Suspected neurological conditions (formerly neurological problems)

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Association of British Neurologists	general	general	We strongly support the development of guidelines to improve access to neurological diagnosis. There is a wealth of evidence that neurological diagnosis is delayed due to a failure to recognise the significance of neurological symptoms. Although many of the same issues are common to adults and children there are important differences in presentation and context that argue that adult and paediatric pathways to referral from primary care should be dealt with separately.	Thank you for your comment. This guideline will cover children, young people and adults. There will be many issues that are the same to all age groups. Where there are differences, the guideline committee will identify issues that are specific to each age group and will consider the best way to present the recommendations.
Association of British Neurologists	3		Although there may be tools and near patient tests which aid primary care physicians in deciding on whether a neurological referral is appropriate, the MAJOR FACTOR in deciding this is an accurate HISTORY and symptom enquiry. Therefore the guidance should place major emphasis on this and on developing ways in which key 'red flag' symptoms are identified in general practice. This is essentially an educational matter and begins in medical school. Page 4, section 2.1 is important in this regard.	Thank you for your comment. The guideline committee will take this into consideration when finalising the review questions and reviewing the evidence.
Association of British Neurologists	3 (point4)		We are concerned that basing the approach to neurological referrals by starting with disease groups is too narrow a focus and risks excluding important or unusual symptoms. A better approach, or one that should at the minimum be employed in parallel, is to search using a list of symptoms which are indicative of neurological disease. These include: Headache Weakness Difficulty with speech and swallowing Altered vision such as double vision Altered sensation (pain, numbness) Difficulty walking, such as unsteadiness	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. The list of conditions will help guide the literature search. Specific symptoms are not highlighted in the scope, but will be determined through the literature search and in collaboration with the guideline committee. We have noted the symptoms you have identified and the guideline committee will take these into account when developing the list of symptoms to be covered.

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			Dizziness Alteration in cognition (memory, orientation, behaviour) Episodic alterations in awareness (such as epilepsy) Tremor and involuntary movement etc	
Association of British Neurologists	7		Although some neurological referrals are unnecessary, it is difficult to envisage a situation in which this could ne completely eliminated. It is important to recognise that neurologists have a very important role in reassuring people with self-limiting symptoms, including those with so-called 'functional' neurological symptoms. This has the important effect of providing explanation and reassurance which is greatly valued by patients and also in limiting unnecessary and costly investigations. Therefore it is important not to view the absence of a formal diagnosis as a negative outcome indicator.	Thank you for your comment. The guideline committee will take this into consideration when reviewing the evidence and making recommendations.
Association of British Neurologists	3	Title	We agree with the proposed change to the guidance title. The key element in ensuring that patients have rapid access to a correct neurological diagnosis and timely treatment is the recognition a) that the patient's symptoms are likely to be due to a neurological problem and b) an assessment of the level of urgency. The change in title correctly reflects the fact that, in general, it is not anticipated that a formal diagnosis will be made in general practice, except in very common and non-progressive conditions such as migraine or Bell's palsy for example. The role of primary care is to recognise neurological conditions and to make an appropriate and timely referral.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.

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Brain&Spine Foundation	2	26 -30	Including both children (over 28 days old) and adults within the guideline will be complex in an already complex area and may not be workable. It may be in everyone's interest to have either separate guidelines, or sub-guidelines under adults and children.	Thank you for your comment. This guideline will cover children, young people and adults. There will be many issues that are the same to all age groups. Where there are differences, the guideline committee will identify issues that are specific to each age group and will consider the best way to present the recommendations.
Brain&Spine Foundation	General	General	Although there is existing NICE guidance on a number of neurological conditions e.g. brain tumour and stroke, we are concerned that these don't all cover recognition and referral, and that there is a need for a single source of guidance on neurological conditions to simplify this for patients and primary care practitioners.	Thank you for your comment. It is correct that not all existing NICE guidance covers recognition and referral. Where this issue is already covered within existing guidance, this guideline will cross-refer. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. We have amended section 1.3 of the scope to make this clearer.
Brain&Spine Foundation	General	General	The condition groups suggested do not include inflammatory conditions, developmental disorders and infections. The Neurology Intelligence Network has developed categories of neurological conditions which could be a useful basis for covering all conditions: http://www.yhpho.org.uk//resource/view.aspx?RID=207314.	Thank you for your comment. The guideline committee will consider the information you have provided when confirming the list of conditions that will be used in the literature search strategy.
Brain&Spine Foundation	General	General	The Brain and Spine Foundation support the development of a guideline to aid the assessment, diagnosis and referral of patients with neurological problems. It is an opportunity to give clear guidance to primary care practitioners, so that patients are referred, informed and supported appropriately.	Thank you for your comment. The aim of this guideline is to support non-specialists in primary and secondary care to make appropriate and timely referrals for suspected neurological conditions.

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			From our experience this can be a protracted, distressing and painful experience for the patient, which is supported by the Neurological Alliance patient experience data http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report Specifically, 31.5% (n=2,140) of respondents had to see their GP five or more times about the health problems caused by their condition before being referred to a neurological specialist. 39.8% (n=2,357) of respondents waited more than 12 months from when they first noticed their symptoms to seeing a neurological specialist.	
Brain&Spine Foundation	General	General	We agree with the proposed title change to, 'Suspected neurological conditions: Recognition and referral'. This a clearer title for patients and health professionals specifically in a non-specialist pre-diagnosis setting and more suitable to a primary care setting.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
British Psychological Society	2	37	We are concerned that primary care professionals also have guidance on when to refer those with existing neurological conditions where the patient presents with a co-morbidity or change in symptoms. This could be added as a clarification to point two by adding in the words 'including referral for those with existing neurological conditions in the event of co-morbidity or change in symptoms.' Linked to this point, we would suggest that the revised title for the guideline be either Suspected Neurological Problems or	Thank you for your comment. We have clarified point two as you suggested. The majority of stakeholders agreed that neurological 'conditions' is preferable to neurological 'problems' and we have therefore kept it in the title.

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			Suspected Neurological Presentations. We support the wording 'Recognition and Referral'.	
British Psychological Society	2	47	We believe that in order to be practical to implement the guideline will need to look at symptoms across the full range of neurological conditions. Where appropriate this will be integrating existing NICE guidelines but this will potentially need to go beyond cross-referencing so that primary care professionals only need to access one guideline rather than several when they are looking to recognise and refer neurological conditions. This point is relevant across section 1.5 on key questions.	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis. When making recommendations, the guideline committee will consider recommendations in existing NICE guidance that relate to the recognition and referral of symptoms. The NICE pathway will be developed alongside the guideline and will bring together the recommendations for this topic and relevant existing guidance in one place.
British Psychological Society	**3**	94	People with a suspected neurological condition, their family or carers could also be advised of the information they can collect in order to ensure their specialist referral is of maximum benefit e.g. a symptom diary.	Thank you for your comment. The needs of patients and their families or carers will be considered at every stage of the guideline development process. The guideline committee will take this into account when reviewing the evidence and making recommendations.
British Psychological Society	7	154	In relation to suspected functional problems the guideline may need to consider who is the appropriate clinician to refer onto as this might not always be a neurologist.	Thank you for your comment. Decisions about referral to other specialist services would usually be made by neurologists. The primary aim of this guideline is to focus on referral to specialist care for further neurological assessment, following initial assessment by non-specialists. The guideline committee may consider referral to other specialist services outside of neurology where appropriate.

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British Thoracic Society	General		Any cross-referencing to existing documents needs to be seamless such that this guideline stands alone. It should be possible to see the symptoms of concern in this guideline and a recommendation as opposed to guidance to "refer to NICE document xxx'	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis. When making recommendations, the guideline committee will consider recommendations in existing NICE guidance that relate to the recognition and referral of symptoms. The NICE pathway will be developed alongside the guideline and will bring together the recommendations for this topic and relevant existing guidance in one place.
British Thoracic Society	General		Question 4) This is obviously a very selective list of neurological conditions as they are intended to be those which are 'less common', and there appears to be a slightly odd division into adult and young people. The way it is written there are many items which would seem to apply to both groups (do young people not get functional disorders?) but which are only listed for one or other of them. Does this relate to there are already being NICE guidelines in these areas? If so than as long as these are appropriately cross referenced as suggested this would seem to be an appropriate list. If the guideline is to be useful it should be structured around neurological presentations, not neurological conditions – which do seem to be rather highlighted in the scope document. (The documentation on which we are asked to comment emphasises that the diagnosis will be made by the specialist, therefore clearly any algorithms, investigations etc will need to be organised by presentation, not by condition.)	Thank you for your comment. It is important to note that the guideline will be developed on a symptom-basis, rather than by condition. The list of conditions will be used to guide the literature search. The guideline committee will consider the information you have provided when confirming the list of conditions that will be used in the literature search strategy.

