [77] RCPSG
- Statement allows for respiratory physiology testing by someone with knowledge of lung function testing, but not necessarily expertise in the delivery of NIV and likelihood of patient benefit. [43] BTS
- Assessment should be completed by a specialist respiratory team. [20, 24] ACPRC
- Statement should say “All patients with MND should be referred for assessment to the long term ventilation service that is linked to the respiratory team with a specialist interest in MND”. [44] BTS
- Patients should be referred to a long term ventilation service, or a respiratory centre with a specific interest/skill in MND for assessment. [22] ACPRC

- Respiratory monitoring should be carried out in the context of specialist respiratory review. Development of local expertise in a dedicated regional neuromuscular respiratory service would be ideal, integrating into the regional MND clinic. [77] RCPSG
- Respiratory Function Tests need to be more specific and detailed, e.g. FEV1, FVC etc. [24, 77] ACPRC, RCPSG
- Main need is for assessments to happen regularly. [32] NHS Eng

Implementation / achievability / resources

- ‘Probably achievable’ given the net resources required. [65]. MNDA

Measurement

- Statement is measurable. [5] RCN
- Suggested outcome measure: Number of unplanned admissions with respiratory failure or pneumonia. [32] NHS Eng
- Data collection may be problematic as only limited data is collected at present. [77] RCPSG
- Process measures only require lung function and to symptoms to be assessed. Should include role of specialist respiratory team. [44] BTS

Audience descriptors

- Assessment should be completed by a specialist respiratory team, not a neuro specialist physiotherapist. [24] ACPRC
- Multidisciplinary team could include respiratory consultants, nurse specialists, physiotherapists and physiologists. [24] ACPRC
- More detail needed on roles of different professionals and their bands. [25]. ACPRC

Timescales (consultation question 6)

Within what timeframe after diagnosis should respiratory function and symptoms be assessed?

Stakeholders expressed a range of views on when the initial assessment should occur:

- No timeframe should be specified – regular MDT review will identify changing needs. [40] COT
- At diagnosis for people with bulbar onset MND. [22] ACPRC
- At diagnosis. [77] RCPSG
- Respiratory symptoms assessed at diagnosis, baseline respiratory function tests within 2 – 4 weeks of diagnosis. [97] ABN
- Two stakeholders recommended as soon as possible after diagnosis, but gave no fixed timescale. [67, 44] MNDA, BTS
- Within 4 weeks of diagnosis. [89] RCSLT
- Within 1 month of diagnosis. [53] SWMNDCN
- Within 6 weeks of diagnosis. [16, 22] ACPRC
- Within 3 months of diagnosis. [5] RCN

Some comments were also made in relation to ongoing assessments:

- Two stakeholders suggested they should occur every 3 months. [27&23, 44] ACPRC, BTS
- Another stakeholder suggested assessment every 4 months. [77] RCPSG

5.4 Draft statement 4

Adults with motor neurone disease (MND) who have respiratory impairment are offered non-invasive ventilation.

Consultation comments

Stakeholder comments on draft statement 4 are summarised below.

Focus of statement

- Should the statement apply to all, or identify and apply to those who would benefit most and who should be considered for NIV? [33] NHS Eng
- Decisions regarding NIV should be made by the specialist respiratory team in conjunction with the MDT, not the other way around. [28, 45] ACPRC, BTS

- Statement should seek to ‘discuss’ and not ‘offer’ NIV. Currently, people are being referred for NIV rather than a comprehensive respiratory assessment. [28] ACPRC
- References to offering NIV at a stage people develop respiratory impairment due to MND should be removed. NIV should be offered at the right time for the person. Referring to specialist respiratory service soon after diagnosis can enable this. [45] BTS
- No mention of tracheostomy. [28, 45] ACPRC, BTS. *Note from NICE team: Tracheostomy was outside of the scope of, and not included in, the underpinning guideline.*
- Utility, benefits and disadvantages of NIV should be discussed with person before NIV is necessary. [78] RCPSG

Implementation / achievability / resources

- Probably achievable given the net resources required. [65] MNDA
- NIV provision can be vulnerable in the event of machine failure. Effective commissioning and resourcing of NIV pathways locally can prevent this resulting in hospital admission. [65] MNDA
- May need increased investment in ‘community infrastructure’ such as district nurses, specialist respiratory nurses / therapists to help people manage their NIV. [6] RCN
- NIV is likely to progress to being needed 24 hours a day which will require regular contact and support from the specialist respiratory centre. This will have cost implications. [28] ACPRC
- 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. [78] RCPSG
- Potential for reducing crisis admissions to hospital, but not clear if it would free up enough resource to allow for disinvestment in acute services. [65] MNDA

Measurement

- Likely to be routinely recorded. [78] RCPSG
- Measure should reflect the following process: patients have opportunity to attend for respiratory surveillance; have a discussion with an expert on the role of NIV in their case; NIV is offered as a possible treatment; and that it is started at an appropriate time. [45] BTS

Timescales

- Referral to specialist respiratory teams should occur as soon after diagnosis as possible to enable the patient to receive information on NIV that is tailored to the person. [45] BTS
- Discussions should be held before NIV is considered necessary. [78] RCPSG

5.5 Draft statement 5

Adults with motor neurone disease (MND) have regular, coordinated assessments by a specialist multidisciplinary team.

Consultation comments

Stakeholder comment on draft statement 5 are summarised below.

Focus of statement

- Considered important by two stakeholders. [7, 79] RCN, RCPSG
- Importance and role of specialist respiratory care is not captured. MDT may act as an additional filter and could delay timely access to NIV. Statement should be split to cover MDT and respiratory care. [46] BTS
- Core MDT team should include an orthotist and pharmacist. [1, 2] BAPO, Barts Health
- Some services for people with MND may be in other specialist centres, for instance AAC [augmentative and alternative communication] hubs; it may not be feasible for these to be regular and fully integrated members of the MDT (but it may be possible to co-ordinate work with them). [69] MNDA
- Description of ‘comprehensive’ and ‘coordinated’ assessments is ‘too neat’ and, whilst this reflects the guideline, practice will vary. Multidisciplinary

assessments will not always be delivered in a straightforward ‘clinic’ format, location may vary, who from the MDT attends will vary and in some localities they may not be possible at all. [66] MNDA

- Regular assessment of swallowing and communication by a speech and language therapist with specific knowledge of MND should also be added. [90] RCSLT
- Similar to statement 6. [7] RCN
- References to expertise in palliative care and access to specialist palliative care welcomed. [29] APMGBI

Implementation / achievability / resources

- Coordination and frequency of assessments will determine effectiveness. [7] RCN
- Key problem is that there is a lack of these teams and therefore lack of regular assessments. Need to be commissioned by CCGs and NHS England. [34] NHS Eng
- Extra resource likely to be needed to achieve statement, and some existing provision is charitably funded. [68] MNDA
- May be a challenge even in tertiary centres which host all components of the relevant specialist services, but this is an extremely important aspect of the guidelines. [79] RCPSG

Measurement

- Outcome measures: Suggestions include speed of post diagnostic support and quality of life measures, e.g. achieving the place of death chosen in advance care planning. [79] RCPSG
- Measures relating to case closure may be useful - difficult to measure inappropriate case closure, but could compare rates for people with MND with wider populations. [58] MNDA

Audience Descriptors

- Text suggests that responsibility for commissioning services is with NHS England. There is confusion around commissioning responsibilities though

- current service specification says all neurology services are specialised, but in practice MND services will be a mix of specialist, local, hospital and community services. Text should reflect the current practice. [69] MNDA

Timescales

- Every 10-12 weeks. [7] RCN
- 3 months. [54] SWMNDCN

Consultation Question 7

There is some overlap between draft quality statements 3, 5, and 6. Statement 5 covers regular assessments of symptoms and needs of people with motor neurone disease including respiratory function, respiratory symptoms and non-invasive ventilation; and physical function, including mobility and activities of daily living. Statements 3 and 6 also cover regular assessment of respiratory function and symptoms and mobility and daily living needs respectively. What is the key area for quality improvement: Is it that comprehensive regular assessments are not taking place (the focus of draft statement 5), or that regular assessments do take place but that respiratory function (draft statement 3) or mobility (draft statement 6) are not well-covered?

