

Suspected neurological conditions

Consultation on draft guideline – deadline for comments **5.00pm** on 19 September 2017 email: NeurologicalProblems@nice.org.uk

	<p>Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.</p> <p>We would like to hear your views on the draft recommendations presented in the short version and any comments you may have on the evidence presented in the full version. We would also welcome views on the Equality Impact Assessment.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none">1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.2. Would implementation of any of the draft recommendations have significant cost implications?3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)4. [Insert any specific questions about the recommendations from the Developer, or delete if not needed] <p>See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.</p>
Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	The Neurological Alliance

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Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.		None		
Name of commentator person completing form:		Sarah Vibert, Chief Executive		
Type		[office use only]		
Comment number	Document (full version, short version or the appendices)	Page number Or 'general' for comments on the whole document	Line number Or 'general' for comments on the whole document	Comments Insert each comment in a new row. Do not paste other tables into this table, because your comments could get lost – type directly into this table.
Example 1	Full	16	45	We are concerned that this recommendation may imply that
Example 2	Full	16	45	Question 1: This recommendation will be a challenging change in practice because
Example 3	Full	16	45	Question 3: Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact.....
1	Full version	26	1-43	We welcome the development of a Guideline on suspected neurological conditions in primary care. As noted in your introduction, our patient experience research demonstrates the time taken from first GP visit to diagnosis can be highly variable across conditions and across different geographies. While some variation is expected; delays in referral often impacts adversely on patient outcome. For example, Motor Neurone Disease (MND) is a rapidly

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2	Full version	27	10-15	<p>The range and complexity of neurological symptoms and conditions make it challenging for GPs and other primary care professionals to recognise and refer patients with suspected neurological conditions. We feel that even with this additional guidance, non-specialists working in primary care may still, in some cases, require additional support and a second opinion.</p> <p>The new models of care set out in NHS England's GP Forward View – primary care networks or hubs – will mean access to greater expertise across a 'hub' area, which may include GPs with a special interest in neurological conditions and specialist nurses. Primary care networks or hubs could also facilitate the development of areas of expertise amongst primary care professionals. These new models of care will increase the pool of knowledge across GP surgery hubs, as the number of neurological cases seen across a hub area will be greater than for an individual GP surgery. The Guidance does not currently make any reference to hubs or network models of care and how this could facilitate implementation of this new Guidance.</p> <p>Furthermore, 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 Walton Centre Vanguard, or the work by the neurology strategic clinical network. Such schemes might be included in the shared learning database to support implementation. We would also urge the Guidance development group to speak to these pilot projects about findings from their work to understand more about the sorts of questions GPs are asking in relation to neurological conditions, to inform the development of this Guidance.</p> <p>Would it possible to consider adding another category to the 'refer urgently', 'refer immediately', 'refer' criteria which stipulates seeking a second opinion? – a phone call to a neurologist is far more efficient than a wasted neurology outpatient appointment – and more likely to lead to the better pathway for the patient.</p>
3	Full version	31	30-33	<p>The draft Guidance notes that the wide range of neurological conditions has meant the scope concentrated on 'more common presentations of neurological symptoms'. We believe that several common presentations of neurological symptoms are missing from this guidance – or not given the emphasis required to effectively detect conditions - which may lead to (even relatively common) neurological conditions being missed or misdiagnosed. Similarly, if one of the intentions of this guideline is to increase referrals of rarer conditions, rarer symptoms must be included to ensure timely diagnosis.</p>

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				<p>We suggest the following signs and symptoms of neurological conditions are added to the Guidance and would be happy to supply further evidence and information in these areas. While some of these symptoms are mentioned in passing in the Guidance, they are not always experienced in tandem with the symptoms listed in the draft Guidance which may lead to them being missed. We believe each of these areas should be covered as separate recommendations given they are common symptoms of several neurological conditions.</p> <ul style="list-style-type: none"> • Disturbance of bladder and bowel function, sexual dysfunction <p>These are also symptoms that patients may be embarrassed or reluctant to mention to their GP. This makes it even more paramount that primary care professionals are aware of their link to neurological conditions so they can ask appropriate questions during consultations. The Guidance should encourage GP's to ask about such symptoms.</p> <ul style="list-style-type: none"> • Headache <p>A glaring gap in the draft Guidance is the absence of headache as a symptom included in the recommendations for adults over 16. Headache (and migraine) is only referred to in relation to other symptoms meaning an opportunity to detect and appropriately refer (or not refer) patients presenting with headache may be missed. Headache affects around one in seven adults. Headache is a special case given it is an area in which the neurology pathway could become more efficient with appropriate detection and referral. Around one third of adult neurology appointments are for headache; many of these cases can and should be managed in primary care. We urge NICE to include headache as a separate recommendation for adults over 16, with reference to the existing NICE Guideline on headache in over 12s.</p> <ul style="list-style-type: none"> • Facial pain <p>Facial pain (which is a symptom of neurological conditions such as trigeminal neuralgia) often presents to the dental profession who are not skilled in this area and so result in irreversible treatments and delay in diagnosis and management.</p> <p>Other symptoms not adequately covered are respiratory symptoms and autonomic failure.</p>
4	Full	72-73	4	<p>We are concerned that in many places the Guideline refers to one or two conditions in relation to specific symptoms – often without obvious logic as to why some very rare conditions are included but not other more common conditions. This may delay appropriate referral of a patient.</p> <p>For example, in relation to recommendations 26, 27 and 33 – all three signs and symptoms could be indicative of a rarer condition such as Transverse Myelitis.</p> <p>Other examples are outlined below.</p>
5	Full	67	1-30	<p>Section 5.4, 'Gait unsteadiness', refers to a number of specific neurological conditions for investigation in relation to unsteadiness of gait. The NICE MND Guideline (NG42) notes that "MND causes progressive muscular weakness that can present as isolated and unexplained symptoms", including "loss of dexterity, falls or trips" (p.5), yet MND is not</p>

