NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1. Quality standard title

Suspected neurological conditions: recognition and referral

Date of quality standards advisory committee post-consultation meeting:
20 August 2020.

1. Introduction

The draft quality standard for suspected neurological conditions: recognition and referral was made available on the NICE website for a 4-week public consultation period between 12 February and 11 March 2020. 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 14 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 highlighted 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.

1. 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 data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed 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:

4. We would like to further understand how non-specialists can recognise and manage the recurrence of symptoms associated with functional neurological conditions. Please describe any examples you may have and whether you think this can be measured in practice.

5. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details on the comments form.

1. General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

* Having 3 statements is a missed opportunity to feature additional areas.
* GPs may benefit from training and awareness in neurological conditions and access to specialist expertise.

### Consultation comments on data collection

* Surveys may enable proposed additional overarching statements.
1. Summary of consultation feedback by draft statement
	1. Draft statement 1

Adults with transient rotational vertigo on head movement are assessed using the Hallpike manoeuvre.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

* The Hallpike manoeuvre should not require a specialist referral and should be performed in primary care.
* Epley’s manoeuvre should be mentioned as it can relieve or can cure BPPV.
* Investment from commissioners is needed to make this effective but it could lead to reductions in secondary care referrals.
* Onward referrals should be to ENT services, not neurology.
* Include a measure of the number of GP surgeries with clinicians trained to perform the Hallpike manoeuvre.
* This is a key area for improvement and will have impact outside of neurology.

### Issues for consideration

* Progress this statement to the final quality standard?
* Should we add a reference to treatment with the Epley manoeuvre in the rationale?
* Should we amend onward referral to ENT services rather than neurology?
* Should we add a measure on the number of GP surgeries with clinicians trained to perform the Hallpike manoeuvre?
	1. Draft statement 2

Children under 12 years with headache and 'red flag' symptoms are referred immediately for neurological assessment.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

* Referrals should be to a paediatric assessment unit or paediatric neurology.
* Guidance on imaging types and timing should be included, including when it is appropriate to refer to imaging.
* Consider referencing re-presentation with symptoms and recent normal investigations.
* The measures are appropriate for this statement.
* There is potential for this statement to reduce inappropriate exposures of ionising radiation.
* Consider referencing behavioural changes, irritability or difficulties at school as potential red flags.

### Issues for consideration

* Progress this statement to the final quality standard?
* Should we amend onward referral to paediatric assessment unit or paediatric neurology?
* Should we add a reference to re-presentation with symptoms and recent normal investigations?
* Should we add a reference to behavioural changes irritability or difficulties at school as potential red flags?
	1. Draft statement 3

Children under 4 years with suspected abnormal head size or shape have their head circumference assessed using a standardised growth chart.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

* Between 3 and 12 months old abnormal head shape is widespread.
* Referrals should be to specialist paediatric assessment rather than neurology.
* Data gathering is difficult as parents hold the relevant health record, however measurement may be possible when/if a child presents to secondary care.
* The statement is important as head circumference is overlooked in childhood measurements.
* The occipitofrontal circumference charts available in the red book currently stops at age 2.
* Decreasing numbers of health visitors may impact ability to implement.

### Issues for consideration

* Progress this statement to the final quality standard?
* Should we amend onward referral to specialist paediatric assessment unit rather than neurology?
* Consider age restrictions on measuring head circumference.
1. Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

* **Prompt access/referral by GPs to specialist neurological assessment and supporting therapies**
* This area is outside of scope of this quality standard.
* **The quality standard should include overarching statements that apply to all people with suspected neurological conditions (particularly around quicker diagnosis and access to treatment)**
* This area is outside of scope of this quality standard.
* **Medication plans with 6-month reviews, with this being particularly important if on anxiolytic medication**
* This area is outside of scope of this quality standard.
* **Referral to fatigue management services/physiotherapy/occupational therapy for a graded exercise program/fatigue management if fatigue becomes a new symptom**
* This area is outside of scope of this quality standard.
* **Signposting to information and support at pre-diagnosis/early diagnosis stage**
* This area is outside of scope of this quality standard.
* **Screening for mental health needs and appropriate referral and signposting**
* This area is outside of scope of this quality standard.
* **Primary care staff accessing specialist expertise to aid referral decisions**
* This area is outside of scope of this quality standard.
* **Referral to a dietitian with neurological expertise before neurological diagnosis is confirmed if there is unintentional weight loss**
* This area is outside of scope of this quality standard.
* **Referral to a speech therapist with neurological expertise before diagnosis is confirmed where there is swallowing difficulties**
* This area is outside of scope of this quality standard.
	1. Non-specialist recognition and management of recurrence of symptoms in patients with functional neurological conditions

At consultation we asked the following question:

Question 4: We would like to further understand how non-specialists can recognise and manage the recurrence of symptoms associated with functional neurological conditions. Please describe any examples you may have and whether you think this can be measured in practice.