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			The name of the condition is less relevant and could confuse the guideline reader. As a non-specialist, it would be preferable to look up 'tremor' in the contents rather than look through all of the conditions to see if the presentation fits. The key areas to be included in relation to respiratory are: 1) effect swallowing, increasing risk of pneumonia 2) effect breathing - neurological or muscle problems eg MND, Duchenne 3) effect sleep so narcolepsy etc	
British Thoracic Society	General		Question 1) There is a big challenge in the very uneven availability of neurological expertise available for inpatients across different trusts. Timely access to such expertise is likely to prove a major challenge in some institutions. It is also quite an ambitious project – signs and symptoms in neurology are frequently so much harder to elicit with confidence as compared to other specialties ('haemoptysis' is a much 'harder' endpoint than 'unsteadiness of gait',) and very dependent on the skill of the practitioner, such that a) coming up with appropriate referral criteria, and b) implementing them effectively may prove a considerable challenge. The GL scope is broad covering both hospital and primary care. Care will be needed to ensure that access to diagnostics is not encouraged in an unselected way which would result in flooding diagnostic services with unnecessary tests.	Thank you for your comment. We agree that we may find it difficult to find data on some of these outcomes measures for the full range of signs and symptoms. Additionally the guideline covers assessment tools and investigative tests that can be used by non-specialists. The use of diagnostic tests in specialist care will not be covered.

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British Thoracic Society	General		Question 3) If the scope of the guidelines is as described – ie assessment and referral – then clearly it is inappropriate to put 'diagnosis' in the title. The obvious potential difficulty this suggests is whether NICE wish to write a guideline implying that every neurological condition needs a specialist for diagnosis. (And this in the age of promoting more generalists?) A further challenge for the title of the guideline seems to be that it is entitled 'Neurological conditions' and yet the brief appears to be to cover uncommon/neglected neurological conditions, and the vast majority of 'neurological conditions' will not be covered as they already have their own guideline. Criteria for referral will depend upon the underlying diagnosis and the same is true of support for patients, the key being faster diagnosis.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. Conditions that are already covered by NICE guidance will therefore not be excluded, but the existing guidance will be cross-referred to where there are already recommendations that cover the recognition and referral of symptoms for those conditions. We have amended section 1.3 of the scope to make this clearer.
BSCN	2	38	Clinical Neurophysiology (CN) uses diagnostic tests to assist with the confirmation (or exclusion) of neurological or muscular conditions, their classification and/or severity grading. Due to 'sensitivity and specificity' issues CN should only be used in the appropriate clinical context, by a referring Clinician who can explain the significance of the test result to the patient and manage the condition appropriately.	Thank you for your comment. The guideline covers assessment tests that can be used by non-specialists to determine whether referral is necessary. The use of diagnostic tests in specialist settings will not be covered.
BSCN	4	89	A non-specialist could refer a patient with "tingling fingers/numbness in the hand" for nerve conduction studies (NCS) to confirm and grade carpal tunnel syndrome prior to referral to a specialist.	Thank you for your comment. The guideline committee will bear this in mind when reviewing the evidence and making the recommendations.

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BSCN	4	89	A non-specialist could refer a patient with a suspected "seizure" for an electroencephalogram (EEG) for syndromic classification, although a simultaneous urgent referral should be made to an epilepsy specialist (see NICE CG 137). An EEG should not be performed in the case of probable syncope.	Thank you for highlighting this. It is important to note that this guideline will not be condition specific and therefore the guideline committee may not be able to make recommendations with this level of detail.
Compassion in Dying	4	94 -98	We note that advance care planning is not listed as 'key issue' in this document. We believe everyone should be made aware of their legal rights and choices when making decisions about their treatment, including how to plan their treatment in advance in a legally binding way. This is true for those approaching the end-of-life, those recently diagnosed with a progressive illness or for people who are healthy. Planning ahead is especially significant for those diagnosed with or suspected of having a neurological condition, as there is an increased risk that they may lose mental capacity, either temporarily or permanently, at a future date and therefore be unable to consent to treatment. We provide information on the tools people can use to plan ahead for their future treatment and care in a legally binding way, should they lose the capacity to make decision for themselves. Our service users frequently tell us how setting out their wishes in an Advance Decision or through appointing a Lasting Power of Attorney for Health and Welfare provides reassurance that their wishes will be respected; removing any fear that they will receive treatment they do not want to receive. For people diagnosed with a neurological condition, this would	Thank you for your comment. Although advance care planning is not specifically listed as a key priority area, it would fall under the information, support and initial management area and may therefore be considered in this review. However, it is beyond the scope of this guideline to provide detailed information about specific issues of advance care planning such as the legal issues.

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			better enable them to focus on other aspects of their life, knowing their wishes had been communicated. There is some evidence that advance care planning improves experience at the end of life. In a poll conducted in May 2015 by YouGov, we asked respondents to think back to the last close relative or friend who died from a short or long-term illness (i.e. someone who should have had planned care) and then asked them questions about that person's experiences at the end of life. 52% of those whose end-of-life wishes had been formally recorded were reported as dying in a good way, whereas, for those whose wishes weren't recorded, only 37% died in a good way. The figures show that those who had their wishes formally recorded were 41% more likely to die well. Similarly, when end-of-life wishes were not recorded people were 53% more likely to receive treatment that they did not want. Whilst the current outline has a focus on effective diagnosis and referral – a time when introducing end-of-life rights and planning to individuals would need to be done sensitively - it is important that patients, carers and, perhaps more crucially at this stage, care professionals have access to information and the necessary support to allow individuals to act on their rights if this is what they want. Our My Life, My Decision service has found that community organisations and care professionals have a varied understanding of advance care planning and differing needs for supporting individuals to plan in advance. The guidance needs to address that relevant professionals should all	

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			have the same level of knowledge in this area and be able to access support and signpost patients to support organisations to help them plan ahead if they wish to. With this in mind, it is critical that Key Issue 3 tackles advance care planning.	
Compassion in Dying	General	General	Compassion in Dying welcomes the development of this clinical guideline. We are a national charity working to inform and empower people to exercise their rights and choices around end-of-life care. We do this by: • providing information and support over our freephone Information Line; • supplying free Advance Decision to Refuse Treatment (ADRT) forms and publications which inform people how they can plan ahead for the end of their life; • delivering one-to-one support to older people through our outreach service, My Life, My Decision; • running information sessions and training for professionals, community groups and volunteers on a range of end-of-life topics, including accredited Continuing Professional Development (CPD) modules; • and conducting and reviewing research into end-of-life issues to inform policy makers and promote patient-centred care.	Thank you for your comment.
Department of Health			Thank you for the opportunity to comment on the draft scope for the above clinical guideline.	Thank you for your comment.

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			I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	
Epilepsy Action	2	27 -30	The inclusion of children (over the age of 28 days) in the guideline will present a challenge to the guideline development process, and the guideline committee should consider whether a separate guideline relating to the recognition of paediatric neurological conditions should be developed. Neurological conditions are a diverse and complex grouping, and the inclusion of children will add additional complexity to an already wide-ranging guideline scope. This will necessarily limit the level of detail that the guideline can contain. It may be preferable to develop a separate guideline covering children presenting with symptoms of a neurological condition in order to ensure that the topic is comprehensively addressed.	Thank you for your comment. This guideline will cover children, young people and adults. There will be many issues that are the same to all age groups. Where there are differences, the guideline committee will identify issues that are specific to each age group and will consider the best way to present the recommendations.
Epilepsy Action	2	44 -68	It will be a challenge to ensure that the guideline complements and supports existing NICE guidance relating to specific neurological conditions. Given that the guideline will focus on the initial assessment of people without a confirmed neurological diagnosis, it should not explicitly exclude any neurological conditions, as many initial signs and symptoms will be common to a wide range of conditions. In addition, existing NICE guidance focuses more strongly on treatment and ongoing management of neurological conditions, rather than on the pre-diagnosis phase. Therefore, this guideline is an opportunity to complement existing condition-specific guidelines relating to neurology.	Thank you for your comment and for bringing these useful resources to our attention. It is important to note that this guideline will be developed on a symptom basis. Because of this, no specific conditions will be excluded from the guideline; however existing NICE guidance will be cross-referred to where there are already recommendations that cover the recognition and referral of symptoms.