- Four stakeholders commented that comprehensive regular assessments are not taking place. [17, 41, 90, 98] ACPRC, COT, RCSLT, ABN
- One stakeholder was of the view that comprehensive regular assessments are not taking place and respiratory function / mobility are not well-covered. [54] SWMNDCN
- One stakeholder stated that comprehensive regular assessments are not always taking place, e.g. not including regular respiratory or cognitive assessments, and in other cases assessments are taking place, but subsequent actions based on assessments take too long to implement, e.g. provision of wheelchairs. [98] ABN
- One stakeholder commented that there was too much variation in practice to generalise; both need addressing even if it results in some overlap between statements. [66] MNDA

- Respiratory assessments need to be more specific and completed by specialist respiratory professionals (not neuro specialists) according to one stakeholder. [17] ACPRC

5.6 Draft statement 6

Adults with motor neurone disease (MND) have their mobility and daily living needs monitored in multidisciplinary team assessments.

Consultation comments

Stakeholder comments on draft statement 6 are summarised below.

Focus of statement

- Statement is welcome - it would stop people being discharged from therapy teams prematurely. [8] RCN
- Statement covers assessing needs, but not needs being met. [70, 80] MNDA, RCPSG
- Speed of access to support / equipment is not addressed – people with MND wait too long to have what is recommended put in place. [80] RCPSG
- Statement should make explicit reference to ‘communication and swallowing’. [84] RCSLT
- Should statement require assessment to be carried out by an experienced practitioner (as competence of occupational therapists in relation to assistive technology will vary significantly)? [49] DLF

Implementation / achievability / resources

- Most components of a full assessment are available, but they are not coordinated and delivered in a patient centred manner, and not always funded to meet needs of someone with MND or their carers. [80] RCSPG.
- Ability to implement will vary significantly given the resources required. Cost pressures and confusion about responsibilities can cause delay in local services meeting needs. [70] MNDA
- Wheelchair services and services to meet daily living needs are highly variable. Shortcomings often the result of cost pressures and under-resourcing. [70] MNDA

- Need to support the assistive technology competence of occupational therapy teams. [50] DLF

5.7 Draft statement 7

Adults with motor neurone disease (MND) have personal care and support carried out by workers known to them and their family members and carers.

Consultation comments

Stakeholder comments on draft statement 7 are summarised below.

Focus of statement

- What constitutes ‘knowing’ a person? [9] RCN
- Speed of access to support is not addressed. [81] RCPSG

Implementation / achievability / resources

- Very hard to implement, could it actually be implemented in every case? [9] RCN
- Resources will be a major obstacle to achieving this quality statement, particularly in social services but also to an extent in the NHS. [71, 81] MNDA, RCPSG

5.8 Draft statement 8

Adults with motor neurone disease (MND) are offered opportunities to discuss their preferences and concerns about end of life care.

Consultation comments

Stakeholder comments on draft statement 8 are summarised below.

Focus of statement

- Statement regarded as important and supported or welcomed by two stakeholders. [10, 30] RCN, APMGBI
- Subject is described in a practical and accessible way. [30] APMGBI
- Statement should refer to DNACPR [Do not attempt cardiopulmonary resuscitation] and ADRT [Advance decision to refuse treatment]. [18] ACPRC

- Patients should have advance care planning in the last year of life as defined by palliative care tools e.g. SPICT [Supportive & Palliative Care Indicators Tool]. [82] RCPSG
- Can statement address End of Life planning when someone is on NIV (or invasive ventilation)? Many people choose to die on NIV despite centres encouraging removal of NIV. [18] ACPRC
- Need to be sensitive about how the offer of a discussion is made, not just the timing. [55] SWMNDCN

Implementation / achievability / resources

- Should be achievable given the net resources required, but training needs to be improved. [72] MNDA
- Responsibility in this area falls heavily on MND co-ordinators or palliative care specialists, without other professionals taking on responsibility. [72] MNDA
- Initial 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; this may lead to ADRTs, or Lasting Power of Attorney for Health and Welfare being set up. [12] CiD
- All patients with MND should have a specialist nurse available via phone and be given the MND association patient information booklet. [48] RCGP
- Early involvement of ‘local palliative care’ may enhance quality, continuity of care will enhance discussions. [82] RCPSG

Measurement

- Difficult to monitor unless a standard care plan, such as the unplanned care plans, is used in conjunction with DNACPR forms and treatment escalation plans and coded in the GP clinical system. [48] RCGP

Trigger points (consultation question 8)

Are there clearly defined points at which offers to discuss end of life care should be made?

Most stakeholders emphasised the need to be sensitive with regards to timings of discussions in relation to end of life care. Suggested trigger points and comments included:

- Four stakeholders suggested when decisions or discussions take place on NIV. [82, 18, 55, 73] RCPSG, ACPRC, SWMNDCN, MNDA
- Three stakeholders suggested changes in respiratory function. [82, 18, 12] RCPSG, ACPRC, CiD
- Two stakeholders suggested gastronomic intervention. [12, 73] CiD MNDA
- Two stakeholders suggested the point of diagnosis. [12, 55] CiD SWMNDCN
- A different stakeholder said it should not be at diagnosis, but soon afterwards when the person is ‘ready’. [73] MNDA
- The need to discuss peg / rig or referral to respiratory team or other specialist team for assessment. [10] RCN
- Progression, new loss of function, new need for consideration of intervention, new requirement for domiciliary care, care home placement. [55] SWMNDCN
- Conversations should be determined by the person with MND and their families / carers. [42] COT
- Not appropriate to mandate discussions at specified time points, except when patients are considering a trial of assisted ventilation. [99] ABN
- Timings will vary greatly depending on individual patients, their wishes and disease trajectories. [99] ABN
- Professionals should be ready to discuss end of life issues at any point the person wishes to raise it. [73] MNDA

6 Suggestions for additional statements

Stakeholders suggested the following be considered for additional statements.

- “All patients with MND should have a nominated key worker whom they can contact for information and advice and in the event of unexpected deterioration”. [35] NHS Eng

- Assessment of nutrition, decisions regarding provision of artificial nutrition, gastronomy, enteral feeding. [36, 83, 92] COT, RCPSG, ABN. *Note from NICE team: Enteral feeding is outside of the scope of the underpinning guideline.*
- Provision of genetic counselling / availability of genetic testing. [83] RCPSG *Note from NICE team: There are no recommendations relating to genetic testing or counselling in the underpinning guideline.*
- “All patients with MND should be referred for assessment to the local long term ventilation service or a respiratory specialist with an interest in neuromuscular disease after the initial diagnosis has been made and explained to the patient and family”. [43] BTS
- Specialised respiratory physiotherapy intervention. [13] ACPRC
- A statement for primary care to ensure that specialists involve GPs in the care of people with MND. [47] RCGP
- Provision of palliative care services specifically for people with MND. [92] ABN

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Section	Comments[1]
1	British Association of Prosthetists and Orthotists	Statement 5	BAPO has reviewed the draft MND QS and is pleased to see recognition of the need for access to orthotic services within QS5, however we believe that the Orthotist should be within the core MDT team to offer the best quality of care to those needing assessment for Orthotics.
2	Barts Health	Statement 5	A pharmacist should be included in the team to ensure existing medication is managed appropriately and plans put in place if swallowing difficulty occurs etc
3	Royal College of Nursing	Statement 1	Yes generally agree with this statement but who identifies the neurologist as having expertise in motor neurone disease? Does this mean neurologists in rural areas will need to refer on to specialist centres so they can tell the patient the diagnosis? How will this be measured?
4	Royal College of Nursing	Statement 2 Statement and Measure	It is not clear how this would work. Would this just be part of the neurological assessment or is the statement suggesting a formal recording of this, such as using an ECAS assessment tool? Without a formal tool it may be difficult to audit that these assessments have been done. Equally, ensuring that every new person with MND having to do an ECAS assessment in clinic is time consuming and would need the correct sensitivity and space to undertake this. Would every clinic have the resources to do this? The time span for this would need to be defined, to say the first three months post diagnosis – allowing for all the other contacts and relationships from a therapeutic perspective that need to be established in the first few weeks / months post diagnosis.
5	Royal College of Nursing	Statement 3	This standard is necessary and measurable and should occur within the first three months post diagnosis.
6	Royal College of Nursing	Statement 4	Yes this should be a standard but as it is a specialised service. It would be difficult for every area to achieve this without referring people through to specialist centres. It would have been helpful to have a standard that