Stakeholders responded:

* Data shows low accuracy of diagnosis by non-specialists, and this will also be true of recurrence. Patients should be helped to be confident in recognising reoccurrence of their own symptoms.
* Non-specialists can help patients manage other symptoms that exacerbate their condition as well as their medication.
* Non-specialists can identify and refer for other associated conditions such as sleep disorders and mental health issues.
* Specialists can educate non-specialists on related diagnoses and when to seek specialist opinions.
* When symptoms are not transient, obviously benign, clearly identifiable in primary care, or similar in nature to existing symptoms, specialist neurological assessment should occur.
* Symptom management plans with no referral to specialists unless new symptoms occur.

### Issues for consideration

* Do consultation responses support development of a quality statement on recognition and management of the recurrence of symptoms associated with functional neurological conditions in primary care?
* At topic prioritisation stakeholders suggested that ‘GPs need more confidence to recognise and manage neurological symptoms that are unlikely to be symptoms of an underlying neurological condition’. We were unable to find current practice information to support this suggestion.
* At the prioritisation QSAC committee members requested development of a quality statement in this area. We attempted to draft a quality statement on recognition of new signs and symptoms based on the available recommendations (NG127 1.2.8, 1.7.7, 1.8.2 and 1.10.7 below). However, during internal review it was considered to be not in line with the original intention of the guideline and unable to be measured.

The following recommendations from NICE guideline 127 cover recognition of symptoms related to diagnosed functional neurological disorders.

Recurrent dizziness as part of a functional neurological disorder

1.2.8 Be aware that, for adults who have been diagnosed with a functional neurological disorder by a specialist, recurrent dizziness might be part of the disorder and the person might not need re‑referral if there are no new neurological signs. New symptoms or signs in adults who have been diagnosed with a functional neurological disorder by a specialist should be assessed as described in the relevant sections of this guideline.

Recurrent limb or facial weakness as part of a functional neurological disorder

1.7.7 Be aware that, for adults who have been diagnosed with a functional neurological disorder by a specialist, recurrent limb weakness might be part of the disorder and the person might not need re‑referral if there are no new neurological signs. New symptoms or signs in adults who have been diagnosed with a functional neurological disorder by a specialist should be assessed as described in the relevant sections of this guideline.

Memory problems as part of an anxiety disorder or a functional neurological disorder

1.8.2 Be aware that, for adults who have an anxiety disorder or have been diagnosed with a functional neurological disorder by a specialist, memory problems and concentration difficulties might be part of the disorder and the person might not need re‑referral if there are no new neurological signs. New symptoms or signs in adults who have been diagnosed with a functional neurological disorder by a specialist should be assessed as described in the relevant sections of this guideline.

Numbness and tingling as part of a functional neurological disorder

1.10.7 Be aware that, for adults who have been diagnosed with a functional neurological disorder by a specialist, recurrent numbness and tingling might be part of the disorder and the person might not need re‑referral if there are no new neurological signs. New symptoms or signs in adults who have been diagnosed with a functional neurological disorder by a specialist should be assessed as described in the relevant sections of this guideline.

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# Appendix 1: Quality standard consultation comments table – registered stakeholders