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			This is particularly important as far as epilepsy is concerned and we strongly request that the possible identification of seizures (epileptic and non-epileptic) be included within the guideline. There are over 40 different types of seizure. However the NICE epilepsy guideline (CG137) does not include comprehensive descriptions of the types of seizure (other than a brief note in the glossary, which we believe to be insufficient for a non-epilepsy expert to interpret), nor any guidelines for identifying potential seizures for GPs or A & E practitioners. The guidance states that a person presenting with a suspected seizure should be seen as soon as possible (within two weeks) by a specialist in the management of the epilepsies, but does not support the non-specialist in identifying suspected seizures. Given the possible consequences of epilepsy going undiagnosed and untreated (risk of injury or death, including Sudden Unexpected Death in Epilepsy) and NICE guidance supporting the need for an early appointment with a specialist, it is clearly vital that the proposed guideline includes information, examinations, assessment tools and tests that non-specialists could use to help them decide whether a person with symptoms suggestive of epilepsy should be referred to a specialist. Epilepsy Action's primary care resource, *The Role of Primary Care in Epilepsy Management,* provides information for GPs on	

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			recognising seizure types (note that this requires updating for new seizure classifications). (https://www.epilepsy.org.uk/professionals/healthcare/primary-care-resource-pack/section-2/general-management/diagnosis) In addition, the resource provides a check list of questions for the primary care physician to ask of the individual and any eye witnesses, in order to facilitate identifying possible seizure activity and to help differentiate from other similar events, such as faints. (https://www.epilepsy.org.uk/sites/epilepsy/files/primary-care-resource/A1-Tool.pdf) All of this information is lacking in CG137 and therefore will be required in the proposed new guideline.	
Epilepsy Action	3-4	77-98	The guidance should advise on what information the non-specialist should include in a referral to a specialist, to assist the specialist in their diagnosis. For example, in suspected epilepsy the primary care team can provide key information to aid the diagnosis, as the GP is often the first to suspect epilepsy and is in the best position to obtain a first-hand witness account and record the diagnostic features. The guidance should include the information, support and initial management advice needs of people who have a suspected neurological problem and their family members and/or carers.	Thank you for your comment. The guideline committee will take this into account when reviewing the evidence and making recommendations.

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			For example, information that should be given out by A&E departments when a tonic-clonic seizure is suspected and could possibly occur again, prior to a first diagnostic appointment taking place (https://www.epilepsy.org.uk/professionals/factsheet-information-a-and-e). Failure to give advice about driving has been a safety concern raised in audits including the National Audit of Seizure Management in Hospitals (http://www.nashstudy.org.uk/Newsletters/St%20Elsewhere's%20Clinical%20Report%20NASH%202.pdf)	
Epilepsy Action	4	108	Gathering evidence on the outcomes and measures listed in this section may be challenging, as there is limited available data relating to neurological conditions. Although the Neurology Intelligence Network (NIN) has begun to compile, publish and analyse available data on neurological conditions, it has only been in operation for around 18 months. Consequently there is less collated data at the national level for neurology than for other condition and service areas. It may be necessary to convene patients, clinicians and other key stakeholders to consider some of the outcomes and generate additional evidence.	Thank you for your comment. We agree that it may be difficult to find data on some of these outcome measures. This is not a definitive or exhaustive list as the final outcomes will be determined when the review questions have been formulated and discussed with the guideline committee.
Epilepsy Action	general	general	Regarding the condition categories suggested above as a focus for literature searches: the guideline committee should refer to the categories of neurological conditions developed by the NIN in 2015 for classification purposes, in order to ensure that all categories are sufficiently represented. These categories are	Thank you for your comment. The guideline will be developed on a symptom-basis, rather than by condition. The list of conditions will be used to guide the literature search. The guideline committee will consider the information you have provided when

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			available via: http://www.yhpho.org.uk//resource/view.aspx?RID=207314.	confirming the list of conditions that will be used in the literature search strategy.
Epilepsy Action	General	General	We support the aim of developing a guideline to support better initial assessment, recognition and referral of people presenting in non-specialist settings with symptoms suggestive of a neurological problem. Patient experience data suggests that this stage of the pathway is not currently working well for people with suspected neurological conditions, with 40% of patients waiting over a year between first onset of symptoms and referral to a specialist (http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report). It is therefore essential that primary care practitioners are supported to assess people presenting with neurological conditions and refer them in a timely manner.	Thank you for your comment. The aim of this guideline is to support non-specialists in primary and secondary care to make appropriate and timely referrals for suspected neurological conditions.
Epilepsy Action	general	general	Existing practical resources and initiatives to note for the development and implementation of this guidance include: - The information and data provided through the Neurology Intelligence Network (NIN), available via: http://www.yhpho.org.uk/default.aspx?RID=198139 - Neurological Alliance patient experience data drawn from almost 7,000 people living with neurological conditions, available at http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report - NHS England's current project scoping models of community care and support for people diagnosed with neurological conditions	Thank you for your comment. The guideline committee will take this information into consideration during guideline development.

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			- The Primary Care Neurology Society http://www.p-cns.org.uk/, a network of primary care professionals with an interest in neurology which collates useful resources - Epilepsy Action's The Role of Primary Care in Epilepsy Management https://www.epilepsy.org.uk/professionals/healthcare/primary-care-resource-pack	
Epilepsy Action	general	general	We agree with the proposed title change to "Suspected neurological conditions: Recognition and referral" as it reflects the symptom-led approach of the guideline and the fact that the guideline refers chiefly to primary care settings where a confirmed diagnosis has not yet been made.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
Fybromyalgia Action UK	3	80-83	There are two commonly used diagnostic methods used to diagnose fibromyalgia: 1. ACR 1990 criteria which includes: a) pain in all four quadrants of the body for at least three months together with b. Pain in at least 11 out 18 tender points sites when they are pressed. 2. ACR 2010 criteria: http://onlinelibrary.wiley.com/doi/10.1002/acr.20140/full which removes the tender point test and gives more significance to the other symptoms that fibromyalgia presents with. Correlation studies have found the new criteria to be >88% effective at	Thank you for your comment. The guideline committee will consider this information during guideline development.

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			We are writing about the diagnostic methods and tools here, even though we understand that this NICE Guidance is not about diagnosis per se but only about referral. We mention both diagnostic methods because it is sometimes unclear, to a non-specialist healthcare professional (namely, a GP) whether it is fibromyalgia or not. Other conditions must be excluded in the first place to diagnose fibromyalgia, for example, and fibromyalgia can have confusing symptoms, as patients can feel better on one day and worse on another; fibromyalgia also has a number of differential diagnoses. For these reasons we include the diagnostic tools commonly used to diagnose fibromyalgia. As if a GP suspects fibromyalgia, but is not sure and wants a diagnosis/ confirmation of the diagnosis by a specialist, then these above mentioned diagnostic tools could also act as an aid to making a referral to a specialist.	
Fybromyalgia Action UK	2	50	The list of conditions in the draft scope and the list in Question 4 on page 1 of this document does not include fibromyalgia. We feel that it should include fibromyalgia, because: a) fibromyalgia is a CNS condition., therefore it is a neurological condition b) it is a common condition, with up to 2. 7 million people in the UK living with it – the prevalence between 2.9 % of the population to 4. 7 %. c) there is no guidance or any other document developed yet by NICE on fibromyalgia. We believe that because of the above fibromyalgia should be included and listed separately as	Thank you for your comment. The guideline committee will consider the information you have provided when confirming the list of conditions that will be used in the literature search strategy. It is important to note that this guideline will be developed on a symptom basis and therefore no specific conditions will be excluded from the guideline unless there are already recommendations in existing NICE

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			all the other major conditions are listed and named. This comment refers also to Question No 4. Evidence to the points a) and b) can be found in the Fibromyalgia Action UK ''Information Booklet for people affected by Fibromyalgia'', published in October 2013, pp 2- 3. The Booklet can also be viewed on our website: http://www.fmauk.org/information-packs-mainmenu-58/booklet-mainmenu-135/490-patient-booklet	guidance that covers the recognition and referral of symptoms.
Fybromyalgia Action UK	1	20	The issue of inequality: we think that there may be an under diagnosis (or diagnosis taking much longer) in men than in women. Many studies show that the prevalence of fibromyalgia is higher in women, at about 80%. From our experience over the years working with thousands of people with fibromyalgia, we could also say that the majority of people who contact us are women. It may be due to fibromyalgia being diagnosed in women. It could also be due to the physical muscalture in men with the reliance on the tender point test, or it could be the social stigma, where men are less likely to approach health professionals or result in a diagnosis. We don't know the exact reasons, but we think it is important to underline this, as non-specialist healthcare professionals need to bear this in mind if they have a male patient reporting symptoms, which might be a sign of fibromyalgia. The awareness about fibromyalgia have greatly increased over the recent years and we notice a good number of men, including	Thank you for your comment. The scope has a broad focus and covers the recognition and referral of symptoms suggestive of suspected neurological conditions. The guideline will not make recommendations about specific conditions, however the potential equality issue you have raised has been noted in the equality impact assessment and will be considered by the guideline committee when reviewing the evidence and making recommendations.

