

# National Institute for Health and Care Excellence

## Suspected neurological conditions

We would like to hear your views on these questions:

1. What are the **key areas for quality improvement** that you would want to see covered by this quality standard? Please **prioritise up to 5 areas** which you consider as having the greatest potential to improve the quality of care. Please state the specific aspects of care or service delivery that should be addressed, including the actions that you feel would most improve quality.

### Organisation details

<b>Organisation name – Stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank)	<b>The Neurological Alliance</b>
<b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	<b>None</b>
<b>Name of person completing form</b>	<b>Katharine McIntosh</b>
<b>Supporting the quality standard</b> Would your organisation like to express an interest in formally supporting this quality standard? <a href="#">More information.</a>	We are potentially interested in supporting the quality standard, however we would only offer formal support after having had the chance to review the final standard.
<b>Type</b>	<b>[Office use only]</b>

## Quality improvement comments

Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
<p>Separately list each key area for quality improvement that you would want to see covered by this quality standard.</p> <p><b>Example:</b> Pulmonary rehabilitation for chronic obstructive pulmonary disease (COPD)</p>	<p><b>Example:</b> There is good evidence that appropriate and effective pulmonary rehabilitation can drive significant improvements in the quality of life and health status of people with COPD.</p> <p>Pulmonary rehabilitation is recommended within NICE guidance. Rehabilitation should be considered at all stages of disease progression when symptoms and disability are present.</p>	<p><b>Example:</b> The National Audit for COPD found that the number of areas offering pulmonary rehabilitation has increased in the last three years and although many people are offered referral, the quality of pulmonary rehabilitation and its availability is still limited in the UK.</p> <p>Individual programmes differ in the precise exercises used, are of different duration, involve variable amounts of</p>	<p>If available, any national data sources that collect data relating to your suggested key areas for quality improvement?</p> <p>Don't paste other tables into this table as your comments could get lost. Type directly into this table.</p> <p>EXAMPLE: Please see the Royal College of Physicians national COPD audit which highlights findings of data collection for quality indicators relating to pulmonary rehabilitation. <a href="http://www.rcplondon.ac.uk/resources/chronic-obstructive-pulmonary-disease-audit">http://www.rcplondon.ac.uk/resources/chronic-obstructive-pulmonary-disease-audit</a></p>

	The threshold for referral would usually be breathlessness equivalent to MRC dyspnoea grade 3, based on the NICE guideline.	home exercise and have different referral criteria.	
Key area for quality improvement 1 <b>Faster referral of people with suspected neurological conditions requiring urgent specialist care (including suspected brain tumour, suspected sub-arachnoid haemorrhage, suspected epilepsy).</b>	Being seen by specialists as soon as possible is key to ensuring better outcomes for people with SAH, brain tumour and epilepsy – conditions which can (epilepsy, brain tumour)/will (SAH) lead to mortality where not treated as soon as possible. Moreover, NHS resource required to optimise outcomes may increase the longer the delay starting treatment (brain tumour).  The NICE guidance on the epilepsies recommends that both children and adults with	22% of brain tumour respondents to the national cancer patient experience survey saw their GP three or more times before told they needed to go to hospital  44% epilepsy respondents to our national neurology patient experience survey saw their GP three or more times before being referred to see a neurologist  Waiting list times being high also contributes to a situation where people are not seen as fast as	Please see our <a href="#">national neurology patient experience survey</a> which collects data relating to referral times as reported by patients.

	<p>a suspected first seizure should be seen as soon as possible by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs.</p> <p>The NICE guideline on suspected cancer: recognition and referral, recommends urgent direct access to MRI scan of the brain to assess for brain or central nervous system cancer in adults with progressive, sub-acute loss of central neurological function.</p>	<p>would be desired, making the onus on quick referral by a GP all the higher.</p> <p>Our national neurology patient experience survey found that of respondents with epilepsy, 22% waited 3-6 months to see a specialist after first being referred, 10% waited 7-12 months, and 20% waited more than 12 months. Of respondents with brain tumour, 30% waited 3-6 months to see a specialist after first being referred, 16% waited 7-12 months, and 24% waited more than 12 months.</p>	
Key area for quality improvement 2	Inappropriate referrals to secondary care drive up waiting times, and can	There is significant room for improvement in GP referrals to neurologists.	Please see our national neurology patient experience survey which collects data relating to how long respondents wait to see a