| **ID** | **Stakeholder** | **Statement number** | **Comments[[1]](#footnote-1)** |
| --- | --- | --- | --- |
| 1 | The Dystonia Society | General | We do not dispute the inclusion of the three quality statements that have been identified on the basis of specific clinical priority. However, these do not address the needs of people with dystonia (or indeed many other neurological conditions) where delays in initial diagnosis have a significant impact on the health and quality of life of those affected. We appreciate that it may not be appropriate to include specific quality statements for every neurological condition. However, we consider that it is possible to include overarching statements that would ensure that patients with dystonia or other neurological conditions do receive prompt and effective early diagnosis and treatment. |
| 2 | The Dystonia Society | General comment | We consider that the inclusion of overarching quality standards will support the introduction of the standards on suspected neurological disorders. We appreciate that detailed measurement may not be straightforward. However, surveys such as those undertaken by The Neurological Alliance as well as local audits of services, would enable the effectiveness of implementing the standards to be assessed and areas for improvement to be identified. |
| 3 | Multiple System Atrophy Trust | General | Does this draft quality standard accurately reflect the key areas for quality improvement? No not at all. We were under the impression that the Quality Standard would support standardisation of identification and referral, including referral for specialist assessment. We also thought that there would be a recognition of the issues around diagnosis and signposting to support for rare neurological conditions.These are all key issues which the standards should address. In the Neurological Alliances report Neuro Patience 34% of people with MSA saw their GP over 3 times before their neurological condition was recognised with 17% having to wait over 12 months for a referral. Yet there is nothing around the importance of G.P. awareness and training or any suggestion that G.P.’s might benefit from access to neurologist expertise by phone or email during or after a consultation which they are unsure of.The majority of people with MSA have an inaccurate initial diagnosis so this issue is crucial to them. Even when people do get a diagnosis, they are often not given sufficient understandable information. In the same report 58% of people with MSA were either not given any information or information they could not fully understand.If the quality standard does not address these issues it has been a wasted opportunity. If there has been insufficient evidence on these issues then this should be addressed in how the consultation was framed and further enquiry should be made. |
| 4 | Society and College of Radiographers | General | The Society and College of Radiographers believes this quality standard has the potential to improve outcomes for patients and in particular children by reducing inappropriate exposures of ionising radiation.It also has the potential to reduce unnecessary diagnostic imaging investigations and so improve radiology reporting turnaround times.These outcomes are in line with the recommendations (1,5 and 6) of the Committee on Medical Aspects of Radiation in the Environment (COMARE) sixteenth report <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/343836/COMARE_16th_Report.pdf> and the Department of Health DH Expert Working Party Response to the Committee on Medical Aspects of Radiation in the Environment's 16th Report "Patient radiation dose issues resulting from the use of CT in the UK". <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/525292/WP_CT_scanning_doses_response_acc.pdf> |
| 5 | The Neurological Alliance | General | Does this draft quality standard accurately reflect the key areas for quality improvement?The Neurological Alliance has concerns about the draft guideline not accurately reflecting the key areas for quality improvement, as established in our 2019 report Neuro Patience, which highlights evidence of what is important to neurological patients from a survey of over 10,000, as well as which groups have particularly poor experiences (e.g. patients with rare diseases). Picking some clinical areas over others is inherently fraught, especially with a quality standard of this nature which includes so many different symptoms indicative of many different conditions. While including standards relating to the Hallpike manoeuvre for patients with suspected vertigo, children under 12 years with headache/'red flag' symptoms being referred immediately, and children under 4 years with suspected abnormal head size or shape having their head circumference assessed will make a positive difference to these patients, it does nothing for the remainder of the population of patients with suspected neurological conditions. Moreover, we note that benign paroxysmal positional vertigo is listed in the ICD-11 under diseases of the ear or mastoid process>diseases of the inner ear not under diseases of the nervous system – and that these patients would often be referred in to ENT/neurotology clinics where these exist, effectively meaning there are no quality standards currently included that would benefit adults with suspected neurological conditionsThere are a number of issues that are important to most if not all patients, and therefore make for a more widely patient focussed definition of high-quality care in priority areas for improvement. We therefore believe it is all the more important to include cross-cutting measures that will benefit the entire population, and not only discrete subsections of it. |
| 6 | The Neurological Alliance | General | We believe the NICE Quality Standard committee should revisit the topics included in the standards. We urge them to include standards relating to:a)Better signposting to information and support for people with neurological symptoms at the pre-diagnosis/early diagnosis stageReason: We hear from patients that they often stumble across sources of support later in their ‘patient journey’ and how much of a difference this would have made if they had discovered this information earlier, around the time of diagnosis. Often this is a time where people feel isolated and anxious, experiencing symptoms with knock-on impacts on their daily lives, and having to try and cope with this without any advice and support. Improved signposting would help alleviate this need for support, and improve their overall experience. Our National Neurological Patient Experience Survey, which surveyed over 10,000 people in 2018/19, found that there are issues with diagnosis and referral to specialist neurological services. * 14% did not see a GP before seeing a neurologist (this includes emergency admissions)

Of the rest: * 41% saw their GP only once or twice
* 20% saw their GP three or four times
* 39% saw their GP five or more times