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			young men, who were diagnosed with fibromyalgia or think they may have fibromyalgia and contact us.	
Fybromyalgia Action UK			First of all we want to underline the importance of understanding of the assessors reading our comments and for any NICE guidelines to clearly state that fibromyalgia is being diagnosed NOT only by specialists, (e. g. Neurologists), but also by GPs. It is often diagnosed by rheumatologists, as well as neurologists and in some cases by specialist nurses. We fell that this is import as the NICE guidelines on Neurological Problems would state that fibromyalgia must be, or can only be, diagnosed by a neurologist and/or that a non-specialist healthcare personnel must or should refer a patient with a suspected fibromyalgia to the neurologist or to a specialist, it would mean negative consequences for the patients. The presentation of symptoms leads to rheumatology being a primary route for diagnosis. Behaviour internationally varies with some countries relying predominantly on neurologists for diagnosis and other countries will rely on rheumatologists with variations occurring depending on post code. However, practice in the UK shows that fibromyalgia is mainly diagnosed by GPs and rheumatologists. Economic reasons may be a factor or it may be related to confidence levels at primary care facilities. Summarising this point, we would like NICE to acknowledge fibromyalgia in the neurological problems guidance and to include all relevant information however it should not be a	Thank you for your comment. This guideline will focus on symptoms that present in such a way that means it is sensible for a neurologist to assess the patient. We acknowledge that this may not be the case for all patients, and therefore this guideline will cover the criteria that indicate there is no need for referral for further neurological assessment, as well as the criteria that suggest referral is appropriate.

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			requirement that excludes primary care facilities such as GP's from being able to diagnose fibromyalgia. We appreciate that this may writing of these guidelines more complicated, however we feel that the wellbeing of patients and a speedy diagnosis should be a paramount. This is because, from our experience as the leading charity working with and for people living with fibromyalgia in the UK, we know that it normally takes many years to diagnose fibromyalgia. Diagnostic wait times of 10 and more years are not unusual; many more would experience 3-6 years. Therefore, we feel that to improve the treatment, patients' life and to prevent an avoidable disability, speedy diagnosis is a paramount. Therefore, we feel that in regards to fibromyalgia, these guidelines should help point GPs and other non-specialist personnel in the right direction in referral and diagnosis of fibromyalgia, but it should not indicate that fibromyalgia could be diagnosed only by a specialist. It should also be clear that fibromyalgia can and often is diagnosed by GPs and other primary health care professionals. Please contact us should you have any questions related to this.	
Fybromyalgia Action UK			Another very important factor in this field is for GP and other non-specialist healthcare professionals is to listen to the patient and see the patient as a whole person, not as a list of not-related symptoms. Giving time to actually listen to the patient and asking the right questions could shorten the time and the number of	Thank you for your comment. The guideline committee will consider this when reviewing the evidence and making recommendations.

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			visits needed to spot the possible symptoms of fibromyalgia or to connect them all together. GPs often only have a 10-minute visit with a patient and this is often not enough for the patient to fully describe his or her fibromyalgia symptoms. Often the patient may not realise that all his/ her symptoms are connected. There are many symptoms of fibromyalgia, some of them are less common. Giving an appropriate time to listen to the patient is, in our opinion, the first step to gather information about the patient's current condition.	
Fybromyalgia Action UK			Information, support and initial management advice for people with suspected fibromyalgia: GPs and other healthcare professionals can signpost patients to Fibromyalgia Action UK (http://www.fmauk.org/). FMA UK already send out medical packs for healthcare professionals on request and at conferences, and distribute patients' booklet as well as young people's booklets. We are also working currently on Employment Booklet, which should be released soon. All the mentioned publications above comply with the NHS information Standard mark. which means that they are accurate, evidenced and up to date. We are the only national fibromyalgia focussed charity in the UK producing information under the Information Standard mark. We also provide helplines for people affected by fibromyalgia, including for those, who think that they may have fibromyalgia.	Thank you for your comment. The information and support needs of patients during the assessment and referral process will be covered within this guideline. However the guideline committee will be unable to signpost to specific information resources. Information for the public is usually published alongside the guideline, and this often includes further sources of support and information for patients and their families and carers.

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			We have over 20 years of expertise in providing support to people with fibromyalgia. It is recommended that once there is a suspicion that a diagnosis of fibromyalgia may be made by a healthcare professional, that patients are directed to our website. This allows that they can find information and support that they crave up until and beyond their diagnosis being made. Our information can also help them achieve a quicker diagnosis, as better informed patients and healthcare professionals. We also send out information to medical professional on request and have received many comments about GPs referring their patients to ourselves prior to a formal diagnosis being made and the patients benefiting from this.	
Huntingdon's Disease Assoc	General	General	A key outcome of this guideline should be the establishment of a database of specialist clinics and resources for GP's to refer to. There needs to be a distinction between what is considered to be a specialist or not (a neurologist is a specialist but may have no specialist knowledge in conditions such as HD. There also needs to be some pointers that even though the diagnosis may be neurological the most appropriate referral may not be to neurology, but to say genetics or psychiatry	Thank you for your comment. The NICE implementation team will work with the guideline committee to consider these issues when developing the implementation support materials for this guideline.
Integrated Neurological Services			A Health Record Book can be very helpful for the person and their family to coordinate all the support and record the person's response to any intervention; e.g. medication, therapy, equipment. They can also keep any valuable information in this book which may improve the quality of life. In this book the	Thank you for your comment. The guideline committee will take this into consideration when discussing the evidence.

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			person can record the symptoms accurately to facilitate diagnosis. This book would help monitor the condition and could assist in finding the most effective and efficient way to support such people who will probably need support for life; e.g. MS, PD, Cerebral Palsy etc.	
Integrated Neurological Services	4	92	Helping people to be aware and understand relevant symptoms so that they can be better historians if they are referred on to a specialist – using a diary or health record book may be useful	Thank you for your comment.
Integrated Neurological Services	4	94	Signposting to websites that meet Information Standards criteria so people are getting sensible information. Helplines on national condition specific charities can also be helpful in providing information or helping people think about questions to ask when they see a specialist.	Thank you for bringing this to our attention. Information for the public is usually published alongside the guideline, and this often includes further sources of support and information for patients and their families and carers.
Integrated Neurological Services	4	95	Explaining early on the term "carer" as people will view themselves as partner/mother/child rather than carer	Thank you for your comment. We acknowledge the point you have raised however the term 'carer' is always used in conjunction with 'families' so we think this is sufficiently clear for the purposes of this guideline scope.
Integrated Neurological Services	4	96	Information, support and advice may also come from the voluntary sector as well as local statutory services The support needs to be holistic	Thank you for your comment. Information for the public is usually published alongside the guideline, and this often includes further sources of support and information for patients and their families and carers.
Integrated Neurological Services	4	112	Partly tied in with quality of life – but also useful if you can measure self-efficacy as this is tied in with how people feel about coping. (I haven't got time this afternoon to find some references for this statement but can do later if you would like me to).	Thank you for your suggestion. This is not a definitive or exhaustive list as the final outcomes will be determined when the clinical questions have been formulated and discussed with the guideline

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				committee. The guideline committee will consider your suggestion.
Integrated Neurological Services			The list should include: Parkinson's disease, PSP, Multiple sclerosis, Brain Tumour, dementia, long lasting effects of Stroke The better the person is rehabilitated the less it will cost the NHS and the better the quality of life for rhe person, the family and the community.	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis. Because of this, no specific conditions will be excluded from the guideline; however existing NICE guidance will be cross-referred to where there are already recommendations that cover the recognition and referral of symptoms.
Integrated Neurological Services			The most important time for the patient and the family is the day of diagnosis. If it is a long-term condition the person and the family will need on-going support for optimum quality of life where the person will need physical. Mental and emotional support to understand how he/she can help him/herself. The home environment and the workplace must be considered along with the great value of self-help therapy groups which can evolve into stimulating activities and outings to help the person and the family be part of the community for as long as possible. The person with a neuro condition will require the assistance of a holistic therapist where there is the example of using conductors as in Conductive Education who can support and teach the person to move, communicate and function optimally over 24 hours, 365 days per year. – that is they can require physiotherapy, occupational therapy, speech and Language therapy with social work support and also counselling. See www.ins.org.uk	Thank you for your comment. The issues you have raised are beyond the scope of this guideline which deals with the recognition and referral of suspected neurological conditions by non-specialists. The information and support needs of patients after diagnosis will not be covered.

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Integrated Neurological Services			**Suspected neurological conditions:Recognition and referral**, yes, I agree for it is very important to have people diagnosed as soon as possible so that positive action can be taken; such as explaining why the symptoms are present and what the person can do to help him/herself – physically, mentally and emotionally . A self-help therapy group is very beneficial with a service which can support them for life.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
Max Appeal	2	1.1	Very likely that those presenting with psychiatric symptoms will need support from parent / carers. Problems associated with genetic conditions could mean other family members supporting them will have cognitive impairments.	Thank you for your comment. The guideline committee will take this into consideration when reviewing the evidence and making recommendations.
Max Appeal	2		Frequent genetic conditions such as 22q11 Deletion Syndrome, (much under diagnosed) present with delayed development, behaviour issues, psychological and psychiatric symptoms (especially in teenage young adulthood). Consideration should be given to the common issues associated with the condition and further investigation needed.	Thank you for your comment. The guideline committee will take this into consideration when reviewing the evidence. However it is important to note that this guideline will be developed on a symptom basis and therefore recommendations on specific conditions may not be appropriate.
Max Appeal	1		Challenging areas will in my opinion relate to behaviour issues in children which have greater significance due to underlying genetic disorders which have been missed in earlier years. If child is unsupported these problems usually increase as the child gets older. Too many professionals suggest this is down to poor parenting and ignore underlying causes. Psychiatric symptoms in teenage years and early adult which are not linked with neurological disorders and managed effectively. Often not picked up by GP's and difficulty to access CAMHS.	Thank you for highlighting this important issue. The guideline committee will consider this when reviewing the evidence and making recommendations.