<p><b>Fewer inappropriate referrals to secondary care</b></p>	<p>result in those who do need to be seen having to wait longer to see a neurologist.</p> <p>For patients, inappropriate referrals can result in disappointment.</p> <p>Better management of patients in the community e.g. the provision of community migraine education clinics, can help meet the needs of some people with neurological conditions in a primary care setting, thereby reducing the number who subsequently feel they still need to see a neurologist.</p>	<p>Neurologists too often receive referrals with little or no information. Moreover, neurologists often have people referred to them who they deem inappropriate as they are not best placed to help them.</p> <p>Advice and guidance can help improve referrals, and drive down inappropriate referrals. For example, The Walton Centre's consultant advice line – for GPs to speak directly to neurologists to ask their advice – has resulted in a reduction in neurology outpatient appointments, as well as improved management of conditions; the top three reasons for calls were for headache (24%),</p>	<p>neurologist, and those who did not need to see a neurologist, and can be broken down by primary condition. It can also be broken down to show regional variation.</p>
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		sensory/ motor problems 20% and seizures (19%)	
<p>Key area for quality improvement 3</p> <p><b>Better signposting to information and support for people with neurological symptoms at the pre-diagnosis/early diagnosis stage</b></p>	<p>The Guideline states at 1.16.1 'Follow the principles in the NICE guideline on <a href="#">patient experience in adult NHS services</a> relating to communication, information and shared decision making.'</p> <p>This guideline is clear that clinicians should, where appropriate, discuss with patients their need for support, and that they should "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)</p>	<p>Our national neuro patient experience survey showed that after receiving a neurological diagnosis, there appears to be an issue with patients being told where they should look for further information about their condition by the professional who gave them their diagnosis, with over half of respondents (56%) not being told anything about finding further information.</p>	<p>Please see our national neurology patient experience survey which collects data relating to</p> <ul style="list-style-type: none"> <li>• Whether people get written info at time of diagnosis</li> <li>• Whether people understand their diagnosis</li> <li>• Whether people feel fully involved in making choices about their health care (which can be segmented by when the respondent was first told they had a neurological condition to show those recently diagnosed/not yet diagnosed)</li> </ul>

	<p>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.</p>		
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<p>Key area for quality improvement 4</p> <p><b>Patients with suspected neurological conditions are screened for mental health needs and referred/signposted on as appropriate</b></p>	<p>The Guideline states at 1.16.1 ‘Follow the principles in the NICE guideline on <a href="#">patient experience in adult NHS services</a> relating to communication, information and shared decision making.’</p> <p>That 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”</p> <p>There is a complex relationship between mental health and neurological conditions such that some people with a neurological condition will experience</p>	<p>There is increasing recognition on a national level that the mental health needs of people with long term conditions are underserved. We found there is a significant level of unmet need through our <a href="#">Parity of Esteem report</a> (which is quoted within the guidance associated within the Guideline), which was compounded by our recent national neuro patient experience survey which showed that overall well over half of respondents had not been asked about their mental health or emotional wellbeing, and that almost a third of respondents were not referred for support with their mental health and wellbeing but would have liked to have been. For</p>	<p>Please see our national neurology patient experience survey which collects data relating to whether people feel their mental health needs are being met. This can be segmented by time of diagnosis, to show those recently diagnosed, and those not yet diagnosed.</p>
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	<p>corresponding mental health problems.</p> <p>Often the point at which a person starts experiencing symptoms 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 screening would help pick up where additional mental health support is needed, and improve a person's overall experience.</p>	<p>respondents not yet diagnosed, 66% had not been asked about their mental health and wellbeing by a health or social care professional, and 26% had not been referred or signposted to support for their mental wellbeing by a health professional, but would have liked this.</p>	
<p>Key area for quality improvement 5</p> <p><b>Establish best practice local pathways, including referral</b></p>	<p>The Guideline provides plenty of guidance on when patients should be referred on. In order for smooth referrals, local pathways into</p>	<p>As outlined above, too many people with neurological conditions have to wait too long to be seen by a neurologist. Moreover, too few people</p>	

<p><b>pathways into mental health services</b></p>	<p>appropriate services should be established. There is a need for commissioners to review system capacity for accepting new referrals into local neurology services, and where appropriate, identify 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.</p> <p>There is a proliferation of guidance on best practice regarding neurology care pathways emerging, including the</p>	<p>are having their mental wellbeing needs met. As the NHS RightCare Progressive Neurological Toolkit outlines, there are a number of national challenges relating to delays in primary and secondary care leading to delayed diagnosis and treatment, and fragmented or uncoordinated multidisciplinary working, as well as a significant opportunity for improvement.</p>	
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	<p>RightCare’s <a href="#">Progressive Neurological Conditions Toolkit</a> (as well as epilepsy toolkit - about to be published, and forthcoming headache and migraine toolkit), as well as the work being undertaken in relation to NHSE’s spec comm neurosciences transformation project and accompany work by the National Neuro Advisory Group to establish best practice pathways across a number of conditions. As such there is a strong opportunity for improvements to be made.</p>		
<p>Additional developmental areas of emergent practice</p>	<p>In submitting these proposals, we are aware that the Guideline, (which will be the primary source of information for developing the Quality Standard), does not have consensus across the neurological community. Concerns of the community range from the Guideline being too complex for a primary</p>		

	<p>care audience, majoring in on some conditions and excluding others (with little evidence to back up why), and a lack of reference to signposting to other sources of support including mental health.</p> <p>We are concerned that maintaining broadly the same committee to develop the Quality Standard will not help resolve the lack of consensus in the neurological community. We would urge NICE to consider broadening the membership of the committee to attempt to build greater consensus on what constitutes quality in relation to this area of care.</p>
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### Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- Please provide concise supporting information for each key area. Provide reference to examples from the published or grey literature such as national, regional or local reports of variation in care, audits, surveys, confidential enquiries, uptake reports and evaluations such as impact of NICE guidance recommendations
- For copyright reasons, do not include attachments of **published** material such as research articles, letters or leaflets. However, if you give us the full citation, we will obtain our own copy
- Attachments of unpublished reports, local reports / documents are permissible. If you wish to provide academic in confidence material i.e. written but not yet published, or commercial in confidence i.e. internal documentation, highlight this using the highlighter function in Word.

Please return to [QStopicengagement@nice.org.uk](mailto:QStopicengagement@nice.org.uk)

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