This does not compare favourably with other condition areas. Well over a third of respondents have to see their GP five or more times. Respondents still face difficulties in obtaining a confirmed and accurate diagnosis for their neurological condition even after seeing a neurologist. Just 24% of respondents were diagnosed immediately upon seeing a neurologist. 38% received a diagnosis in under 3 months. 31% were diagnosed in 3-12 months. However, over a fifth (21%) waited over 12 months for a confirmed and accurate diagnosis.Finally, NHS England’s own figures show that in neurology there has been a 71% increase in the number of patients not seen by a specialist within 18 weeks, with people with people with rare neurological conditions having to wait longer to see a specialist.Free text comments to the National Neurological Patient Experience Survey, such as the following, clearly indicate a need for additional support while patients are awaiting referral.‘I find it very difficult to discuss things with [my GP] as their answer is always ‘just wait’. I am at a loose end with my health and wellbeing deteriorating and not having anywhere to turn. Seeing a neurologist would help on so many levels but unfortunately my GP will not refer…and I don’t feel well enough to fight.’ SURVEY RESPONDENTFinally, the survey also found that 62% (n=184) of survey respondents who were still awaiting diagnosis and responded to a question on wellbeing indicated that their mental wellbeing needs were either not being met at all (44%) or only being met to a small extent (12%). Taken together, this is strongly suggestive of a need for signposting to information and support amongst those with suspected neurological conditions.Given that we know a number of our member organisations are of a similar view, and submitted responses to the Quality Standard scoping exercise asking for a Quality Standard on this, we can only infer that these comments have been disregarded because the Guideline itself is severely lacking on these important points. We note that the full guideline document states:“…the scope covers assessment and referral so it would be difficult to give guidance on what information primary care physicians should provide to people without unduly worrying them before a final diagnosis is made” (6.2, page 107).We strongly disagree with this statement and feel that the lack of guidance relating to information and support for patients is a huge weakness of the Guideline. Our experience is patients are more likely to worry without appropriate information and support, particularly while waiting for a neurologist appointment. Third sector organisations are highly skilled in supporting patients at every stage on the care pathway – even before diagnosis. Indeed, many provide support in understanding the next steps such as what will happen at a neurologist appointment, what tests may be carried out and why. Many third sector organisations work closely together in relation to patients who have similar symptoms or may be incorrectly diagnosed. Much of the information developed by third sector organisations is peer reviewed and developed with reference to academic research, medical expertise and has the NHS England information standardWe had hoped that this weakness could be partially overcome by inclusion of standards relating to information and support included in the Quality Standard, with reference to the Patient experience in adult NHS services: improving the experience of care for people using adult NHS services clinical guideline [CG138].Justification in relation to NICE Guidelines:The Suspected Neurological Conditions Guideline states at 1.16.1 “Follow the principles in the NICE guideline on patient experience in adult NHS services relating to communication, information and shared decision making.”This guideline is clear that clinicians should, where appropriate, discuss with patients their need for support, and that they should “Give the patient information, and the support they need to make use of the information, in order to promote their active participation in care and self-management.” (1.5.11).Moreover, the full version of the Suspected Neurological Conditions Guideline states, at 6.2 page 107, “People with neurological conditions should be advised where they might find reliable high-quality information and support after consultations, from sources such as national and local support groups, networks and information services.”Other Quality Standards relating to suspected conditions within large diverse populations, namely Quality standard [QS161] (sepsis) and Quality Standard [QS124] (suspected cancer), include statements about information provision. In QS124, statement 4 states people with suspected cancer who are referred to a cancer services should be given written information encouraging them to attend. In QS161, statement 5 states people with suspected sepsis who have been stratified as at low risk of severe illness or death are given information about symptoms to monitor and how to access medical care. Both recognise the importance of accurate, written information in ensuring good quality, timely care. We strongly therefore urge the Committee to include a statement on information provision and support, which should include reference to signposting to local and national groups and networks (both condition-specific and pan-neurological). The Neurological Alliance is well-placed to work with sector colleagues to produce a signposting resource, if this is included as a Quality Statement (indeed we are already in talks with the Association for British Neurologists and the Brain and Spine Foundation on this). Additional Justification: see section belowb) Patients with suspected neurological conditions being screened for mental health needs and referred/signposted on as appropriateReason: Neurological conditions have a different relationship to mental health conditions than other long term conditions, given that by their nature they relate to the brain and nervous system. So, the interaction between physical needs and broader emotional, cognitive and mental health needs is complex. Changes in the brain can directly affect a person’s emotions, cognitive abilities and executive functioning. Conversely, depression or anxiety can exist alongside neurological symptoms. People’s mental health difficulties often impact their neurological condition, triggering or exacerbating it. In other cases, apparent mental health issues may reflect an undiagnosed neurological condition. For people with functional or dissociative conditions ‘neurological’ symptoms are not caused by structural changes in the brain. As such, there are likely to be specific mental health needs in this population that need to be effectively picked up on, so that they can be addressed appropriately. A few areas have already started work to implement appropriate pathways – see for example the Cheshire and Merseyside document attached below. But impetus is needed