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Max Appeal	4.1 & 2		For 22q11 Syndrome, The Consensus Document for 22q11.2 Deletion Syndrome is an excellent minimum standards care pathway written by clinicians for use in the NHS.	Thank you for your comment.
Max Appeal	3		Agree with proposed title.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
Medicines and Prescribing Programme	**2**	41	**Indications for referral to specialist care.** Does this include urgency of referral? Non-specialists can find it difficult to gauge how urgently to refer people with neurological conditions**.**	Thank you for highlighting this issue. This guideline will consider the 'red flag' symptoms that determine whether referral is necessary. There is an assumption that a 'red flag' indicates a need for urgency. The guideline committee will take this issue into consideration when reviewing the evidence and making recommendations.
Medicines and Prescribing Programme	**3**	77	Key issues and questions. In terms of assessment and investigation, should there be a question about which models of care provide most rapid and accurate diagnoses, to take account of and interrogate different models of care, such as those where specialist advice can be accessed daily by a telephone 'hotline', or models where there is open access to certain investigations such as imaging?	Thank you for your comment. A comparison of models of care is not within the scope of this guideline.
Medicines and Prescribing Programme	4	92	**Which criteria (symptoms, signs, risk factors and red flags) indicate the need for referral to specialist neurological care?** As comment 3, will this include urgency of referral?	Thank you for highlighting this issue. This guideline will consider the 'red flag' symptoms that determine whether referral is necessary. There is an assumption that a 'red flag' indicates a need for urgency. The guideline committee will take this issue into consideration when reviewing the evidence and making recommendations.

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Medicines and Prescribing Programme	4	5	**Diagnostic accuracy of tests** Should this be positive predictive value of tests (the proportion of those with a positive test result who actually have disease) and negative predictive value of tests(the proportion of those with a negative test result who do not have disease); these are what are important to the GP and the patient with a test result in front of them to interpret	Thank you for your comment. Predictive value of tests will be included as a part of the diagnostic accuracy of the tests.
Medicines and Prescribing Programme	6	137	NICE Pathway. I realise this is just an outline of the pathway, but in the 3rd box, 'Identify red flags (signs and symptoms) should be lower down the list, as you can't elicit signs and symptoms without an assessment and examination.	Thank you for your comment. The NICE Pathways team will take this into consideration when developing the pathway.
Medicines and Prescribing Programme	6	140-150	Key facts and figures. Where is this data from (and should it be referenced)? The NAO report 'Services for people with neurological conditions: progress review July 2015' (https://www.nao.org.uk/wp-content/uploads/2015/07/Services-for-people-with-neurological-conditions-progress-review.pdf) cited the Neurological Alliance's document 'Neuro numbers' (http://www.neural.org.uk/store/assets/files/381/original/Final_-_Neuro_Numbers_30_April_2014_.pdf), which does cite its sources and has different figures to those quoted here, although it does not include all of the statistics quoted.	Thank you for your comment. The data you refer to is taken from the 'Local adult neurology services for the next decade: Report of a working party', published in 2011 by the Royal College of Physicians and Association of British Neurologists. A reference has been added to section 3.1.
Medicines and Prescribing Programme			4.1 Literature searches. MPP think the following important neurological conditions need to be captured for adults: **Sub-arachnoid haemorrhage;** often present to primary care, not covered in headaches guidance. **Encephalitis**; not covered in existing guidance, important to spot early, often present to primary care. **Parkinsonism/Parkinsonian disorders**; the Parkinson's	Thank you for your comment. The guideline committee will consider the information you have provided when confirming the list of conditions that will be used in the literature search strategy.

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			Disease (PD) guideline only covers PD itself, other parkinsonian disorders (e.g. PSP, MSA) not covered, and there may be overlap with tremor and ataxia literature. If a patient presents with a tremor or a wobbly gait, this requires recognition and referral, and isn't covered in existing guidance. **Ataxia;** not listed above under movement disorders, a presenting sign in a number of different neurological conditions that present to primary care who need to recognise and refer appropriately. **Neurodegenerative conditions**; included in children but not adult searches; these can present in adulthood so need to be recognised.	
Medicines and Prescribing Programme	1		Suspected neurological conditions: Recognition and referral – MPP agrees with this alternative title as it better reflects practice; non-specialist should be able to recognise that there is a neurological problem, but may not be able to diagnose this accurately with the experience and resources they have.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
Motor Neurone Disease Assoc	4	102-112	We agree with the list of proposed outcomes to consider.	Thank you for your comment.
Motor Neurone Disease Assoc	2	37-50	We welcome the focus on recognition of a potential neurological problem by a non-specialist and appropriate referral for diagnosis. In 2013 we conducted the Improving MND Care Survey which, with 951 respondents, is the largest survey of people with MND ever conducted in the UK. It found that one in	Thank you for your comment and for sharing the results of your survey with us.

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			four people with MND took over nine months to be referred to a neurologist after first going to their GP, and over half were referred to another specialist before a neurologist. Other specialisms that people were referred to include physiotherapy, orthopaedics and ear, nose and throat.	
Motor Neurone Disease Assoc	General	General	We welcome the development of this guideline. Although a dedicated guideline for motor neurone disease (MND) is in development, this guideline will still be helpful in respect of MND for several reasons. Some professionals may be unaware of the separate MND guidance and turn to this one for advice. Accurate and speedy referral is as important for MND as for any other neurological condition. And the absence of a diagnostic test for MND means that it must be diagnosed by elimination: an investigation of possible MND will involve testing for, and ruling out, other neurological problems that could be responsible for the patient's symptoms – these other conditions will often be among those covered by this guideline. To support GPs to make timely referrals, the MND Association has produced a 'Red Flags' tool with the Royal College of General Practitioners. This outlines the key symptoms of MND and recommends referral to a neurologist if they are present and there appears to be progression. While this is an MND specific tool, many of the same symptoms will be relevant in other progressive neurological conditions, and we hope that NICE will find it useful to refer to the tool in the guideline, as has been done in the draft version of the MND guideline.	Thank you for your comment. The guideline committee will take this information into consideration during guideline development.

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Multiple System Atrophy Trust	2	27 -30	Consideration should be given to splitting up Guidelines for children and adults, otherwise there is a risk that the Guidelines could become too unwieldy.	Thank you for your comment. This guideline will cover children, young people and adults. There will be many issues that are the same to all age groups. Where there are differences, the guideline committee will identify issues that are specific to each age group and will consider the best way to present the recommendations.
Multiple System Atrophy Trust	4	105-112	One of the key issues for people with MSA is the journey to their diagnosis. Most people are diagnosed with Parkinson's initially and then by a process of elimination are subsequently diagnosed with MSA. Some can be re-diagnosed back to Parkinson's. In fact the only failsafe means of diagnosis is through an analysis of the person's brain after death. So lines 106 – time to diagnosis and lines 109 diagnostic accuracy of tests might be applicable in most conditions but the most important thing for our client group is time taken to get on the appropriate neurological pathway, and especially the time getting access to a specialist neurologist.	Thank you for your comment. The list of outcomes presented in the scope is not a definitive or exhaustive list as the final outcomes will be determined when the review questions have been formulated and discussed with the guideline committee.
Multiple System Atrophy Trust	4	112	Quality of life in many instances will be very difficult to measure as many conditions will be characterised by deterioration. If NICE are looking at the economic issues surely something worth looking at would be the financial impact of failure to diagnose in a timely and appropriate way. For example, some people with MSA are initially referred to a urologist or another special area depending upon initial symptoms. We hear of cases where there is no recognition of the wider cause (MSA) and therefore an effective diagnosis does not occur. There must be costs both to	Thank you for highlighting this issue. When considering the health economic impact of delayed diagnoses, all costs that fall on the NHS will be considered. This will include the impact of additional resources allocated to unnecessary referrals. Likewise any negative health impacts on patients will also be taken into account.

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			the individual and the NHS that are incurred because of these situations and identifying these could help all round.	
Multiple System Atrophy Trust	General	General	We support the change of Guideline title.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
Muscular Dystrophy UK	General	General	Question 4: Muscular Dystrophy UK acknowledges the inclusion of muscular dystrophy and neuromuscular conditions in the conditions group list and we offer our assistance with the literature searches for the guideline.	Thank you for your comment.
Muscular Dystrophy UK	General	General	Question 1: The challenge is to ensure that primary and secondary care health professionals have at least some knowledge of complex and rare neurological conditions such as muscular dystrophy and neuromuscular conditions, which require specialist multi-disciplinary care and support. Specialist support and advice during the diagnostic process and along the patient pathway is essential. Therefore it is imperative that strong links in the referral process to tertiary and quaternary specialised services are in place to ensure a high standard of care for muscular dystrophy and neuromuscular conditions is delivered across the country.	Thank you for your comment. The aim of this guideline is indeed to increase awareness among non-specialists of symptoms suggestive of suspected neurological conditions, including the rarer ones. This guideline will cover primary and secondary care settings only.
Muscular Dystrophy UK	General	General	Question 2: Muscular Dystrophy UK's National Patient Survey in 2013 had revealed: • One in five patients said their GP had offered inaccurate advice in the past year, and nearly half of patients	Thank you for your comment and for sharing the results of your survey with us. The guideline committee will take this information into consideration during guideline development.