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				covered here.
	Short version	31	12-15	<p>This recommendation refers only to cauda equine syndrome. These symptoms could reflect other conditions, for example Multiple System Atrophy.</p> <p>Overall, we recommend NICE reviews the parts of the Guidance that refer only to one or two specific conditions and where there is evidence that symptoms may be indicative of other conditions, adding these conditions to the list. Alternatively, there should be a note in the Guidance explaining that other rarer neurological conditions should also be considered in relation to recommendations which stipulate one or two conditions. This is important not only so that patients are not stuck on the incorrect pathway, but also to ensure patients have as much information as possible about their potential diagnosis when leaving the GP surgery. Patients can and do research possible diagnoses online and should be given the broadest possible amount of information at this stage.</p> <p>A more general, but related point, is that in many places the Guidance is written around a handful of more common conditions and it is hard to see how rarer conditions would fit in. In other places, the Guidance refers to very rare conditions. It is hard to follow the logic of why some conditions are included but not others.</p>
6	Full version	104	16	<p>Getting timely information and support is very important to people affected by neurological conditions yet our recent patient experience survey found 45% of patients were dissatisfied with information they had received about their condition, 63% were dissatisfied with information they had received about sources of emotional support, and 53% dissatisfied with information they had received about third sector support available. (See <i>Falling Short, Neurological Alliance, 2017</i>)</p> <p>The only advice the Guideline recommends is to check the DVLA notification guidelines and to consider telling their employer, school or college. We are concerned with both of these pieces of advice being given in isolation to additional information and support.</p> <ul style="list-style-type: none"> • Telling an employer, school or college about a suspected neurological condition can have huge implications for individual patients and it may not always be appropriate to do so before a diagnosis has been confirmed. Indeed, until diagnosis is confirmed, patients/employees do not have legal protection under the Equality Act 2010. Patients will often benefit from additional support in informing an employer or education institution, and patient organisations – such as Neurological Alliance member charities – provide a wealth of support and information in areas such as this. Patients must be made aware of this broader support in parallel to being advised to consider telling an employer or education institution about a suspected neurological condition. • Similarly, while safety concerns are paramount in relation to DVLA notification, surrendering a driving license can have a huge impact on an individual's life, for which they may benefit from additional support – and indeed signposting to financial support that may be available to help with alternative transport. Again, third sector organisations are ideally placed to provide such support. See for example Epilepsy Action's advice and information about driving and epilepsy. <p>We welcome the inclusion here of the principles in the NICE Guideline on Patient Experience in Adult NHS Services. Yet, without specific reference to the importance of information and an individualised approach to services in the</p>

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				neurological conditions guideline, we feel GPs may miss the opportunity to sign post patients to information, helplines and support groups available. The committee notes that it was concerned about unduly worrying patients before diagnosis was confirmed. 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 standard.
7	Full version	General	General	<p>The draft Guidance is attempting to make the demand side of neurology outpatient appointments more effective and efficient. One of the major problems in this approach is that without any action to also address the supply side of neurology services, it is likely to fail. It is well documented that there is huge geographical variation in neurology services:</p> <ul style="list-style-type: none"> • Not all GPs can refer directly for MRI scans meaning an outpatient neurology appointment is required to get referral for imaging. • There is a national shortage of neurologists, with some areas carrying long standing vacancies. • In other specialisms such as neuropsychiatry and neuropsychology, access is even more patchy across the country. • Brexit is likely to make recruitment issues worse in areas such as neuroradiology and other related specialisms. • The complexity of many neurological conditions requires care by a multi disciplinary team and our research shows health care professionals do not consistently work collaboratively in providing care for neurological patients. See our 2017 report <i>Falling Short</i>. • There are frequent references in the Guidance to ‘functional symptoms’. Services for people with functional neurological disorder are very patchy. <p>It is paramount that work is undertaken by Health Education England, NHS England, the Association of British Neurologists and others to address the supply side in relation to access to neurology services across the country. We would welcome conversations with other agencies about how the Neurological Alliance could support initiatives to address these issues.</p>
8	Full version	General	General	An overall comment is that for several conditions (headache and migraine, as well as rarer conditions such as Transverse Myelitis), there is a greater urgency in the children’s guideline than in the adult’s guidance. The children’s Guideline is also clearer in places. We feel overall that this Guidance may be more effective as two sets of Guidance – one for children and one for adults – ensuring each piece of Guidance is comprehensive.
9	Full version	General	General	We do not feel this guidance is appropriately pitched for generalist health professionals working in primary care. An