for best practice to spread more widely. Our National Neurological Patient Experience Survey, which surveyed over 10,000 people in 2018/19, found a very significant level of unmet mental health need, with 40% (n=2879) of respondents indicating that their mental health needs weren’t being met at all.Justification in relation to NICE Guidelines: The Suspected Neurological Conditions Guideline states at 1.16.1 “Follow the principles in the NICE guideline on patient experience in adult NHS services relating to communication, information and shared decision making.”The latter guideline states “Patients have needs other than the treatment of their specific health conditions. There should be recognition of the potential need for psychological and emotional support” (1.2). It is clear that clinicians should, if appropriate, “discuss with the patient their need for psychological, social, spiritual and/or financial support. Offer support and information to the patient and/or direct them to sources of support and information. Review their circumstances and need for support regularly..” (1.1.7)Additional Justification: see section belowc) Primary care practitioners s establish ways to access neurological clinical expertise to help them decide whether or not to refer, in cases they are still unsure ofReason: By their nature, GPs are generalists. While the suspected neurological conditions guideline is intended to help them to make judgements about whether or not to make referrals, there will inevitably still be many cases which are not clear cut. This is particularly the case for rarer conditions, where there is a particularly acute need to improved recognition and referral (people with rarer conditions currently have the longest time to diagnosis out of all people with neurological conditions, according to our national neuro patient experience survey which received over 10,000 responses), and for which the Guideline is not comprehensive. Our 2016 Neurology and Primary Care report found that an overwhelming majority of GP respondents in England (84%, n=701) felt that they could benefit from further training on identifying and managing people presenting with neurological conditions. And the recently published workforce report by the Association for British Neurologists provides evidence that we have an acute shortage of adult neurologists, as compared to similar high income European countries (1.1 FTE per 100,000 as compared to 1 per less than 25,000). It is therefore imperative that GPs are supported to make the right referrals. A Quality Standard that encourages GPs/primary care practitioners to establish ways to access neurological expertise to help them decide whether or not to refer, in cases they are unsure of, would be highly complementary to the purpose of the Guideline. It is supported by evidence: pilot schemes to enable GPs to speak to neurologists on the phone or via video conference have been successful in improving appropriate referral rates – see for example the Consultant Advice Line at the Walton Centre. It would also potentially capitalise on new ways of working including primary care networks.Finally, this suggested Quality Standard would provide another reason for the sector to get behind the Quality Standard – as it would help to disseminate good practice. Without cross-cutting, meaningful Standards such as this suggested one, sector support is very likely to be negligible if not absent.Justification in relation to NICE Guidelines:The Guideline on Suspected Neurological Conditions states at 4.7.4 “Healthcare providers need to use clinical judgement, knowledge and expertise when deciding whether it is appropriate to apply guidelines. The recommendations cited here are a guide and may not be appropriate for use in all situations. The decision to adopt any of the recommendations cited here must be made by practitioners in light of individual patient circumstances, the wishes of the patient, clinical expertise and resources.” On section 2 (page 26 of the full guideline methods, evidence and recommendations document, it states“It is impractical for a generalist to keep abreast of the range of neurological treatments available and sometimes to appreciate the significance of neurological symptoms. The decision to refer to secondary care is therefore often difficult and may be contentious. This guideline aims to facilitate these decisions.”On page 27 of the Suspected Neurological Conditions methods, evidence and recommendations document, it states “the guideline committee accepted that a high level of competence in neurological examination would not be expected of a generalist.”Additional Justification: see section belowAdditional Justification for all three suggested standards:The Suspected Neurological Conditions Quality Standard may be a stand alone product from a NICE perspective, but ought to be seen and understood as one of a number of tools for service improvement in neurology (as it will be by all those using it). It therefore ought to coordinate with other existing products/resources in this domain, such as the suite of relevant NHS RightCare toolkits on progressive neurological conditions, migraine, and epilepsy. These include best practice examples that relate to a, b and c above, such as the following recommendations:* “Ensure local pathways include assessment and on-going support of patients’ mental and psychological wellbeing and cognitive status” (Progressive Neurological Conditions toolkit)
* “All people should be signposted for emotional wellbeing support at the point of first seizure. If appropriate, there should be an offer of a mental health referral. Encourage the use of mental health screening tools such as PHQ9 and GAD7.” (Epilepsy Toolkit)
* “Encourage clinicians to signpost patients’ families and carers to online support from epilepsy specific voluntary sector websites and education such as booklets, online courses and support groups to enable self-education.” (Epilepsy Toolkit)
* “Signpost people to third sector resources including local support groups or national advice lines to reduce attendance at A&E departments. Ensure that services that are commissioned give people with a primary headache disorder information, education and support to manage their condition to reduce attendance at A&E.” (Headache and Migraine Toolkit)
* “Information or signposting to information should be available for all patients to enable informed decisions from diagnosis.” (Progressive Neurological Conditions Toolkit)
* “Key Messages…For Commissioners” “Are there opportunities for new service models in primary care to speed up referrals to specialists e.g. utilising specialist nurses to triage referrals that may be able to reduce waiting times for first and follow up appointments, electronic referral systems, or an advice line for GPs to get advice from a specialist consultant to support management of patients with suspected neurological condition.” (Progressive Neurological Conditions Toolkit)

