Template for stakeholder workshop subgroup discussions: Neurological problems guideline Thursday 12th November 2015, 15:00 – 17:00	
Area of scope	**Stakeholder views**
Title: Current title of the guideline: • Neurological Problems: Assessment, diagnosis and referral of neurological problems	Stakeholders strongly agreed that the guideline needs to be symptoms-focused because it will focus on the front end of the pathway, and patients present with symptoms rather than common/uncommon diagnoses. GPs would not know whether what they were presented with was a sign of an uncommon condition or not. Moreover many uncommon conditions have common symptoms. 'Neurological symptoms' was proposed by several stakeholders as an alternative title. Multiple stakeholders also recommended avoiding the term 'uncommon' in general, as it is uncertain how this is being defined. One group also felt it may imply less important. Another group questioned whether certain audiences may be lost with the use of 'uncommon', while a different highlighted the lack of a sister guideline for 'common' neurological conditions and wondered whether this would confuse the audience. Most groups agreed there is a need for a guideline to help with referral of neurological conditions, however 2 groups suggested that an umbrella approach might be more appropriate than naming condition groups. One stakeholder commented that improving the education and training of GPs and medical students is the real issue, and queried whether this is in fact a topic that NICE should be addressing with a guideline. One group also commented that delayed diagnosis is not just an issue for uncommon neurological conditions, but for common ones too.

1.1 Population
Groups that will be covered:
• Children, young people and adults
 	
Groups that will not be covered:
• People with a confirmed diagnosis of:
  ○ Brain cancers
  ○ Cerebral palsy
  ○ Delirium
  ○ Dementia
  ○ Epilepsy
  ○ Faecal incontinence
  ○ Headaches
  ○ Metastatic spinal cord compression
  ○ Motor neurone disease
  ○ Multiple sclerosis
  ○ Neuropathic pain
  ○ Parkinson's disease
  ○ Spasticity
  ○ Spinal conditions
  ○ Stroke
  ○ Transient loss of consciousness
  ○ Urinary incontinence
	Stakeholders strongly agreed that there is a need for the guideline to cover adults and children, and there was agreement that the evidence/recommendations would most likely need to be separate and specific to each group. One stakeholder (adult neurologist) highlighted that children and adults are completely different populations and there would be very limited overlap (potentially with epilepsy as one condition in which there would be overlap in symptoms).
	
	Several stakeholders commented that the list of groups that will not be covered includes symptoms (eg. Headaches, spasticity) as well as neurological conditions. There were also questions from stakeholders in another group as to whether faecal incontinence is a neurological condition, and which conditions are covered under the 'spinal conditions' category, as this does not include all spinal conditions such as Transverse myelitis. This group agreed that none of these diagnoses can be ruled out at the point of presentation until initial investigations are done. It was suggested that the NICE catalogue of guidance needs to be reviewed to identify exactly which conditions are and are not covered under the categories listed. Another group queried whether all the guidance for so-called 'common' neurological conditions deals with referral and diagnosis, or just management.
	
	One group felt that children under 5 should be a separate subgroup as they do not present symptoms in the same way and it is easy for GPs to miss symptoms due to developmental factors such as muscle tone, as well as cognitive and communication issues.
	
	One group highlighted that guidance on 'common' neurological conditions often did not cover certain subgroups of that condition, and provided a list as follows. The group felt that these should be covered within this

	guideline: • Traumatic brain injuries (long term survivors of TBI important) • Alcohol-related brain injury (this population being seen more and more) • Child survivors of brain cancer and brain injury who present with neurological problems (this population is increasing due to an increase in long-term survival after new treatments for brain cancer; guideline should cover neuropsychiatric outcomes in children who survive) • Spinal stroke (not covered in stroke guideline) • Chiari malformations • Ataxia and fibromyalgia (but question about whether this is rheumatology)) • Post-polio syndrome (due to migration this has increased and needs recognition) In terms of potential equality issues, two groups highlighted the variability in access to services, with one stakeholder pointing out that specialist nurses are available for 'common' conditions but not for 'uncommon' conditions. One stakeholder mentioned that neurological conditions presenting with sexual dysfunction may pose an equality issue due to men potentially finding it more difficult to talk about this with clinicians.
1.2 Settings **Settings that will be covered** • Primary and secondary care **Settings that will not be covered** • Tertiary care	All groups agreed that the settings were appropriate. One group felt that emergency departments should be included as a setting.