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				<p>example of this include the way in which functional symptoms are referred to within the guidance. Indeed, leading neurologists often struggle to correctly identify functional symptoms as distinct from an organic neurological condition. Another example is that the Guidance recommends ‘urgent referral for adults whose blackout is accompanied by features that are strongly suggestive of epilepsy seizures’, but does not indicate what these features might be. We do not believe non-neurological specialists working in primary care – not just GPs but also health visitors, pharmacists, dentists, optometrists and others - will be able to effectively use this Guidance to identify and appropriately refer patients with suspected neurological conditions without significant amendments. Furthermore, the Guidance is not suitable for use by patients and carers.</p>
10	Full version	General	General	<p>Given the complexity of this area of health care, and length of even the short version of the Guidance, we are concerned that it will not be widely taken up by primary care professionals; especially given there are few contractual incentives in primary care relating to neurology. This Guidance is being launched in a vacuum;</p> <ul style="list-style-type: none"> • Neurology is not a priority for many Clinical Commissioning Groups and Sustainability and Transformation Partnerships. Our 2016 CCG audit found that only 21% of CCGs have made an assessment of the number of people using neurological services in their area. • Survey data produced for our 2016 report <i>Neurology and Primary Care</i> found that 84% of GPs feel that they could benefit from further training on identifying and managing people presenting with neurological conditions. <p>Consequently, while we believe that the development this guideline is an important and welcome initiative, there needs to be additional work alongside the launch of the Guideline to ensure it is effective. Professional education, an awareness campaign, ongoing audit as part of accountability frameworks, and a simple algorithm are all tools that would support the intentions behind this Guideline to be realised. We would welcome a further conversation with NICE (the Royal College of General Practitioners, Primary Care Neurology Society, and others) about how the Neurological Alliance can support this Guidance to be used. We would also like to understand more about the role of the NICE implementation team in relation to ensuring this Guidance is used.</p>
11	Full version	General	General	<p>We would be interested to explore the extent to which other (non-neurological) NICE Guidance refers to potential neurological conditions (and in time should cross refer to this new guidance). Neurological patients often find themselves ‘stuck’ in the wrong part of the health service, for example in ear nose and throat clinics or continence services – without appropriate referral to neurology. This new guidance is an opportunity to review the representation of neurology in other guidance beyond neurology, where symptoms may be indicative of neurological condition.</p>
12	Full version	General	General	<p>We note that mental health is mentioned only twice in the whole Guideline – in relation to tic disorder. Our recent report <i>Parity of Esteem for people affected by Neurological Conditions</i> (2017) found that around 50% of neurological patients (and as high as 86% of patients with Tourette’s Syndrome and 80% of patients with multiple system atrophy) have co-morbid mental health conditions. This is higher than for the general long-term condition patient population, where 30% of patients have a mental health condition. This is due to the complex interplay between a neurological conditions and mental health condition (see our report for further detail). These patients would benefit from a</p>

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				<p>multidisciplinary approach including liaison psychiatry and clinical psychology. The omission of any mention or consideration of co-morbid mental health conditions in this Guidance is a missed opportunity for early detection of mental health conditions in neurological patients.</p>
13	Appendices	General	General	<p>We note that many appendices are empty and assume this is due to inadequate evidence. This is indicative of a broader issue in neurosciences in that investment in research is inadequate meaning evidence of 'what works' is sparse, particularly for rarer conditions, and particularly in primary care settings. In some cases, this is also due to lack of service infrastructure to support research. One example of this is the lack of research into adults with Duchenne Muscular Dystrophy. This is clearly an issue for NIHR and other bodies than NICE. However, NICE's focus on what is deemed 'high quality evidence' hampers development of neurological guidance. For many rarer conditions double blind randomised controlled trials are not only unethical, but also impracticable, given the small pool of patients that are potential participants for such research. We would urge NICE to more widely adopt a consensus based approach to what is deemed adequate evidence.</p>

Insert extra rows as needed

Checklist for submitting comments

- Use this comment form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include page and line number (not section number) of the text each comment is about.
- 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
- For copyright reasons, comment forms do not include attachments such as research articles, letters or leaflets (for copyright reasons).

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

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