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			surveyed said their GP did not understand their condition well enough to plan local care. Therefore to address this, earlier this year Muscular Dystrophy UK and the Royal College of General Practitioners (RCGP) came together to create the first ever online course for GPs on the presentation and management of neuromuscular conditions in primary care, which has been taken by over 400 GPs. The new training module, which has involved neuromuscular clinical experts, people with muscle-wasting conditions and GPs, includes important information in an easy to use format. The course will now help GPs have a better understanding of their role in the management of neuromuscular conditions and to recognise the key moments when a patient needs to be referred to a specialist neuromuscular service. Muscular Dystrophy UK undertook a survey from January to March 2015 of people's experiences of the diagnosis process because we want to make sure families and individuals have the support they need at this crucial time. Our nationwide survey brought together the experiences of 700 people living with muscle-wasting conditions. It revealed that many people feel that the services in place for people with rare conditions, at the time of diagnosis, are inadequate, exacerbate	

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			feelings of isolation and have led to mental health problems. **Key findings:** - One in five patients reported having experienced suicidal feelings at some point in the diagnostic process. - Over half of patients experience feelings of depression when coming to terms with their diagnosis. One in four respondents were forced to wait more than three years for their diagnosis after first raising concerns with a health professional.	
Muscular Dystrophy UK	General	General	Question 3: We agree with the proposed change to the title of the guideline and the rationale behind it. We hope that greater understanding of muscular dystrophy and neuromuscular conditions will be increased as more GPs complete Muscular Dystrophy UK's online training module.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
Myaware	2	35	Many people with neurological problems end up in A&E – we feel that it is important that this setting is covered in the guideline.	Thank you for your comment. A&E will indeed be covered by this guideline under the secondary care setting. In addition there will be representation from A&E on the guideline committee.
Myaware	3	69 – 76	We are concerned that economic modelling will be of limited value and given the scarce data currently available (despite some recent progress with the Neurology Intelligence Network) relating to neurological conditions wonder how any modelling of future plans can be compared with current practices.	Thank you for your comment. An economic model will only be built if clinical evidence is available. If clinical evidence is not available, or not good enough to build a model, then the health economic impact will still be addressed by presenting unit costs and conducting threshold analyses. If it is felt that there is a large change in NHS resource use resulting from the

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				recommendation and only a model can resolve the uncertainty surrounding cost-effectiveness, then this will feed into the final recommendations that are made.
Myaware	4	94 - 98	Please don't overlook the wealth of high quality information and support that is already available to those affected by neurological conditions from patient groups. Finding ways for the NHS to signpost patients to the information and support that is already available from the third sector would be cost effective to the NHS and of huge benefit to patients.	Thank you for bringing this to our attention.
Myaware	4	94 – 98	We would hope that NICE will consider the enormously beneficial impact that specialist nurses have for people with neurological conditions, in particular in offering information, support and initial management. Myaware has evidence of the value that specialist myasthenia nurses deliver both in terms of patient care and in cost saving to the NHS and would be happy to share this with NICE. Specialist nurses are not only for common neurological conditions, but also for less common conditions such as myasthenia. Other patient groups have similar data.	Thank you for your comment. While the scoping group appreciated the beneficial role that specialist nurses have for people with neurological conditions, they did not feel that a specialist nurse was required as a full member of the guideline committee. This is because specialist nurses are rarely involved in the care of patients with neurological conditions until after a diagnosis has been made. Nurse input may be sought as an expert advisor during guideline development instead.
Myaware	4	102 – 112	We are concerned that given the limited data currently available relating to neurological conditions it will be difficult to gather and compare outcomes when searching for and assessing evidence. Myaware has some useful data about myasthenia and would be happy to share this with NICE – we are sure other patient groups have similar data that could be used. We also endorse using 'The Invisible Patient' data produced by Neurological Alliance.	Thank you for bringing this data to our attention. We agree that it may be difficult to find data on some of these outcomes measures. If we do not find any data from the evidence base the guideline committee may wish to ask stakeholders to submit additional evidence. However it is important to note that this guideline will be developed on a symptom basis and

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				therefore evidence pertaining to specific conditions may not be appropriate.
Neurological Alliance	2	27 -30	The inclusion of children (over the age of 28 days) in the guideline will present a challenge to the guideline development process, and the guideline committee should consider whether a separate guideline relating to the recognition of paediatric neurological conditions should be developed. Neurological conditions are a diverse and complex grouping, and the inclusion of children will add additional complexity to an already wide-ranging guideline scope. This will necessarily limit the level of detail that the guideline can contain. It may be preferable to develop a separate guideline covering children presenting with symptoms of a neurological condition in order to ensure that the topic is comprehensively addressed.	Thank you for your comment. This guideline will cover children, young people and adults. There will be many issues that are the same to all age groups. Where there are differences, the guideline committee will identify issues that are specific to each age group and will consider the best way to present the recommendations.
Neurological Alliance	2	57 -68	It will be a challenge to ensure that the guideline complements and supports existing NICE guidance relating to specific neurological conditions. Given that the guideline will focus on the initial assessment of people without a confirmed neurological diagnosis, it should not explicitly exclude any neurological conditions, as many initial signs and symptoms will be common to a wide range of conditions. In addition, existing NICE guidance focuses more strongly on treatment and ongoing management of neurological conditions, rather than on the pre-diagnosis phase. Therefore, this guideline is an opportunity to complement existing condition-specific guidelines relating to neurology.	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. This guideline will cover the recognition and referral of symptoms suggestive of a neurological condition, before a diagnosis has been made. Conditions that are already covered by NICE guidance will therefore not be excluded, but the existing guidance will be cross-referred to where there are already recommendations that cover the recognition and referral of symptoms. We have amended section 1.3 of the scope to make this clearer.

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Neurological Alliance	4	102-112	Gathering evidence on the outcomes and measures listed in this section may be challenging, as there is limited available data relating to neurological conditions. Although the Neurology Intelligence Network has begun to compile, publish and analyse available data on neurological conditions, it has only been in operation for around 18 months. Consequently there is less collated data at the national level for neurology than for other condition and service areas. It may be necessary to convene patients, clinicians and other key stakeholders to consider some of the outcomes and generate additional evidence. It is important that these outcomes and measures capture the issues affecting neurological patients' journey to their diagnosis. For example, people may be initially misdiagnosed with more common disorders (e.g. in the case of rarer movement disorders misdiagnosed as Parkinson's disease). Measures such as 'time taken to get on the appropriate neurological pathway of care' and 'time taken to access a specialist neurologist' would help to capture issues related to accessing the correct care pathway.	Thank you for your comment. We agree that it may be difficult to find data on some of these outcome measures. This is not a definitive or exhaustive list as the final outcomes will be determined when the review questions have been formulated and discussed with the guideline committee.
Neurological Alliance	4	109	Include "relevance of investigations" in this list, as many can be wasted and inappropriate when patients first present with neurological symptoms.	Thank you for your comment. We would not be able to search for 'relevance of investigation' as an outcome per se. However, the systematic review of the evidence for the commonly used investigations will determine which are the most accurate and useful and conversely which are not appropriate or useful.
Neurological Alliance	6	137	For additional detail, could include a list of 'red flags' and/or suggestions on what else the symptoms might be if not neurological.	Thank you for your suggestion. This would be a significant addition to the scope and therefore beyond the resources available for this guideline.

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Neurological Alliance	7	160	The word 'uncommon' should be removed as misdiagnosis rates are up to 25% in more common neurological conditions as well, including epilepsy and Parkinson's disease.	Thank you for your comment. We have amended section 3.2 and removed the word 'uncommon'.
Neurological Alliance	general	general	Regarding the condition categories suggested above as a focus for literature searches: the guideline committee should refer to the categories of neurological conditions developed by the Neurology Intelligence Network in 2015 for classification purposes, in order to ensure that all categories are sufficiently represented. These categories are available via: http://www.yhpho.org.uk//resource/view.aspx?RID=207314. The Neurology Intelligence Network categories include a number of categories not currently included in the list above, including sleep disorders, inflammatory disorders and developmental disorders.	Thank you for your comment. The guideline committee will consider the information you have provided when confirming the list of conditions that will be used in the literature search strategy.
Neurological Alliance	general	general	We support the aim of developing a guideline to support better initial assessment, recognition and referral of people presenting in non-specialist settings with symptoms suggestive of a neurological problem. Patient experience data suggests that this stage of the pathway is not currently working well for people with suspected neurological conditions, with 40% of patients waiting over a year between first onset of symptoms and referral to a specialist (http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report). It is therefore essential that primary care practitioners are supported to assess people presenting with neurological conditions and refer them in a timely manner.	Thank you for your comment. The aim of this guideline is to support non-specialists in primary and secondary care to make appropriate and timely referrals for suspected neurological conditions.