1.3 Key issues that will be covered: **<u>Early assessment and referral</u>** **Identifying 'red flags' or circumstances within which referral is appropriate** • Which signs and symptoms are indicative of people with [each type of neurological condition] when they present to a non-specialist? Disease groups that will be covered for adults: • Movement disorders (tremors, dystonia, gait apraxia) • Muscular disorders/dystrophies and myopathies • Functional disorders including non-epileptic dissociative seizures • Neuropathies including entrapment neuropathies and Guillain-Barre syndrome • Radiculopathies Disease groups that will be covered for children: • Brain tumours • Guillain-Barre syndrome • Movement disorders including dystonia • Neuromuscular conditions including myopathies, myasthenia and muscular dystrophies • Neurodegenerative conditions **Identifying simple assessment tools and tests that could be used by non-specialists to aid decision-making about investigation and referral** • What assessment tools, such as algorithms, can be used by a non-	Stakeholders agreed that identifying red flag symptoms is appropriate and an algorithmic approach would be useful for non-specialists. One group mentioned that a traffic light system might be a good approach, and commented that it is important to identify which symptoms GPs do not need to refer but would need 'safety netting'. Another group stressed that because individual symptoms can have many causes, perhaps it is better to think in terms of symptom groups or clusters. This was echoed by another group who discussed the possibility of organising the symptoms by system (ie. sensory system, muscular system). One group did not feel it was particularly useful or necessary to name particular neurological conditions in the scope if the guideline is taking an umbrella approach and considering symptoms that strongly suggest a neurological condition (and should therefore be referred) as opposed to those that require further consideration or investigation. On the other hand, one stakeholder commented that the guideline should be condition specific, and should focus on Duchenne muscular dystrophy, with the rationale that if there is quality guidance for Duchenne, the majority of neurological conditions will benefit as a result. Two groups felt that spasticity should be considered a red flag, while one group also wanted cognitive and communication issues considered a red flag. Several stakeholders commented that it would be fairly easy to identify a list of key symptoms for neurological conditions and attempted to provide one. The combined list includes weakness/tingling/numbness, falls/clumsiness, loss of consciousness, tremor, visual impairments or other sensory symptoms, dizziness, headaches, abnormal movements, balance difficulties, memory and cognitive difficulties, amnesia, sleep disorders. One stakeholder highlighted that it is important to consider

specialist to aid decision-making when assessing patients with suspected [each type of neurological problem]? • What investigative tests should be undertaken by a non-specialist when assessing patients with suspected [each type of neurological problem]? • What assessment tools, such as algorithms, can be used by a non-specialist to aid in the identification of patients with a suspected neurological condition?	where in the body the symptom (eg. Tingling) is occurring as this may indicate higher priority. Regarding the lists of disease groups, one group felt that Guillain-Barre syndrome should be referred to as acute and chronic inflammatory peripheral neuropathy as there are similar conditions. They also felt that with conditions like Guillain-Barre, the mild symptoms that escalate quickly are of particular concern. One stakeholder noted that some neurodegenerative conditions have been picked up and others not. Additional conditions that were suggested for inclusion by stakeholders include primary ataxia, atrophy, sleep apnoea, and sleeping difficulties. One group queried whether it would be better to name specific conditions rather than groups such as 'movement disorders'. One stakeholder (adult neurologist) noted that entrapment neuropathies and radiculopathies are very common, as are tic disorders. Another stakeholder noted that if included, the question should not be 'should tic disorders be referred?', but 'which tic disorder patients should be referred?' Two groups discussed functional disorders and questioned whether this is something that should be looked at in a separate guideline as it is necessary to rule everything else out first. Functional disorders cannot be diagnosed by a GP so it was discussed as to whether it is appropriate to include within this guideline. However another stakeholder pointed out that the presentation of functional disorders is the same as for organic ones, so they should not be excluded. In terms of assessment tools and tests that could be undertaken by a non-specialist, there was general agreement across groups that neurological examination is key, but this process might need to be refined and sped up for non-specialists. Identifying family history was also identified as