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Section	Comments[1]
			supports investment in infrastructure in the community to help people manage their non-invasive ventilation when they are started on it, such as increased numbers of district nurses and access to specialist respiratory nurses/ therapists who are available for other conditions in the community, such as Chronic Obstructive Pulmonary Disease but denied to people with motor neurone disease.
7	Royal College of Nursing	Statement 5	This standard is important and is welcomed. It is similar to statement 6. The key to effective implementation is coordination of these assessments and how often is regular? Every 10-12 weeks would seem appropriate.
8	Royal College of Nursing	Statement 6	This standard is welcomed. It would stop people being discharged from therapy teams prematurely.
9	Royal College of Nursing	Statement 7	This would be very hard to implement and difficult to monitor. How could this be reasonably implemented in every case? What constitutes knowing the person?
10	Royal College of Nursing	Statement 8	This standard is important and supported. We could use trigger points for this, such as the need to discuss peg / rig or referral to respiratory team or other specialist team for assessment and if not already known to palliative care services at these points then this would help people to discuss advance care planning and end of life care?
11	Compassion in Dying	Question 4	Evidence suggests that if services strive towards satisfying Statement 8 this will lead to fewer hospital admissions and a reduction in unnecessary treatments, which will both in turn lead to cost savings. In a poll conducted in May 2015 by YouGov, respondents were asked to think back to the last close relative or friend who died from a short or long-term illness (i.e. someone who should have had planned care) and then asked them questions about that person's experiences at the end of life.[2] The results show that those who had their wishes formally recorded were 41% more likely to die well and when end-of-life wishes were not recorded people were 53% more likely to receive treatment they did not want. Crucially, the poll also revealed that 34% of those whose end-of-life wishes were not formally recorded were thought to have spent time in hospital that could have been avoided, compared to 28% of those whose wishes were recorded. Even a small reduction in the number of unplanned end-of-life hospital admissions would allow a significant increase in the number of patients who die at home or in their usual place of residence.[3]

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[2] YouGov, 2015

[3] Public Health England (2013) What we know now 2013: New information collated by the National End of Life Care Intelligence Network; SCIE (May 2013) Dying Well at Home: the case of integrated working. Costs of dying at home

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			We have commissioned the International Longevity Centre to conduct a literature review of existing evidence on the economic and social impact of advance care planning. This will be available in early April. Research shows that a reduction is emergency hospital admissions for those who have an advance care plan in place leads to fewer days in hospital in the last year of life and reduced hospital costs incurred as a result of emergency admissions (a mean reduction of 28% and 8% respectively).[4]
12	Compassion in Dying	Statement 8: Question 8	While sensitivity to timing should be a factor, we believe people should be able to discuss their wishes and treatment preferences for the end of life 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 intervention provide identifiable stages for treatment preferences to be reviewed and updated. We suggested this be included in NICE's Motor neurone disease: assessment and management guidance and were pleased to see that Section 1.7.1 of the final guidance made this recommendation. Feedback from our outreach service, *My Life, My Decision*, suggests that initially people may be reluctant to discuss their 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. 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

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[4] Abel *et al.* The impact of advance care planning of place of death, a hospice retrospective cohort study. *BMJ Supportive & Palliative Care,* 2013;00:1–6.

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			progresses.
13	The Association of Chartered Physiotherapists in Respiratory Care	Question 1	No-we feel there are multiple omissions with regards to specialised respiratory physiotherapy intervention with this patient group. We feel happy with the titles of each Quality statement, and agree that these are keys areas, but the detail within each quality statement is not sufficiently specific or detailed.
14	The Association of Chartered Physiotherapists in Respiratory Care	Question 2	We believe there probably are local systems and structures in place to collect data. Some form of guidance would be required. What we would question is whether the quality standards are actually specific enough. For example timings of assessment following diagnosis 2-3 months; this should read 3 months. Please see additional comments below for more specific examples relating to individual standards.
15	The Association of Chartered Physiotherapists in Respiratory Care	Question 4	No. More detail is required to enable commissioners to plan accordingly, and for equality of care across both smaller and larger specialist centres. There is a lack of specific resources mentioned (with regards to respiratory assessment and treatment-please see later comments on QS3). With regards to potential cost savings, with this patient group we believe that timely assessment and intervention are key to preventing unplanned hospital admissions which are extremely costly.
16	The Association of Chartered Physiotherapists in Respiratory Care	Statement 3: Question 6	Respiratory function (more detail as to content of respiratory function required) and symptoms should be assessed as soon after diagnosis as possible, but no longer than 6 weeks.
17	The Association of Chartered Physiotherapists in Respiratory Care	Statement 5: Question 7	We believe that comprehensive regular assessments are not taking place, and that respiratory assessments need to be more specific and timely, and completed by specialist respiratory professionals (not neuro specialists).
18	The Association of Chartered Physiotherapists in Respiratory Care	Statement 8: Question 8	Yes. We believe that as a patients respiratory function declines and NIV discussions start, then EOL discussions should occur alongside, or even as part of these discussions. Many of our members have strongly emphasised that when EOL discussions have started early they have seen a higher quality of patient care-the patient has had more control over decisions, and no decisions are rushed.

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			No mention of DNACPR or ADRT's-we think these should both be included within the EOL Quality Statement. Often a difficult situation is EOL planning when a patient is on NIV (or invasive ventilation). Many patients do die on NIV (at their request) despite centres encouraging removal of NIV with pharmacological symptom management. This is an extremely grey area, and one which is not currently covered by the quality statements.
19	The Association of Chartered Physiotherapists in Respiratory Care	Statement 1	"knowledge and expertise in the following"…..support groups should be added in, for example MNDA-such groups are invaluable for patients and are highly used by patients, families and carers and should not therefore be overlooked.
20	The Association of Chartered Physiotherapists in Respiratory Care	Statement 3	Adults with MND have their respiratory function and symptoms assessed at diagnosis *by a specialist respiratory team* ….
21	The Association of Chartered Physiotherapists in Respiratory Care	Statement 3 Rationale	We would like the following to be added: Respiratory muscle weakness is a major component of MND. *Therefore it is essential patients are referred for specialist respiratory assessment and follow up*. …..strategies such as NIV *and cough augmentation* can be considered. We believe that quite often a form of cough augmentation will be started prior to NIV being initiated, or the 2 strategies will be started simultaneously. Both are equally important so we feel the lack of specific mention of cough augmentation techniques should be revised.
22	The Association of Chartered Physiotherapists in Respiratory Care	Statement 3 Measures: Structure a) p16	Patients should be referred to a long term ventilation service, or a respiratory centre with a specific interest/skill in MND. Assessment should occur within 6 weeks of diagnosis in order for timely and effective intervention to be implemented. We feel it important to be specific about the timing of assessment in order for audit of standards. A side note may need to be added with regards to bulbar onset MND-ideally this patient group should be referred for a specialist respiratory assessment at the point of diagnosis, due to the speed at which they can decline. Timely intervention in this group is extremely important.
23	The Association of	Statement 3	Rather than 2-3 months, we would recommend 3 months (especially for rapid onset bulbar MND). As per