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
Neurological Alliance	general	general	It is important that the guideline and scope recognise the full range of different types of symptoms linked to neurological disorders, including non-movement related symptoms such as sleep disorders, pain, chronic fatigue and digestive disorders.	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. Specific symptoms are not highlighted in the scope, but will be determined through literature searches and in collaboration with the guideline committee.
Neurological Alliance	general	general	Existing practical resources and initiatives to note for the development and implementation of this guidance include: - The information and data provided through the Neurology Intelligence Network, available via: http://www.yhpho.org.uk/default.aspx?RID=198139 - Neurological Alliance patient experience data drawn from almost 7,000 people living with neurological conditions, available at http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report - NHS England's current project scoping models of community care and support for people diagnosed with neurological conditions - The Primary Care Neurology Society http://www.p-cns.org.uk/, a network of primary care professionals with an interest in neurology which collates useful resources.	Thank you for your comment. The guideline committee will take this information into consideration during guideline development.
Neurological Alliance	general	general	We agree with the proposed title change to "Suspected neurological conditions: Recognition and referral" as it reflects the symptom-led approach of the guideline and the fact that the guideline refers chiefly to primary care settings where a confirmed diagnosis has not yet been made.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.

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NHS England	2	26	It will be a challenge to give common advice for both children and adults. I am uncertain if recognition and referral is a problem in children. Do you have any evidence about this? Also in adults the problem is probably more over referral due to inability to satisfy the customer! I suspect that the NA survey picks up GP reluctance which is possibly entirely appropriate in some/many instances. More consideration needs to be given to these issues please before embarking on the scope. Have you asked the paediatricians what they think about a joint guideline? Having consulted my NHSE paediatric colleague NCD she is firmly of the view that there should be separate guidance for children and adults. It is critical to explore this further before finalising the scope.	Thank you for your comment. This guideline will cover children, young people and adults. There will be many issues that are the same to all age groups. Where there are differences, the guideline committee will identify issues that are specific to each age group and will consider the best way to present the recommendations.
NHS England	2	37	Key areas should be the questions to ask to explore the nature of the symptoms. This is crucial and more important than examination.	Thank you for your comment. The guideline committee will bear this in mind when finalising the review questions and reviewing the evidence.
NHS England	3	69	Please can you define economic aspects in this context	Thank you for your comment. If any recommendation has an impact on NHS resource use then economic aspects will be taken into consideration, meaning that the resource impact to the NHS will be weighed up against the net health effect of the recommendation.
NICE	General	General	The Quality Standards programme has no comments to make at this scope consultation phase	Thank you for your comment.
Optical Confederation	3	80, 81, 82	Optometrists currently have a range of clinical investigations available to them for the assessment of neurological or possible neurological problems. These include:	Thank you for your comment. The scoping group considered that patients presenting in optometry settings with symptoms suggestive of a neurological condition would generally be referred to their GP

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			• Assessment of the optic nerve head for swelling (papilloedema) and optic atrophy using a variety of ophthalmoscopic devices • Full assessment of the pupillary reflexes • Assessment of central and in many cases peripheral visual fields. Optometrists are trained in the differentiation of neurological form other causes of visual field loss • Assessment of the oculomotor balance and the ability to identify incomitant squint caused by neurological disease These skills and competencies together with equipment normally found in community optical practices enable an optometrist to identify and refer patients with vision loss or visual system deficits secondary to neurological disease.	before onward referral to neurology. This guideline will consider examinations, assessment tools and investigative tests that can be used across non-specialist settings and do not require specialist training or competencies.
Optical Confederation	4	86	We suggest that an algorithm designed to help classify headache indicative of serious neurological disease, or rather neurological disease that required specialist assessment by a neurologist, would be extremely useful to non-specialists clinicians in primary care.	Thank you for your comment. We have included a proposed review question on the value of assessment tools (such as algorithms) that may help non-specialists decide whether referral for further neurological assessment is necessary.
Optical Confederation	4	89, 90	As in comment 1 above, optometrists currently have a range of clinical investigations available to them for the assessment of neurological or possible neurological problems. These include: • Assessment of the optic nerve head for swelling (papilloedema) and optic atrophy using a variety of ophthalmoscopic devices • Full assessment of the pupillary reflexes	Thank you for your comment. The scoping group considered that patients presenting in optometry settings with symptoms suggestive of a neurological condition would generally be referred to their GP before onward referral to specialist care. This guideline will consider examinations, assessment tools and investigative tests that can be used across

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			• Assessment of central and in many cases peripheral visual fields. Optometrists are trained in the differentiation of neurological form other causes of visual field loss • Assessment of the oculomotor balance and the ability to identify incomitant squint caused by neurological disease These skills and competencies together with equipment normally found in community optical practices enable an optometrist to identify and refer patients with vision loss or visual system deficits secondary to neurological disease.	non-specialist settings and do not require specialist training or competencies.
Optical Confederation	4	91	Conventional referral pathways for community optometrists commonly involve referral to the patient's GP with a preliminary diagnosis unless an urgent referral direct to secondary care is indicated such as with cases of papilloedema. The GP will then agree (or disagree) that the need for referral to a neurologist is indicated and add value to the referral by including other relevant clinical data	Thank you for your comment. The guideline committee will take this into consideration when making the recommendations.
Optical Confederation	4	92, 93	Specific referral criteria for the referral of patients with vision related signs and symptoms would be welcomed by optometrists.	Thank you for your comment. This is covered by the scope of this guideline.
Optical Confederation	4	103,104	We suggest that consideration is given to determining the professional group or groups best suited to assessing presenting signs and symptoms – for example optometrists in primary care, who have the necessary skills and instrumentation, would be best placed to assess anomalies of the visual system caused by	Thank you for your comment. The aim of this guideline is to support non specialist to make appropriate and timely referrals for suspected neurological conditions to specialist care. This guideline will therefore consider examinations, assessment tools and investigative tests that can be

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			neurological disease either causing symptoms or evidenced by functional deficits such as clumsiness .	used across non-specialist settings and do not require specialist training or competencies.
Optical Confederation	4	108	We would encourage the committee to consider specific vision and vision related symptoms as well as other symptoms of neurological disease when conducting a review of evidence.	Thank you for your comment. Vision related signs and symptoms are within the scope of this guideline.
Optical Confederation	4	109	We would encourage the committee to, where appropriate, consider combinations of tests where this can be shown to improve diagnostic accuracy.	Thank you for your comment. The guideline committee will take this into consideration when developing the review protocols.
Parkinson's UK	2	27 -30	We believe that including children over the age of 28 days will be challenging for the development of the guideline and suggest a separate guideline is developed that relates to paediatric neurological problems. The number and severity of neurological problems is varied, so adding children will add further complexity for the guideline development team.	Thank you for your comment. This guideline will cover children, young people and adults. There will be many issues that are the same to all age groups. Where there are differences, the guideline committee will identify issues that are specific to each age group and will consider the best way to present the recommendations.
Parkinson's UK	2	57 -68	Parkinson's UK thinks it will be a huge challenge to ensure the existing guidelines NICE have developed for specific neurological problems (for instance Parkinson's CG35, Multiple Sclerosis CG186 or Epilepsy CG137) will complement this guideline. We recognise the focus of this guideline will be different i.e. on initial assessment of those without a confirmed diagnosis, however as many neurological conditions present similarly on initial assessment we believe it is important this guideline does not exclude any neurological condition, even those that have their own guideline.	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. This guideline will cover the recognition and referral of symptoms suggestive of a neurological condition, before a diagnosis has been made. Conditions that are already covered by NICE guidance will therefore not be excluded, but the existing guidance will be cross-referred to where there are already recommendations that cover the recognition and referral of symptoms.

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				We have amended section 1.3 of the scope to make this clearer.
Parkinson's UK	3	General	We are concerned that the scoping document does not cross refer to other guidelines NICE have already developed including depression, falls, palliative care, mental health and mental wellbeing at work and for over 65s. On the same basis NICE have excluded these areas from the scope this guideline should cross-refer to ensure that the guideline is comprehensive and useful for those referring to it. Also we are concerned that no social care guidelines have been mentioned throughout this scoping document and it makes sense to at least cross-refer to some as people living with neurological problems will need to access social care, even at the initial advice phase and so this really should be factored in.	Thank you for your comment. The guideline will cross-refer to all related guidelines including any social care guidelines if available. We will make this clear in the final document and the NICE pathway will clarify this further.
Parkinson's UK	4	94	We are concerned that the scope only talks about initial management advice for people with a suspected neurological problem; we would recommend the guideline also outlines the ongoing management advice to ensure it is a useful reference point for health and care professionals.	Thank you for your comment. The needs of patients and their families or carers will be considered at every stage of the guideline development process. However it is important to note that this is not a condition specific guideline. Therefore, the guideline committee will only be considering initial management advice up to the point of diagnosis and will not be able to make recommendations on the ongoing management of specific conditions.
Parkinson's UK	4	96	This will depend on the condition; however it would be useful for the guideline to refer to the various third sector organisations that support people with neurological conditions as they will have information and possibly support to help the individual with the	Thank you for your comment. Information for the public is usually published alongside the guideline, and this often includes further sources of support and information for patient and their families and carers.