These toolkits also provide a number of practical examples of how implementation could be done (in relation to question 3) |
| 7 | The Neurological Alliance | General | The Guideline Committee’s reluctance to include wider cross-population standards as we have outlined in comment 2 and as we (and others) asked for in the scoping consultation may relate to these areas not having been the main focus of the Guideline. We do not believe this constitutes a good enough reason for their exclusion. NICE has already shown it is willing to be flexible in its approach in the very way in which the Guideline was developed as outlined in the Methods section of the Suspected Neurological Conditions methods, evidence and recommendations document (p.31), which discusses the “alternative” approach taken. It would therefore be inconsistent if NICE were to rule out what we and other patient organisations are asking for in relation to the Quality Standard. The Suspected Neurological Conditions Quality Standard is substantively different from the vast majority of Quality Standards, and therefore merits exceptional treatment/alternative approaches.  |
| 8 | The Neurological Alliance | General | Only having three standards is missing an opportunity and this ought to be rectified. We believe this quality standard should have at least 5 statements, as does the suspected sepsis Quality Standard, if not more. This is justified both in light of the need for the inclusion of standards that relate to the whole patient population, as outlined above, and in light of this topic being different and distinct from most addressed by NICE Guidelines/Quality Standards. This was recognised in the distinct approach undertaken in the development of the Guideline, as outlined in the Methods section of the Suspected Neurological Conditions methods, evidence and recommendations document (p.31), which discusses the “alternative” approach taken. |
| 9 | The Neurological Alliance | General | It is standard practice for NICE to seek endorsement for Quality Standards from relevant organisations. We believe that as it is written, and failing to address the points we have made in comments 1 - 4, will result in key stakeholders including ourselves as well as many others being unwilling to offer this endorsement, or to work with NICE to promote the Standard to commissioners and service providers. Therefore, in order to have a useful end product, we urge NICE to look again at including cross-cutting standards that focus on improving quality for the whole patient population as part of the Quality Standard. If the Quality Standard remains as it is it will be a wasted opportunity and it will be of no clinical use. |
| 10 | Action for MdDS UK | Question 1 | Do these 3 statements accurately reflect the key areas for quality improvementIn my opinion, no. |
| 11 | Primary care and Community Neurology Society | Question 1 | Another key area should added to the quality statement regarding prompt referral to a dietitian with neurological expertise before neurological diagnosis is confirmed if there is unintentional weight loss because often the amount of weight lost by the time diagnosis is confirmed is not easily rectified and can be life limiting in the case of Motor Neurone Disease. Also referral to a non-neurological dietitian may result in PEG discussion and placement being missed. (Evidence from my neurological dietetic experience can be provided, NICE QS15). |
| 12 | Primary care and Community Neurology Society | Question 1 | The above suggestion would be achievable locally with accurate prompt referral from doctor to dietitian on seeing the patient. |
| 13 | Primary care and Community Neurology Society | Question 1 | Another key area that should also be addressed is prompt referral to a speech therapist (ideally experienced with neurological conditions) if there are swallowing difficulties also before neurological diagnosis is confirmed especially if there is unintentional weight loss or signs of aspiration. (Evidence from NHS experience can be provided, NICE QS15). |
| 14 | Primary care and Community Neurology Society | Question 1 | The above suggestion would be achievable locally with accurate prompt referral from doctor to speech therapist on seeing the patient. |
| 15 | Primary care and Community Neurology Society | Question 1 | We have highlighted two examples of key not covered by this Quality Standard. We have significant concerns that this Quality Standard is failing to provide the guidance to raise the standards of care of people presenting with neurological condition. |
| 16 | Action for MdDS UK | Question 4 | How non-specialists can recognize and manage the recurrence of symptoms associated with functional neurological conditions.I think you're asking the wrong question. A better one might be 'How can non-specialists prevent people from being asked to self-diagnose with 'conversion disorder' and prevent the other incredibly bad practices that go on around the making of 'functional' diagnoses?' If you want to add 'How do we cure medical gaslighting and the trauma that results from it?' that would be cool. |
| 17 | FND Hope UK | Question 4 | Data has confirmed that non-specialists have a relatively low accuracy of being able to diagnose Functional Neurological Disorders, due to this, non-specialists will also have limited knowledge in recognising reoccurrence of symptoms.Part of the treatment of FND should be helping patients to recognise and be confident about the nature of their symptoms when they relapse. If someone with FND presents with a new neurological symptom that1. isn’t transient and sensory or obviously benign2. isn’t clearly identifiable in primary care (e.g. migraine, carpal tunnel syndrome) or3. is similar in nature to their previous FND diagnosed symptomsThen they ought to be reviewed by someone with expertise in neurological diagnosis. |
| 18 | FND Hope UK | Question 4 | However GPs can support patients with FND by helping to manage other symptoms such as pain and fatigue which can exacerbate FND and impede function greatly. I.e. optimising pain medications (or decreasing opioid use), recognising the need for onward referrals to specialist fatigue and pain management services, referrals for community Physiotherapy and Occupational Therapy to instigate graded exercise programs / fatigue management. |
| 19 | FND Hope UK | Question 4 | Identification of and onward referrals for sleep disorders such as sleep apnoea is also a common recommendation that GP’s can make for patients with FND as in our experience these are often undiagnosed and untreated (and obviously markedly impact on fatigue, quality of life and exacerbate FND). |
| 20 | FND Hope UK | Question 4 | GPs are very good at spotting/treating common psychological co morbidities, especially depression/anxiety, but probably less so for PTSD for which there are good treatments in terms of medication, psychotherapies +/- EMDR so can be missed.How to we ensure that the GP’s can recognise the symptoms of PTSD, have they had the training? Not sure how this could be measured. |
| 21 | FND Hope UK | Question 4 | Resisting prescriptions (or De-prescribing) anxiolytics (especially Benzodiazepines) also important |
| 22 | FND Hope UK | Question 4 | It is also worth considering FND specialists educating non-specialists on the borderland/related diagnoses and when to question/get expert help if the patients are also diagnosed with (Lyme disease, POTS, EDS, CRPS etc)Unsure how this could be measured? |
| 23 | FND Hope UK | Question 4 | Quality Statement People with FND have a symptom management plan in place, and are only re-referred to neurological expertise where new symptoms occur. |
| 24 | FND Hope UK | Question 4 | Quality Statement People with FND have a medication plan in place, and is reviewed every 6 months especially if patient is on anxiolytic medication |
| 25 | FND Hope UK | Question 4 | Quality Statement People with FND have a symptom management plan in place, and are referred to Fatigue Management Services/Physiotherapy/Occupational Therapy for a graded exercise program/fatigue management if fatigue becomes a new symptom |
| 26 | FND Hope UK | Question 4 | Quality Statement People with FND have a symptom management plan in place, and are referred to a sleep clinic if a sleep disorder is identified |
| 27 | Royal College of Paediatrics and Child Health (responding on behalf of the Clinical Genetics Society and the Paediatric Mental Health Association) | Question 4 | ‘We would like to further understand how non-specialists can recognize and manage the recurrence of symptoms associated with functional neurological conditions. Please describe any examples you may have and whether you think this can be measured in practice.’This relates to quality statement 2, ‘headache with one or more red flag symptoms.’ It is not uncommon for functional headache to present with what appear to be a red flag symptom i.e. ‘worsening’. Introduction of the concept of functional symptoms to the formulation as soon as ‘red flag’ pathologies have been ruled out, is a cornerstone of effective management.Is there scope for the guidance to include reference to ‘re-presentation with symptoms and recent normal investigations’, where it would be appropriate to introduce this concept? Fear of missing a pathological cause, makes it difficult even for specialists to manage these cases, but reference to this in the NICE guidance would be a step forward. |
| 28 | The Dystonia Society | Additional statement proposed | People with suspected neurological disorders should receive prompt referral by GPs to neurologists for assessmentIt is evident from feedback from members of The Dystonia Society that symptoms of dystonia are often not recognised in primary care. This is because incidence of this condition is relatively rare. However, primary care networks can address this by ensuring that they each have network members with enough experience of such neurological conditions. Patients often tell us of frequent visits to GPs before they are referred to a neurologist. Last year’s survey, Neuro Patience, published by The Neurological Alliance (to which over 500 patients with dystonia responded) identified that 39% of respondents saw their GP 5 or more times before being told they needed to see a neurologist. Prompt referral would ensure:* Fewer visits to GPs, freeing up their valuable time