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	Chartered Physiotherapists in Respiratory Care	Measures: Structure b) p16	previous comments, being more specific will make audit easier. Patients who have slower progressing MND may only require 6 monthly specialist assessment, and 3 monthly assessments with a local MND team (if this is available).
24	The Association of Chartered Physiotherapists in Respiratory Care	Statement 3 Audience descriptors Healthcare professionals p18	Assessment should be completed by a specialist respiratory team, we would have concerns that such detailed respiratory assessment could then be completed by a neuro specialist physiotherapist. Our skills and knowledge are extremely different. MDT could include respiratory consultants, nurse specialists, physiotherapists and physiologists. Access to other specialities such as occupational therapists, dieticians, and speech and language therapists is also extremely important, and something that commissioners need to be aware of and consider. Respiratory Function Tests also needs to be more specific and detailed. The detail of assessment has important implications with regards to time, which commissioners need to consider when doing costings. In this patient group we would recommend lung function tests including FEV1, FVC, MIPs, MEPs, SNIP and PCF. Capillary blood gases. Subjective assessment of respiratory symptoms, to include sleep disordered breathing. For more complex patients it can also be of benefit to have availability to additional assessment techniques such as overnight capnography studies, chest x-rays and sputum cultures.
25	The Association of Chartered Physiotherapists in Respiratory Care	Statement 3 Audience descriptors Commissioners p18	More detail is required as to potential healthcare professionals that should be involved (see comments above), and also the bandings of said professionals. From a respiratory physiotherapy point of view, we would recommend that costings are completed for a Band 6 as a minimum to ensure that specialist skills and knowledge are present. Ideally they would be supported by a Band 7 respiratory physiotherapist with experience of this patient group.
26	The Association of Chartered Physiotherapists in Respiratory Care	Statement 3 Definitions Symptoms and signs of potential	Measurement of PCF is essential, and would ideally be in conjunction with SNIPs, MIPs and MEPs. The measurement of PCF is cheap and non time consuming. There is no mention following PCF assessment of any cough augmentation strategies which we feel is a huge omission, and extremely important. Please see later comments for more detail.

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		respiratory impairment p19	
27	The Association of Chartered Physiotherapists in Respiratory Care	Statement 3 General	Respiratory muscle weakness is often present at the time of diagnosis but not fully assessed, and is therefore either missed totally or under-estimated. We recommend 3 monthly intervals between assessment to ensure that changes in the disease stage and progressions are picked up on in a timely manner. Regular assessments have been associated with better outcomes i.e. timely NIV application, a reduction in initiation of NIV in an emergency situation, and increased survival duration from time of diagnosis. Cough is an essential defence mechanism. An effective cough can clear secretions reducing an individuals risk of infection. Chest infections remain a common cause of hospital admission in this patient group. When cough effectiveness is reduced due to respiratory muscle weakness, the infection process can be accelerated which has huge implications for hospital resources once a patient is admitted to hospital. Cough augmentation techniques aim to either enhance or mimic cough when it is weak due to disease. Standard ‘respiratory physiotherapy’ techniques will not suffice for this patient group, i.e. suctioning, deep breathing exercises and postural drainage. Respiratory specialist physiotherapists are extremely skilled and knowledgeable with regards cough augmentation techniques. For example breath stacking using lung volume recruitment bag can reverse or prevent areas of atelectasis, which will then optimise gas exchange. Optimising the inspiratory capacity has been shown in multiple studies to enhance a patients PCF. Mechanical Insufflation-Exsufflation is a device which offers alternating positive and negative pressures on inspiration and expiration respectively-thus mimicking a cough. These techniques (which should be selected depending on the severity of a patients PCF) have been shown to optimise secretion clearance, reduce hospital admissions (especially when used prophylactically) and prevent/delay the need for tracheostomy. There are enhanced benefits with regards to survival when cough augmentation strategies are used in conjunction with NIV. Access to detailed assessment for and provision of cough augmentation devices currently varies dramatically across the UK. Funding remains an issue for the range of devices from breath stacking with an ambu bag, lung volume recruitment bag, upto mechanical insufflation-exsufflation. Funding across acute hospitals through to the community setting should also be considered. From experience it is apparent that many patients re only assessed for such devices when they are admitted in acute crisis. This isn’t appropriate and

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			is extremely costly. We need to ensure commissioners are aware of the importance of cough augmentations strategies, what these strategies involve and when they should be initiated. Timely initiation will provide cost savings through reduced hospital admissions in the long run. References: Chatwin et al., 2003; Sancho et al., 2004; BTS/ACPRC Guidelines-Bott et al., 2009; Bento et al., 2010; Morrow et al., 2014; NICE MND Guidelines 2016.
28	The Association of Chartered Physiotherapists in Respiratory Care	Statement 4 General	We would recommend that NIV is *discussed* rather than offered to patients with MND and respiratory muscle impairment. If patients are referred at the time of diagnosis then respiratory specific teams will then be able to approach this in a sensitive and timely manner-an empathetic approach is essential. From ACPRC member feedback we are led to believe that patients are being referred for NIV rather than a comprehensive respiratory assessment. These are not the same assessment-this needs to be made clearer. It should be highlighted that not all MND patients are candidates for NIV (for a multitude of reasons)-could the numerator and denominator (p20) therefore be revised? We would also recommend that decisions regarding NIV should be made by the specialist respiratory team in conjunction with the MDT (rather than the other way around). From a commissioning point of view we feel additional detail is required. As MND is a life limiting disease, initiation of NIV is likely to progress to a patient requiring NIV 24 hours a day. Regular contact and support will be required from the specialist respiratory centre which may involve the service travelling to the patient (in the community)-this again has huge cost implications but should be seen as the Gold standard of care for MND in the end stages of the disease. MND and community services will also need to be included in commissioning figures. There is no mention within Quality Statement 4:NIV (or any of the statements) regarding tracheostomy. This does equate to a small number of patients, but we believe most UK services will have at least one tracheostomy ventilated patient. We therefore feel this important to consider.
29	Association for Palliative Medicine of Great Britain and Ireland	Statement 5	We welcome the recognition that patients with MND should have access to specialist palliative care if needed, and that the MND doctor or nurse is likely to have expertise in this area as well
30	Association for Palliative Medicine of Great Britain	Statement 8	We welcome the inclusion of advance care planning and discussions around end of life planning and feel that this has been described in a practical and accessible way

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	and Ireland		
31	NHS England	Statement 1	Add and be referred automatically to the key worker who will coordinate the regular assessments and care usually the MND specialist nurse who may well be present at communication of the diagnosis.
32	NHS England	Statement 3	The real need is for these assessments to take place regularly. The best outcome measure is the number of unplanned admissions with respiratory failure or pneumonia. This would need to be specifically audited.
33	NHS England	Statement 4	This needs to be clarified. Are you suggesting all or should this QS define those who might benefit in terms of QUAL? It might be best to state whom it should be considered for.
34	NHS England	Statement 5	The major problem is the lack of these teams and consequently the lack of regular assessments. They need to be commissioned jointly by CCGs and NHSE.
35	NHS England	Additional statements	Would it be worthwhile including "all patients with MND should have a nominated key worker whom they can contact for information and advice and in the event of unexpected deterioration"?
36	College of Occupational Therapists	Question 1	The College of Occupational Therapists is satisfied that the quality standard accurately reflects the key areas of diagnosis, cognition, respiratory function, non-invasive ventilation, regular co-ordinated assessment, mobility, ADL, personal care and end of life care. Although not directly related to occupational therapy practice many people with MND require enteral feeding and the College is interested to know why this has not been included as an area for quality improvement.
37	College of Occupational Therapists	Question 2	It is likely that this information will be available locally although it may require the development of systems and processes to facilitate more accurate data collection. The College supports the accurate collection of this data to improve the quality of services to people with MND.
38	College of Occupational Therapists	Question 4	The College agrees that the standards are achievable with evidence of some local services already delivering care to this standard. One of the challenges, however, is ensuring the development of occupational therapists with specialist knowledge and skills to manage MND given the prevalence and incidence of the condition. Occupational therapists within rotational posts are unlikely to build sufficient experience of MND to achieve the level of expertise required to achieve the quality standards. This may therefore have resource implications as experienced occupational therapists may be perceived as an expensive resource with evidence that funding for specialist occupational therapists is being withdrawn across the wider neurological conditions.
39	College of Occupational	Statement 2:	There is evidence that some MND services are already achieving this within two months of diagnosis where