	important. Other tools suggested include patient diaries, but one group felt there would be a general lack of validated tools identified in the evidence. Suggested tests included temperature, weight, strength/grip/gait, skin sensitivity, brief cognitive tests/cognitive screening and certain blood tests. MRI was raised in several groups, with varying views on how useful this is. One stakeholder pointed out that GPs could access MRIs more quickly than secondary care, but another stakeholder noted that sometimes the MRI needed by a neurologist is more complex than a GP would request, in which case there is a risk of duplication and delay. It was felt by one stakeholder that a GP should be able to request an MRI after a conversation with a neurologist. One group felt that overall there is not much that a non-specialist can use in the way of assessment tools and tests before referring. There was a general view across groups that there would not be much evidence in this area, certainly a lack of epidemiological studies, but possibly some retrospective studies linking diagnoses back to symptoms. Two groups suggested the recommendation would likely need to be based on consensus, with one group considering that a formal consensus method such as a Delphi survey may be a good approach.

<u>Principles of shared care and early management</u> **Identifying broad principles for successful sharing and continuity of management and care between settings** • What are the barriers and facilitators to ensuring continuity of care during referral and early management for patients with neurological conditions?	There was general agreement that shared care and early management is a relevant topic. However it was felt by several groups to be of a lower priority, and the definition of 'early management' was also queried by others. One group suggested there is geographic variation in terms of access to effective shared care. Two groups felt that having a diagnosis is key to being able to provide quality shared care and management. However there are some general principles that should apply pre-diagnosis – for example continued evaluation of symptoms and continued access to a GP post-referral. This group felt that if this question is covered, shared care and early management should be two separate questions. Another group felt that good practice in shared care means having an assigned person to ensure that effective communication takes place. This could be a lead nurse practitioner/liaison/coordinator (needs to be a clinician). One stakeholder commented on the provision of specialist nurses for common neurological conditions, and how this makes a huge difference to continuity of care. Another stakeholder felt that the issue of transition between children and adult services was important and could be added to the proposed review question. It was also felt that the referral management process could benefit from standardisation. Some particular issues that were raised by stakeholders include the lack of follow up and communication between GPs and neurologist (for example after a scan has taken place). Appropriate referrals when patients re-present with repeated or new symptoms. How a patient gets back into the pathway if they have refused a diagnosis or treatment. One group agreed that shortening the waiting time for patients is key, but

	felt this would be outside the remit of this guideline as it is more applicable to service delivery guidance.
<u>Patient experience</u> **Information and support for patients, families and carers** • What are the information needs of patients suspected of having neurological conditions and their carers/families?	When information should be provided was raised as a key issue by one group, highlighting the impact on patients of providing too much information too early. It was noted that GPs are often reluctant to mention conditions/words associated with a diagnosis because people will worry, and in line with this some stakeholders felt that information should be provided at the time of diagnosis. Pre-diagnosis, information should focus on what the tests are for, what is involved, appointment duration and how long the results will take. Most groups discussed the importance of signposting patients in the early stages, whether to charities, other services or helplines. Emotional support/counselling was raised, but there were varied opinions on when this would be needed, with one group commenting that it would be more likely to be needed post-diagnosis, so could be outside the remit of this guideline. Family referral was highlighted by one group as a model of good practice. It was felt that advice about issues such as house adaptation for example, is better provided by third sector organisations rather than the NHS. Access to clinical information was discussed by one group, with one stakeholder commenting that sometimes, up to years later, patients will want to understand what happened to them during periods of acute illness, and can request access to their brain scans for example. It was noted that a hospital case worker could be responsible for arranging this. One group highlighted communication as an issue, firstly between doctors and patients regarding communicating the diagnosis, and secondly