Earlier diagnosis and commencement of treatment giving earlier reduction in pain or other distressing symptoms, less time off work or avoiding loss of employment, earlier access to other support services including therapies, charities and social support and consequent reduction of social, economic and psychological impact |
| 29 | The Dystonia Society | Additional statement proposed | People with suspected neurological disorders should receive prompt access to specialist neurologist and supporting therapiesThe Neuro Patience report also identified that 29% of respondents who needed to see a neurologist waited more than 12 months. We understand that other improvement work being undertaken in the NHS such as GIRFT (Getting It Right First Time) is also identifying the unevenness of access to specialist neurology services. This clearly needs to be addressed with the benefit being again fewer visits to GPs (for pain relief or to address psychological symptoms) as well as the benefits of earlier diagnosis and commencement of treatment as identified above. Another key factor here is the need (and benefit) of patients receiving written information when they are given a diagnosis. Dystonia is a long-term condition without a cure. Patients will receive symptomatic treatment for the rest of their lives. The sooner that they are enabled to understand their condition, become involved in treatment decisions and evolve coping strategies, the better will be their ability to learn how to live with the condition and maintain as good a quality of life as is feasible. Early diagnosis should be accompanied by early access to supporting therapies, including mental health support, which in the long run may reduce the incidence of more acute psychological conditions emerging. |
| 30 | Action for MdDS UK | 1 | 1.Adults with transient rotational vertigo on head movement are assessed using the Hallpike manoeuvre.Great :) I take it that you know that the Epley manoeuvre, used to treat BBPV etc after the Hallpike manoeuvre is done, doesn't seem to have FDA approval yet. And that doing it on people with Meniere's and MdDS etc could, just possibly, be counter productive. |
| 31 | The Royal College of Emergency Medicine | 1 | The wording of the document makes it sound like the Hallpike's test requires a specialist. It should be done by a GP without needing a specialist or ED referral. Emergency Departments should also know how to do this. |
| 32 | The Royal College of Emergency Medicine | 1 | This should not be the Emergency Department, paediatric assessment unit/paediatric neurology would be more appropriate. Wording surrounding paediatric assessment unit/paediatric neurology raises some concern.There is no mentioning of imaging in this group, we recommend adding guidance on what imaging (CT/MRI) should be done and when.There is no mention of Epley's manoeuvre. This can sometimes help, and can cure, BPPV. However, this does require some training. |
| 33 | Royal College of General Practitioners | 1 | The quality standard desired outcome is for ‘appropriate referrals to secondary care’. To reduce the number of patients referred into secondary care vertigo/ENT services from primary care and improve patient outcomes, the Hallpike manoeuvre could easily be performed in primary care if appropriate training is given. For this to have an impact and to increase the number of clinicians performing this technique, it would take investment from commissioners but would then ultimately reduce the number of secondary care referrals and meet the desired outcome. A more beneficial question would then read:Numerator: the number of patients assessed using the Hallpike technique in primary careDenominator: the number of adults with transient rotational vertigo on head movement |
| 34 | Royal College of General Practitioners | 1 | It is feasible that patient satisfaction surveys, audits, check lists for referrals and data collection could be carried out in general practice for BPPV but is dependent on the coding in place at individual practices. Another way to look at this and to improve services would be to ask commissioners to determine:Numerator: the number of GP surgeries who have clinicians trained to perform the Hallpike manoeuvreDenominator: the number of GP surgeries |
| 35 | Society and College of Radiographers | 1 | The Society and College of Radiographers suggests this statement is given some perspective within the diagnostic journey. For example: Adults with transient rotational vertigo on head movement are assessed using the Hallpike manoeuvre (to exclude BPPV) prior to referral for diagnostic imaging investigations  |
| 36 | Society and College of Radiographers | 1 | The quality measures seem to be appropriate for this statement |
| 37 | Action for MdDS UK | 2 | 2. Children under 12 years with headache and 'red flag' symptoms are referred immediately for neurological assessment.Fantastic. Adults get to look after these children. Red flags for us? Not so much. Oh and if we do get referred to neurology, what are the chances of us getting stitched up with a 'conversion disorder' diagnosis? |
| 38 | Royal College of General Practitioners | 2 | Children under 12 with headaches and red flag symptoms are referred from primary care to paediatrics and not neurology. Can the quality standard reflect this stating “referred to paediatric for neurological assessment” at each point in statement 2? |
| 39 | Royal College of General Practitioners | 2 | Health care professionals. Please include paediatricians in this list as this is the pathway of referral from primary care, not to neurology. “They are aware of the “red flag” symptoms and the requirement for immediate referral to neurological services….”. Please consider changing this to paediatric services or to secondary care services rather than neurological services |