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	Therapists	Question 5	there is Neuropsychological support. In the absence of Neuropsychologists the College acknowledges that occupational therapist have the knowledge and expertise to contribute to cognitive assessments and support the achievement of this quality standard.
40	College of Occupational Therapists	Statement 3: Question 6	The College would like to suggest that no fixed timeframe should be attributed to diagnosis of respiratory function as comprehensive multidisciplinary assessment and regular review should allow the individual needs of the person living with MND to be identified with subsequent referral to the most appropriate clinical specialist as required in response to their changing needs.
41	College of Occupational Therapists	Statement 5: Question 7	The College would like to suggest that the key area for quality improvement is that comprehensive regular multidisciplinary assessment may not be taking place. This is necessary to identify the changing needs of the person living with MND from a holistic perspective and should not focus exclusively on respiratory function and mobility.
42	College of Occupational Therapists	Statement 8: Question 8	The College believes that conversations about end of life care should be determined by the person living with MND and their families and carers incorporating their preferences and wishes. The multidisciplinary team must be sensitive to this and all members of the team should feel sufficiently skilled to engage in difficult conversations in response to individual needs.
43	British Thoracic Society	General [Statements 3 to 5] [Additional statements]	The British Thoracic Society is disappointed to see the content of this Quality Standard. In the current format BTS cannot support the Quality Standard, and a major rethink is required as the Quality Standard does not reflect good or current practice. The standard is vague with little emphasis on the role of specialist respiratory physician/long term ventilation service for monitoring and assessing the patient. The importance of the respiratory team has been emphasised on a number of occasions during the preparation of the standard but has again been overlooked. While the standard includes respiratory function testing it makes no mention of proactive respiratory specialist review. We support a simple and easily measurable standard. All patients with MND should be referred for assessment to the local long term ventilation service or a respiratory specialist with an interest in neuromuscular disease after the initial diagnosis has been made and explained to the patient and family. Initial assessment should involve subjective and objective assessment of respiratory muscles and the need for NIV and cough augmentation techniques. Follow up should be 3 monthly unless assessed differently by the respiratory specialist team.

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			It is known that: 1. Respiratory function to assess the need for NIV cannot be reliably assessed by spirometry alone. 2. Understanding the role of NIV at an early stage improves uptake of NIV (Ando et al 2012). 3. NIV is the only treatment that provides a survival improvement > 6 months. 4. NIV is not the only treatment option that is provided by the specialist respiratory team; specialist respiratory physiotherapy input (secretion clearance and cough augmentation, for example) are also important aspects of overall care. This points to early engagement with specialist respiratory services. Despite this, the standards (3-5) allow for respiratory physiology testing by an individual with knowledge regarding lung function testing, but not necessarily expertise in the delivery of NIV and relative likelihood of patient benefit. This may occur in a neurological clinic, with referral for NIV taking place at the time that the neurologist thinks it is needed. This is too reactive. The available evidence (Bourke et al 2006) show that survival time may be shorter than 2 weeks once a decision to start NIV has been reached. The same evidence shows that some patients may gain greater benefit from NIV than others. Hence, discussions regarding this form of treatment need to be conducted by an expert team with experience in the management of the respiratory complications of MND. The British Thoracic Society is unable to support the Quality Standard unless specific changes to the current draft are made to address the points raised in this response.
44	British Thoracic Society	Statement 3	*Quality statement 3: Assessment of Respiratory Function* Statement 3 should include; All patients with MND should be referred for assessment to the long term ventilation service that is linked to the respiratory team with a specialist interest in MND. Referral be offered as soon after the initial diagnosis has been made. Specialist respiratory assessment should involve subjective and objective assessment of respiratory muscles alongside specialist clinical review to determine the need for NIV and other respiratory interventions, such as cough augmentation techniques. As such, respiratory monitoring should be overseen by clinicians with expertise in this area. For patients that have impaired airway clearance, poor inspiratory and/or expiratory muscle strength or

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			reduced peak cough flow they should be seen by a specialist respiratory physiotherapist. Specialist treatment options include lung volume recruitment and airway clearance techniques. The assessment and provision of mechanical airway clearance devices will usually fall under the remit of the respiratory care (i.e. the long-term home ventilation centre). Follow up should be 3 monthly unless assessed differently by the respiratory specialist team. Improving quantification of the standard; The process questions should incorporate the specialist respiratory team, rather than the vague criteria that requires only a measure of lung function and symptoms to be assessed.
45	British Thoracic Society	Statement 4	*Standard 4: Non-Invasive Ventilation* As stated in the response to statement 3, references that suggest that NIV should be offered to patients at a stage that they develop respiratory impairment due to MND should be removed. This is imprecise. The key point is to offer NIV at the right time (not too early, not too late) and for the patient concerned to feel confident in the purpose of therapy and the team delivering it. Pro-active care involves referral to specialist respiratory teams as soon after diagnosis as possible. This enables the patient to receive information around NIV that is individualised to the patient. It is accepted that not all patients will wish to take up the offer of NIV. Nevertheless, since NIV is the only treatment that provides a significant improvement in survival for selected patients, then such decision-making is important. It should not take place in the setting of an avoidable respiratory crisis once respiratory failure has already developed. The standard states that decisions regarding NIV should be made by the MDT in conjunction with the respiratory team. With pro-active respiratory care, it usually happens the other way around in clinical practice. This includes decisions around respiratory fitness for procedures such as PEG insertion. The neurological MDT will often defer to the respiratory team for such decisions. Embedding the respiratory team into the quality standard as soon after diagnosis as is possible is likely to improve the delivery of care. There is no mention of tracheostomy ventilation. Whilst uncommon in UK practice compared to international data, most centres will have patients with MND who are ventilated via tracheostomy. Long-term ventilation is highly complex, high-cost care. Shouldn't it be captured within a quality standard? Improving quantification of the standard: The measure should reflect the fact that patients have the opportunity to attend for respiratory surveillance, have a discussion with an expert regarding the role of NIV in their case, that NIV is offered as a possible treatment, and that it is started (if that is the wish of the patient) at an appropriate time.

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46	British Thoracic Society	Statement 5	*Statement 5: Multidisciplinary Care* The current statement 'The multidisciplinary team should have established relationships with, and prompt access to….respiratory ventilation services' fails to capture the importance of pro-active specialist respiratory care. It is the patient who should have direct access to respiratory ventilation services and this can only be achieved effectively via early referral ahead of the need for NIV. Adding the filter of the neurological MDT may prevent some patients from accessing NIV in a timely manner (or at all). Quality standard 5 should have 2 categories; one for MDT care, and a separate one for respiratory care (not just measurement of lung function).
47	RCGP	General [Additional statements]	The RCGP feels the document is correct to imply that the disease is sufficiently unusual that GPs will only see patients with it occasionally, and they will be correctly referred to specialist neurologists. The RCGP welcomes this quality standard and has two comments: 1. The areas that clinicians should focus on do seem to be appropriate. However, the RCGP is keen to highlight the importance of patient-centred care. In several places the document raises the question of the timeframe, and this could be consider too rigid. For instance, it cannot be right that someone with early disease, in whom there is no obvious reason to suspect cognitive impairment, should have a formal mental assessment (and similarly for all the other components of care). It seems appropriate to provide good medical care that tailors assessments to the individuals and the progress of disease for each patient rather than setting up measurable outcomes. 2.The RCGP would like to see the role of primary care specifically in this document. It is not mentioned in any role specifically in the sections on continuity of care or arrangements for end of life care – areas where most general practitioners have considerable expertise. The RCGP feels appropriate to include one statement for primary care to encourage specialists involve GPs in the care of these patients. (DJ)
48	RCGP	Statement 8	This will be difficult to monitor unless a standard care plan such as the unplanned care plans is used in conjunction with DNACPR forms and treatment escalation plans and coded in the GP clinical system. All patients with Motor neurone disease should have a specialist nurse available via phone and be given the MND association patient information booklet in a language appropriate to them http://www.mndassociation.org/wp-content/uploads/2015/07/living-with-mnd.pdf?c8bf39 (MH)
49	Disabled Living	Statement 6	The assessment of the daily living needs of people with MND can be complex. The competence of OTs in