	between GPs and secondary care, in terms of whose responsibility it is to communicate the diagnosis to the patient.
1.4 Key clinical issues that will not be covered: • Specialist tests and specialist care provided in tertiary centres • Infectious and transmissable neurological conditions (for example meningococcal disease, prion disease) • Cauda equina syndrome • Tic disorders in children	There was general agreement with excluding specialist tests and care provided in tertiary centres. Tic disorders in children was queried by several stakeholders, as although they are relatively common, a key issue is knowing which manifestations of tic disorders should be referred. One stakeholder queried the exclusion of infectious and transmissible neurological conditions if this guideline is taking a broad approach – patients present with symptoms so it would not be known in the early stages whether the symptom represents one of these conditions or not.
2. Guideline Committee composition • 1 Chair (adult neurologist) • 1 adult neurologist from district general hospital • 1 Paediatric Neurologist (already recruited as early GC member) • 2 GPs • 1 general/community paediatrician • 1 health visitor • 1 emergency department representative • 3 lay members (1 adult, 1 young person, 1 parent/carer) • Co-opted members (expert advisors) to be agreed	Two groups suggested that it would be important to ensure there is emergency department representation on the guideline committee as in some cases A&E may be the first point of contact for someone with a neurological condition. Psychology and psychiatry was discussed by several groups. A neuropsychologist was suggested by two groups, but there was disagreement as to whether it would be possible to get someone who sees both children and adults, or whether 2 positions would be needed. Several groups wanted to add a physiotherapist, while one group discussed why a physiotherapist would be preferred over a speech/language therapist or occupational therapist. The group agreed that a physiotherapist would be more likely to be involved in the early stages or receive inappropriate referrals.

	Nurse input was regarded as important by several groups, with clinical nurse specialists and community matrons both highlighted as options. It was felt by two groups that a health visitor may be useful in terms of paediatrics, but ultimately it would be less important to have their input as they would generally see patients pre-GP, and be likely to refer on. Junior doctor input was regarded as important by several groups. One stakeholder also highlighted the increased role that pharmacists are playing in the medicines management of various conditions. The following roles were suggested as potential co-opted roles: endocrinologist, renal specialist, cardiologist, geneticist, neuromuscular specialist. In terms of lay members, one group thought it might be necessary to recruit more than 3 lay members given the breadth of the guideline. Another group suggested that involving a stakeholder organisation (alongside the 3 lay members) to represent the views of patients may mean a wider range of views is included. Particular organisations that were mentioned include the Neurological Alliance and Rare Diseases Forum.
Further questions (only covered if time)	

Are there any critical clinical issues that have been missed from the Scope that will make a difference to patient care?	One group highlighted the following issues for consideration: • There is a need for the guideline to have a community focus, to improve patient care in this area. • Anosanosognosia (lack of awareness of your own disability) – it is important for primary care clinicians to be aware of this in people presenting with for example a loss of muscle strength, but not being able to attribute it to a neurological or rare genetic disorder. • Cognitive and emotional issues during or after diagnosis, or as a consequence/comorbidity of neurological disorders is significant. For example, in children, there could be subtle changes not commonly recognised as being attributable to the condition, for example loss of self-care, loss of friends, loss of social network. This is a significant problem for primary care clinicians and non-specialists to be aware of.
Which area of the scope is likely to have the most marked or biggest health implications for patients?	The whole guideline was agreed to have the potential to have a lasting effect on patients in this clinical area.
Which practices will have the most marked/biggest cost implications for the NHS?	One group raised the following issues for consideration: • Quality of life: Maintaining employment is one of the biggest implications for people with neurological conditions. Societal implications of this include the burden of receiving benefits versus paying tax. An early diagnosis could determine whether a person sustains employment or not, and can affect their quality of life. • Early diagnosis is also a significant issue. For the Motor Neurone Disease guideline, multidisciplinary teams are required for early diagnosis. There are increased costs but it is still cost-effective due to increased quality of life. • QALYs do not capture the true burden of long term conditions.

1. Are there any service delivery or service configuration issues that you think are important?	One group commented that referral pathways and structures of shared care are important. For example, can services be aligned by systems of care?
2. Other issues raised during subgroup discussion for noting:	One group raised the following issues for consideration: • National Service Framework on long term conditions (2005) – it was agreed that this was an important document and would be useful to look at in the development of this guideline. • Type of evidence – members highlighted the importance of including the correct type of evidence, for example prevalence studies, survival analysis, the lifespan approach, qualitative studies, case reports, Delphi surveys, and studies with single subject randomisation. Due to the breadth of this guideline coupled with the lack of high-powered studies, the group felt that NICE should be flexible with the type of evidence that is considered for this guideline.