| 40 | Society and College of Radiographers | 2 | The Society and College of Radiographers has concerns that this statement may be interpreted differently in different healthcare settings. If neurological assessment is not immediately available will some clinicians refer the child for inappropriate diagnostic imaging prior to neurological assessment? Can the statement be further qualified? For example Children under 12 years with headache and 'red flag' symptoms are referred immediately for neurological assessment prior to referral for diagnostic imaging investigations |
| 41 | Society and College of Radiographers | 2 | This supports the previous statement about appropriate diagnostic imaging |
| 42 | Society and College of Radiographers | 2 | The quality measures seem to be appropriate for this statement |
| 43 | Association of Paediatric Chartered Physiotherapists | 2 | There is no mention of behavioural changes, irritability or difficulties at school as potential signs of brain tumour when presenting in conjunction with a headache. The Brain Pathways Guideline (2017) advises that a child with a persistent headache and one or more other common symptoms should warrant a scan. |
| 44 | Action for MdDS UK | 3 | 3. Children under 4 years with suspected abnormal head size or shape have their head circumference assessed using a standardised growth chart.Great again. Maybe that would have helped my mate with foetal alcohol syndrome if any one had got around to thinking about this back then. |
| 45 | Royal College of General Practitioners | 3 | “In children under 4 years, abnormalities of head shape or size are likely to indicate brain growth disorders…”. Abnormal head shape is almost universal (between 3 and 12 months) since the 'back to sleep' public health campaign to prevent SIDS. This statement therefore requires evidence to back it up or to be changed. Can the committee consider “in some circumstances may indicate” rather than “is likely to indicate” brain growth disorders? |
| 46 | Royal College of General Practitioners | 3 | Referral for specialist paediatric assessment would be more appropriate. Primary care and health visitors do not refer directly to neurology. |
| 47 | Royal College of General Practitioners | 3 | Determining the number of children in primary care who have this head circumference measurement taken will be almost impossible as the health records are held by parents and not within the practice. It will require a self-declaration of measurement plotted.A better measurement would be of those presenting to secondary care with suspected abnormal head shape who had their head circumference measured and plotted on the growth chart but to accurately measure this would require secondary care clinicians to fill in a proforma when seeing the patients and this type of data collection on a large scale will be difficult. Individual paediatricians who are receiving referral may be able to collate this information in a personal audit, but numbers will be low. |
| 48 | Royal College of Paediatrics and Child Health (responding on behalf of the Clinical Genetics Society and the Paediatric Mental Health Association) | 3 | This is an important quality standard because, in the reviewer’s experience, head circumference is frequently overlooked in childhood measurements. However, is the OFC chart in the red book OFC charts due to be amended? To the reviewer’s knowledge the current version stops at age 2. HVs and GPs will not be able to readily access the WHO chart to age 4.  |
| 49 | Royal College of Paediatrics and Child Health (responding on behalf of the Clinical Genetics Society and the Paediatric Mental Health Association) | 3 | The action to be taken is referral to a specialist. Should there be clearer guidance on what type of specialist to refer to? |
| 50 | Royal College of Paediatrics and Child Health (responding on behalf of the Clinical Genetics Society and the Paediatric Mental Health Association) | 3 | Not all the three measurements done at the one appointment are recorded. In practise, only the largest measurement is recorded.The reviewer found the numerator in this statement very specific about the number of children who had the longest of the 3 head circumference measurements plotted. This will be difficult to establish, as in practise the one (longest) measurement is only recorded. It would be difficult to establish for sure if the measurements were done thrice. |
| 51 | Royal College of Nursing | 3 | While we welcome the standards overall, we have concern about the decreasing number of health visitors, and due to decreases in public health funding and local authority funding, some areas have stated that they will no longer be undertaking the five mandated checks as per Healthy Child Programme, and a recent survey which indicated health checks after 6 weeks are often not undertaken by a registered health visitor. |

## Registered stakeholders who submitted comments at consultation

* Action for MdDS UK
* Association of Paediatric Chartered Physiotherapists
* FND Hope UK
* Multiple System Atrophy Trust.
* Primary care and Community Neurology Society
* RCGP
* RCN
* Royal College of Emergency Medicine
* Royal College of Paediatrics and Child Health (responding on behalf of the Clinical Genetics Society and the Paediatric Mental Health Association)
* Society and College of Radiographers
* The Dystonia Society
* The Neurological Alliance
* The Pernicious Anaemia Society

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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. [↑](#footnote-ref-1)