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	Foundation (DLF)		relation to assistive technology (a broad term that includes daily living equipment and telecare or environmental services) varies significantly given the limited amount of training they can receive at University and in their placement. It is therefore probably worth considering a recommendation that assessment of daily living needs is carried out by an experienced practitioner.
50	Disabled Living Foundation (DLF)	Statement 6	A key area for quality improvement is to support the assistive technology competence of OT teams to ensure people with motor neurone disease receive adequate assessment and advice.
51	South Wales Motor Neurone Disease Care Network	Statement 1	We propose that people '*... are given information ... by a Consultant Neurologist or, in suitable cases, a specialty trainee under the consultant's supervision*.' Restricting this to consultants would limit the training opportunities and would mean that a neurologist's first experience of giving this information would be as a consultant, unsupervised, and with no opportunity for selection.
52	South Wales Motor Neurone Disease Care Network	Statement 2: Question 5	We suggest including a timeframe within which this assessment should be done. The assessment should be early, but if done immediately after diagnosis it may be compromised by the emotion of dealing with the diagnosis. Immediate assessment is not always wanted by the patient and family. High quality services typically offer routine follow up at three monthly intervals so to allow this early assessment to be accommodated we propose that people are '*assessed for any behavioural or cognitive changes at or within 4 months of diagnosis*.'
53	South Wales Motor Neurone Disease Care Network	Statement 3: Question 6	Because some people present and are diagnosed in atypical settings, we think there should be some latitude in how soon after diagnosis the baseline assessment of respiratory function is done. We propose that people '*have their respiratory function and symptoms assessed at or within one month of diagnosis...*'.
54	South Wales Motor Neurone Disease Care Network	Statement 5: Question 7	We know of gaps in both domains, in the frequency of re-assessment and in whether it includes respiratory function and mobility. We propose that the quality improvement should focus on both these factors. We propose a target interval of *three months* for the reassessment in each of these domains.

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55	South Wales Motor Neurone Disease Care Network	Statement 8: Question 8	We propose that defined points when there should be an offer to discuss end of life care should include: diagnosis, progression, new loss of function (*eg* motor, respiratory, nutritional), new need for consideration of intervention (*eg* gastrostomy, noninvasive ventilation), new requirement for domiciliary care, care home placement. This is so that the necessary conversation and decisions can be grounded in that context if the patient wishes to take that opportunity. We strongly endorse the proposal that we should be 'sensitive about the timing of discussions' and would add that this sensitivity has to extend to how the offer is made. For many patients and families it is highly sensitive and unexpected, and for some it is unwanted even when the professional view is that discussion of end of life care is now necessary. The offer has to be there, or only the best informed people will be able to discuss end of life care; but it must not become an obligation on the patient and family. A clear strategy for developing and deploying the necessary communication skills is needed to strike the balance.
56	Motor Neurone Disease Association	General	We welcome this draft quality standard, and the opportunity to comment on it. We hope that the implementation and monitoring of the standard will prove effective in raising standards in MND care in England, and improving consistency, by working with the outcomes-focused architecture of the NHS and social services.
57	Motor Neurone Disease Association	General Introduction	Some of the text in the quality standard appears to be drawn from the draft guideline, although in other places wording from the final version is used. For instance, the statement that MND "mainly affects people aged 50 to 65 years" appeared in the draft guideline, but was deleted from the final published version, and an age range of 55-79 cited instead. We recommend that the quality standard should consistently reflect the published version of the MND guideline.
58	Motor Neurone Disease Association	Question 1	On balance we feel the draft quality standard does a fair job of reflecting the key areas for quality improvement. If there is scope for doing so more effectively, we feel it may lie in a greater focus on the delivery of care to meet assessed need, as opposed to assessing need regularly and in a timely way. Most of the current quality statements focus on the latter, although this is undeniably an important part of MND care – one way in which MND care can go wrong is by assessing needs only once they have developed, rather than having regular assessments to spot emerging problems and anticipate future needs, so the focus on assessment is, of itself, welcome. One or more measures relating to case closure may also be useful: inappropriate case closure can lead to longer waiting times for re-assessment, and therefore service delivery, and to a lack of continuity in care; the

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			full guideline's statement on case closure was therefore very helpful. While identifying inappropriate case closure *per se* in data would be very difficult, we might expect case closure rates to be lower for people with MND than for wider patient populations if good practice is being adhered to, which might be detectable with appropriate data collection.
59	Motor Neurone Disease Association	Question 2	Generally, we are doubtful that systems and structures are currently in place to collect much of the data for the proposed quality measures. For instance, we know that there are substantial problems with the coding of neurology activity, which the clinical reference group on neurology is seeking to address. We also know that much of the data that is already collected does not include diagnosis – for instance, the specialised Alternative and Augmentative Communication (AAC) hubs in England have begun collection to a minimum dataset, but we have been unable to persuade them or NHS England to collect MND-specific data consistently. Local authorities also do not routinely collect data on diagnosis in respect of users of social care services. We note also that there appears not to be a willingness or ability to invest in data collection in England: the relevant part of the Department of Health's and NHS England's budgets are not within the scope of the protection afforded to the NHS in the recent spending review, and the recently-instituted Neurology Intelligence Network is under threat of being subsumed into wider data monitoring initiatives.
60	Motor Neurone Disease Association	Statement 1	We believe that there may not be quite enough neurologists in England with expertise in MND to achieve this quality statement. While England has a notably low number of neurologists relative to the size of the population, NHS England has indicated that it does not propose to increase the priority attached to neurology within current training arrangements. Attracting further neurologists to specialise in MND will take time to achieve and to pay off, but any such efforts would divert neurologists away from general neurology or other specialisms.
61	Motor Neurone Disease Association	Statement 1 Measures	We are unsure whether data collection to assess whether this statement is being achieved will be possible. It may be, if one assumes that in England all such neurologists will be working in designated neuroscience centres – although identifying MND specialists within these centres may not be possible within existing data collection. The underlying assumption may not be sound, however: some neurologists who specialise in MND, albeit a small proportion, work outside the designated centres, so identifying their work within existing data collection may not be possible. A survey of patients may be a more effective route to collecting this data, or at least of some value in triangulating and verifying it. Our Improving MND Care Survey records whether people with MND are satisfied that their diagnosis was given to them by clinicians with expert knowledge; this is currently only run every three years, but is the largest survey of people with MND in the country.

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62	Motor Neurone Disease Association	Statement 1 Audience descriptors	The quality standard recommends that CCGs and NHS England commission these services; as noted above, we would generally expect MND specialists to be commissioned by NHS England, but some will work in CCG-commissioned local hospitals. Other local services, commissioned by CCGs, will have a role in identifying possible cases of MND and making appropriate referrals to neurology (and then on to an MND specialist in due course). It has been our experience that commissioners in both CCGs and NHS England generally lack the detailed level of oversight necessary to be aware of services available in respect of MND, even though they may be paying for them. Some expert MND neurologists, however, are employed by universities and not commissioned by the NHS at all; the quality standard should address this in its recommendations.
63	Motor Neurone Disease Association	Statement 2: Question 5	Our own guidance to professionals does not recommend a firm timescale after diagnosis within which a person with MND should be assessed for behavioural or cognitive change. The statement as drafted suggests that assessment should take place as soon as the person with MND is comfortable to have it take place. We question the use of this concept here – in respect of cognition, it can often be hard for the person to recognise that they have undergone a change, or for professionals to find a ‘right’ time to make an assessment. We suggest that professional judgement and discussions with those close to the person with MND might be more important and appropriate triggers.
64	Motor Neurone Disease Association	Statement 2	Cognitive and behavioural changes in MND are an area of rapidly developing knowledge, and many professionals will need further and improved training in order for this quality statement to be achievable. We recommend that the healthcare professionals referred to in the recommendation are not limited to neurologists and specialist MDTs – all professionals should at least be alert to recognising cognitive change, and have a role to play in doing so (including social care professionals, although we acknowledge that the formatting of the quality standard requires it to refer to healthcare professionals only). Cognitive impairment may have a bearing on a person’s ability to use particular items of equipment or benefit from particular services, so it is potentially relevant to all professionals.
65	Motor Neurone Disease Association	Statement 3 and Statement 4	Respiratory services are not among those where we receive regular and substantial reports of problems for people with MND, so we expect that these quality statements are probably achievable given the net resources required. Effective respiratory support has substantial potential for reducing crisis admissions to

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			hospital, although whether this would free up enough resource to allow for disinvestment in acute services is less clear. We have observed that NIV provision can be vulnerable in the event of a machine failure, when support can be inadequate to prevent a hospital admission – effective commissioning and resourcing of NIV pathways locally can prevent this.
66	Motor Neurone Disease Association	Statement 5: Question 7	In respect of comprehensive and regular assessments, we do not feel it is possible to generalise to good effect about which problem these quality statements should seek to address – ie, whether the problem is a lack of consistent assessments, or that such assessments do take place but certain priorities (respiratory function, mobility) are not well covered within them. There is too much variation in practice across England to draw one conclusion firmly over the other: in some areas, multidisciplinary assessments do not take place regularly enough, or there is insufficient co-ordination to deliver them to good effect; in others, shortcomings with specific local services mean that particular aspects of MND care are not assessed effectively. In order to drive up standards in assessment, we recommend that this guidance should address both problems, even at the risk of some overlap between quality statements. As in our comment 1, we note that effective action to address need must follow from an effective assessment; this is a third respect in which provision can sometimes fall short. More broadly, we feel that the description of 'comprehensive' and 'coordinated' assessments in the quality standard is in a sense too neat, and does not correspond thoroughly with existing practice. This reflects the structure of the guideline, although we were pleased to see improvements in that between consultation and publication. So, while the guideline recognises that the MND 'clinic' offering the multidisciplinary service may be in a hospital or in the community, it should be recognised that even effective multidisciplinary assessments will not always be delivered in a straightforward 'clinic' format. Multidisciplinary teams may often face time constraints that limit their ability to meet regularly, let alone to assess patients in the same place at the same time. These constraints, and differing professional views about good practice, may mean that any joint assessments, whether in a clinic setting of some sort or in the person's home, may involve only a few members of the MDT, and in some localities they may not be possible at all. Some professionals are not supportive of assessments by entire teams in one go, and clinic arrangements can be problematic for people with MND who may, for example, be distressed by seeing other people whose illness is further advanced than their own. Multiple assessments may instead take place, as part of an approach to care that is made multidisciplinary by virtue of effective co-ordination and information sharing. In short, practice varies considerably, and the draft quality statements do not entirely reflect this. Evidence in this area remains slight, which may make it difficult to amend the draft quality standard substantially: we note the research recommendation on this topic attached to the full guideline; our own

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			Models of Care research suggests a picture of considerable variation, but also that effective co-ordination of assessments and care delivery, including strong information sharing, are important to making such exercises effective, even if they are not undertaken by an entire team acting together simultaneously and in the presence of the patient.
67	Motor Neurone Disease Association	Statement 3: Question 6	We recommend that a baseline assessment of a person's respiratory function and symptoms should be undertaken as soon as possible after diagnosis, but our own guidance to professionals does not place a firm timescale on this.
68	Motor Neurone Disease Association	Statement 5	Extra resource is probably needed to achieve this quality statement. Notwithstanding our comments about the variability of multidisciplinary assessment when it is undertaken, there are still some areas where a lack of effective co-ordination of care means that assessment across all the necessary disciplines is not carried out to good effect. It should also be noted that some provision, for instance in respect of co-ordinator roles both in hospital and in the community, is charitably funded at present.
69	Motor Neurone Disease Association	Statement 5 Audience descriptors	The wording of this section of the quality statement should take account of the ongoing confusion around commissioning responsibility for neurology services. The current text appears to place responsibility for these solely with NHS England, but in practice services for people with MND will often be a mix of hospital and community services, so CCGs have responsibilities here as well. The current service specification states both that all neurology services are specialised and, additionally, that all MND services are specialised – we and other neurological charities have made repeated representations to NHS England about this error, which contradicts the identification rules for specialised services, and we hope that a revised service specification will ultimately be published. In the meantime, we recommend that the quality standard is worded, as far as possible, in a way that reflects current practice and with which a future service specification will hopefully be aligned. It should also be noted that some services used by people with MND may be in other specialist centres, for instance AAC hubs; while it may be possible to co-ordinate work with specialist SLTs in a hub, it may not be feasible for them to come on board as regular and fully integrated members of the MDT, although local arrangements will no doubt vary
70	Motor Neurone Disease Association	Statement 6	This statement is an example of one that does not say anything about the needs in question being met. There will be considerable local variability in how feasible it is to achieve this statement given the net resources

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			required. Cost pressures and confusion about responsibilities can often cause delay in local services meeting the needs of people with MND. Wheelchair services and services to meet daily living needs are highly variable, and shortcomings can often be the result of cost pressures and under-resourcing.
71	Motor Neurone Disease Association	Statement 7	Resources will be a major obstacle to achieving this quality statement, particularly in social services but also to an extent in the NHS. Rotation and turnover of care workers in social services are ultimately driven by cost considerations. Similarly, growing pressure on Continuing Healthcare funding is making it harder to secure eligibility, and the commissioning of appropriate care packages also seems to be suffering for cost reasons.
72	Motor Neurone Disease Association	Statement 8	Given that any professional caring for someone with MND could, and should, be prepared to discuss end of life issues when needed, we believe this should be achievable given the net resources required. Training does need to be improved in order for this to be the case, however: we do see reports of extraordinary insensitivity by professionals from time to time; and often, responsibility in this area falls heavily on MND co-ordinators or palliative care specialists, without other professionals taking on responsibility.
73	Motor Neurone Disease Association	Statement 8: Question 8	Our advice to professionals is that the timing of discussions about end of life care requires judgement: it should not be immediate upon diagnosis, but should be undertaken as soon as the person is ready afterwards. Some people may expect the professional to raise the subject, but others may give indications in conversation that they are ready to be given information about it. Generalising further may not be usefully possible, as reactions and adjustment to a diagnosis of MND can vary so much. We also suggested in our comments on the draft guideline, however, that professionals should be ready to discuss issues around the end of life at any point when the person with MND wishes to discuss it, and we were pleased to see this recommendation included in the final guideline. When people with MND might wish to raise such issues will vary considerably, but we know that people with MND find it unhelpful, and sometimes worrying or even upsetting, if such a conversation is shut down by a professional just when they have mustered the determination to talk about it. Discussion about end of life may also be necessary at particular points in a person's care, such as when decisions are made about whether or not to initiate NIV or fit a gastrostomy.
74	Department of Health	No comments	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.

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75	Royal College of Physicians and Surgeons of Glasgow	Statement 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.
76	Royal College of Physicians and Surgeons of Glasgow	Statement 2	This is reasonable however there should be mechanisms in place to deal with the consequences of a super added diagnosis of dementia.
77	Royal College of Physicians and Surgeons of Glasgow	Statement 3	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. 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 CO2. Overnight transcutaneous measurement of CO2 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. 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.
78	Royal College of Physicians and Surgeons of Glasgow	Statement 4	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

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			relationship with regular clinical review. 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. 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. 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.
79	Royal College of Physicians and Surgeons of Glasgow	Statement 5	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. 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. 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.
80	Royal College of Physicians and Surgeons of Glasgow	Statement 6	The pressing issue is that while the majority of the components of a full assessment are available they are not 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

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			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
81	Royal College of Physicians and Surgeons of Glasgow	Statement 7	Please see response to 6 The pressing issue is that while the majority of the components of a full assessment are available they are not 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
82	Royal College of Physicians and Surgeons of Glasgow	Statement 8	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. 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.
83	Royal College of Physicians and Surgeons of Glasgow	Additional statements	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?
84	Royal College of Speech and Language Therapists	Question 1 [Statement 6]	This statement refers to 'mobility and daily living needs'. RCSLT feel that 'communication and swallowing' should be specifically included under this heading as well and cannot just be assumed under the heading of 'daily needs'. Regular clinical swallowing assessments by a speech and language therapist should be carried

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			out particularly in those patients with bulbar symptoms. This may need in some cases to be supplemented by an instrumental assessment such as video fluoroscopic examination. This is a key quality improvement because in some areas an assessment of swallowing is purely based on patient or carer report alone without observation or clinical evaluation of the person with MND actually eating or drinking.
85	Royal College of Speech and Language Therapists	Question 2	(Re: data collection) Local systems may only be able to capture local data and MND patient care often has to be reliant on crossing regional/trust boundaries. Accurate data collection required for audit of the guideline will therefore be reliant on collaborations to be put in place to ensure data from all those involved is amalgamated i.e. MND care centres, hospice, local hospital, respiratory service (which may be at a different hospital), local community therapy team and social services. Several trusts may be involved.
86	Royal College of Speech and Language Therapists	Question 3	(Re: example from practice of implementing the care described in paper) The King's College Hospital, Motor Nerve Clinic provides the necessary specialist services to fulfil statements 1, 2,3,4,5,6,8 but not 7. Many services will require collaborations across service providers and regional boundaries to implement the full care as described in the draft quality standard.
87	Royal College of Speech and Language Therapists	Question 4	(Deliverability) As above. Local services may need the support of tertiary services / specialist centres to deliver the care as outlined in the draft quality standard.
88	Royal College of Speech and Language Therapists	Statement 2: Question 5	(Timeframe of statement) Ideally, assessment of cognitive and behavioural changes should be as shortly after diagnosis as possible, whilst taking into account the distress receiving of the diagnosis may have imposed. Certainly an assessment within six months of diagnosis would be helpful (or sooner if changes are suspected) so as to know if cognitive changes have occurred and to ensure this is tactfully communicated and taken into consideration when the person with MND has to make complex decisions about interventions such as gastrostomy and ventilation as the disease progresses.
89	Royal College of Speech and Language Therapists	Statement 3: Question 6	Preferable at time of diagnosis, but at least within 4 weeks.
90	Royal College of Speech and Language Therapists	Statement 5: Question 7	(Re: key area for quality improvements) Regular assessments of all aspects of care should be stated. Respiratory assessments are a specific issues as they usually require instrumentation to get quantitative measures rather than solely reliant on patient or carer report. Regular assessment of swallowing and communication by a speech and language therapist with specific knowledge of MND should also be added as this cannot be assumed under the heading of 'daily living'. This lack of a specific mention is a big omission from the quality statements.
91	Association of British	General	Overall this is a comprehensive document detailing quality standards for the care and support of people with

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	Neurologists		MND. These quality standards cover many areas of impact for people with MND. The standards are long and detailed: it is difficult to tease out the key elements that need to be prioritised.
92	Association of British Neurologists	Question 1	The key areas are covered, excepting that of provision of appropriate Palliative Care services specifically for people with MND. It is good that opportunities to discuss preferences and concerns about end of life care are specifically mentioned. It is also particularly welcome to see Statement 2, detailing assessment of cognitive and behavioural changes, as this is an area in which service provision across the country is patchy. I note that there is no specific quality statement regarding advice on gastrostomy placement and nutritional supplementation - although this is likely to be covered satisfactorily in Statement 5, relating to specialist multidisciplinary team reviews.
93	Association of British Neurologists	Question 2	Some MND Care Centres will be well placed to collect data for most, if not all, of the proposed quality measures. However not all patients with MND are seen in such specialist multidisciplinary Care Centres and I think it unlikely that local system and structures are in place to collect the required data. It should be feasible for systems and structures to be put in place to collect such data in the MND Care Centres – but I think it unlikely to be feasible to collect this information from those with MND diagnosed and cared for outwith these centres.
94	Association of British Neurologists	Question 3	Several of the MND Care and Research Centres will have data on implementation of the care described as part of their regular monitoring of their service, as requested by the MND Association UK who provide support to these centres.
95	Association of British Neurologists	Question 4	Having worked with the MND Association for many years, I think it likely that most patients with MND are diagnosed and cared for in a setting in which most of these quality statements are/could be achieved. However, even in large centres, with reputations for delivering excellent care for people with MND, there are not resources to achieve all of the quality standards suggested e.g. the centre in which I have worked for the last 16 years does not have sufficient neuropsychology support to allow all newly diagnosed adults to have timely assessment and ongoing input and I think it likely that other centres have similar gaps in their service provision. I cannot see any clear potential for cost savings or opportunities for disinvestment evident in these draft standards other than to say that if patients with MND are provided with care as outlined in these standards, there may be fewer inappropriate acute hospital admissions.
96	Association of British Neurologists	Statement 2: Question 5	I think it appropriate for all newly diagnosed patients to undergo cognitive assessment at, or shortly after (within a few weeks) of diagnosis. Administration of cognitive assessment scales, such as the Edinburgh

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			Cognitive and Behavioural ALS Screen, can be undertaken by Clinical Nurse Specialists, and do not need to be performed by a Neuropsychologist.
97	Association of British Neurologists	Statement 3: Question 6	I recommend that respiratory symptoms be assessed at diagnosis, and baseline respiratory function tests are performed within a few weeks (2 – 4 weeks) of diagnosis.
98	Association of British Neurologists	Statement 5: Question 7	My view here is that comprehensive regular assessments are not always taking place. For example not all patients in whom it would be appropriate are having regular respiratory or cognitive assessments. In other cases relevant assessments are taking place, for example for provision of wheelchairs, but then the subsequent implementation of recommendations based on these assessments takes much too long.
99	Association of British Neurologists	Statement 8: Question 8	Clearly this will depend very much on individual patients and their wishes. I think that offers to discuss end-of life-care should be made when patients are considering a trial of assisted ventilation, but otherwise do not think that it is appropriate to mandate such discussions at specified time points. I think that the fact that MND is progressive, and incurable and that most people with MND die due to complications of the disease should be sensitively discussed with all patients at, or shortly after, diagnosis by a consultant neurologist with expertise in treating people with MND. This is different from a detailed discussion about end-of-life care the timing of which will vary greatly depending on individual disease trajectories in individual patients.

Registered stakeholders who submitted comments at consultation

- Association for Palliative Medicine of Great Britain and Ireland (APMGBI)
- Association of British Neurologists (ABN)
- Association of Chartered Physiotherapists in Respiratory Care (ACPRC)
- Barts Health (Barts Health)
- British Association of Prosthetists and Orthotists (BAPO)
- British Thoracic Society (BTS)
- College of Occupational Therapists (COT)

- Compassion in Dying (CiD)
- Department of Health (DoH)
- Disabled Living Foundation (DLF)
- Motor Neurone Disease Association (MNDA)
- NHS England (NHS Eng)
- Royal College of General Practitioners (RCGP)
- Royal College of Nursing (RCN)
- Royal College of Physicians and Surgeons of Glasgow (RCPSG)
- Royal College of Speech and Language Therapists (RCSLT)
- South Wales Motor Neurone Disease Care Network (SWMNDCN)