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			suspected neurological problem. It might be useful to note that for a condition like Parkinson's we have developed resources based on user testing with people with the condition and their families and carers that is dependent on their stage of the condition. The research we conducted found that those newly diagnosed with the condition could not handle all of the information about how their condition may progress, but welcomed some information, along with avenues for support.	
Parkinson's UK	5	121	We believe the Parkinson's guideline CG35 should be included here.	Thank you for your comment. We agree and have amended the scope to acknowledge the Parkinson's guideline.
Parkinson's UK	7	176	The National Service Framework for Long Term Conditions is not a current document used as a policy to direct the care of neurological problems.	Thank you for bringing this to our attention. We have amended the document accordingly and removed the reference to the National Service Framework.
Parkinson's UK	7	180	It is worth noting the Public Accounts Committee has recently undertaken an inquiry into the progress review of neurology services and this should be reporting in the coming months. We would suggest this is included in this section.	Thank you for your comment. We will assess this inquiry when it is published and reference it in the full guideline if appropriate.
Parkinson's UK	General	General	We would recommend that you refer to the National Neurology Intelligence Network – (http://www.yhpho.org.uk//resource/view.aspx?RID=207314) for a wider list of neurological conditions to ensure that the literature searches you outline in the scope are comprehensive.	Thank you for your comment. The guideline committee will consider the information you have provided when confirming the list of conditions that will be used in the literature search strategy.
Parkinson's UK	General	General	We believe the proposal to change the title to "Suspected neurological conditions: Recognition and referral" makes more sense.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.

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Primary Care Neurology Society	2	27	Subtle neurological symptoms that are not immediately suggestive of brain tumours but are in fact a result of hydrocephalus due to a cyst eg. Pineal cyst needs to be incorporated into this guideline, as the NICE guideline on brain cancer doesn't cover this and this is directly relevant to a primary care professional.	Thank you for your comment. The guideline committee will take this into consideration during guideline development.
Primary Care Neurology Society	2	44	There needs to be consideration given to issues that could get raised as part of the development of this new guideline that could then impact on existing NICE guidance. Not only should there be cross referral, but consideration needs to be given to whether existing guidelines need to be modified.	Thank you for your comment. The guideline committee will consider the relationship with existing NICE guidance when making recommendations. If there is any discordance with existing recommendations in published NICE guidance, this will be proactively managed during the process of guideline development.
Primary Care Neurology Society	1	11-13	If this guideline is directed at non specialist healthcare professionals, then the group involved in developing the guideline should include a diverse range of professionals and should consider including a nurse representative. Our reason for this is to ensure that the information being produced takes into account the fact that the nurses are often having to explain what has been told to them by the specialist, which can result from inadequate communication of diagnosis and treatment options etc. Therefore, having a nurse on the group you would gain insight into this to ensure that the diagnostic phase was better managed.	Thank you for your comment. The scoping group felt that nurses do not tend to make decisions about whether to refer people with suspected neurological conditions to specialist care, and therefore did not feel that there was a need for nurses to be represented as a full member of the guideline committee. Nurse input may be sought as an expert advisor during guideline development instead.
Primary Care Neurology Society	1	4	We believe the title should be more reflective of the fact that patient present with neurological symptoms and therefore the	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'. The focus on symptoms is implicit within the

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			title needs to include the word 'symptoms' and perhaps it should also include the phrase 'when to wait or refer'.	new title, as is the fact that referral may not always be appropriate.
RCGP	General	General	There are an increasing number advances in basic neuroscience research, gene identification, neurogenomics, neurodiagnostic tools including advanced neuroimaging technologies which will help diagnostics in primary and secondary care. The draft scope currently focuses only on assessment, diagnosis and referral and does not address the issues of new treatment modalities for existing conditions such as Fragile X. Traditionally secondary care neurology services "diagnose and adios patients" leaving primary care having to manage more people with age related neurologic disorders such as dementia, stroke, Parkinson's disease, epilepsy, and autoimmune disorders.	Thank you for your comment. The guideline covers assessment tools and investigative tests that can be used by non-specialists. The use of diagnostic tests in specialist care will not be covered.
RCGP	General	General	There appears to be increasing subspecialisation in neurology which means patients and their carers may have to see several specialist particularly where epilepsy is involved. Dementia treatment is now not seen as part of neurological services but part of elderly care psychiatry and similar problems can occur with young people who fall between paediatric and adult neurological services. The use of multidisciplinary services has helped cancer services and may be useful in the increasing specialised and difficult to access neurological services. Specialist nurses in Parkinson's, dementia and epilepsy have been useful to patients and their carers in the community.	Thank you for your comment. The guideline committee will take this into consideration when reviewing the evidence and making the recommendations.

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RCGP	General	General	It would appear that access to neuroradiology and genetic medicine services are likely to be increasing important for diagnostics with specialist community based nurses to support patients in the community. The scope should reference and support the UK strategy for rare diseases https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/260562/UK_Strategy_for_Rare_Diseases.pdf	Thank you for your comment. The guideline covers assessment tools and investigative tests that can be used by non-specialists. The use of diagnostic tests in specialist care will not be covered. The UK Strategy on Rare Diseases has been added to section 3.3 of the scope.
RCP			The RCP is grateful for the opportunity to respond to the above consultation. We would like to formally endorse the response submitted by the British Thoracic Society.	Thank you for your comment.
Royal College of Psychiatrists			The guidance for neurological symptoms should be inclusive with the explicit intention of cross-referring to other guidelines already dealing with specific neurological conditions. Not covering a long list of conditions on the basis that they are covered specifically elsewhere negates much of the value of developing this particular set of guidelines. We presume that the scope refers to non-specialists in primary care, with psychiatrists considered to be specialists.	Thank you for your comment. This guideline will cover the recognition and referral of symptoms suggestive of a neurological condition, before a diagnosis has been made. Conditions that are already covered by NICE guidance will therefore not be excluded, but the existing guidance will be cross-referred to where there are recommendations that cover the recognition and referral of symptoms. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. We have amended section 1.3 of the scope to make this clearer. The scope covers non-specialists in both primary and secondary care, in recognition of the fact that patients

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				may present to non-neurological specialists in either setting.
Royal College of Psychiatrists			Some consideration may be needed for the following: It is reasonable in present clinical management <u>not to</u> request CT or MRI head scans routinely in those presenting with first episode psychosis, in the absence of signs or symptoms suggestive of intracranial pathology.* Despite the potential benefits of routine scanning, the current evidence base is too weak to support any clinical benefits in routinely using MRI or CT scanning in people with first-episode psychosis. However, it would be useful if the scope consultation for neurological problems could be more specific about what constitutes appropriate suspicion, and comment on the value of different imaging techniques into neurological evaluations. It should be noted that CT and MRI are not interchangeable. *a. Structural neuroimaging in first-episode psychosis; NICE technology appraisal guidance [TA136] Published date: February 2008. http://www.nice.org.uk/guidance/TA136 b. Albon E, Tsourapas A, Frew E, Davenport C, Oyebode F, Bayliss S, *et al*. Structural neuroimaging in psychosis: a systematic review and economic evaluation. *Health Technol Assess* 2008;**12**(18).	Thank you for your comment. The guideline will focus on examinations, assessment tools and investigative tests that can be carried out or ordered by non-specialists to determine whether referral is appropriate. This may include CT and MRI.
Royal College of Psychiatrists			It is suggested that the final document should include also some guidance on when to refer on to neuropsychiatry services. We acknowledge that non-specialists may not always have access to neuropsychiatry services, outside of major centres. Also, the majority of referrals to neuropsychiatry come through neurology rather than via primary care as it will often be appropriate for patients to be assessed	Thank you for your comment. Decisions about referral to other specialist services would usually be made by neurologists. The primary aim of this guideline is to focus on referral to specialist care for further neurological assessment, following initial assessment

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			by neurology first. Though this particular NICE guideline / pathway needs to comment on neuropsychiatry.	by non-specialists. The guideline committee may consider referral to other specialist services outside of neurology where appropriate**.**
Royal College of Psychiatrists			The pathways for referral of neurological problems may of course change with the advent of new treatments for distinct neurological disorders, as may be emerging for dementia: *Speaking to The Independent, Professor Rossor, who was a member of the expert panel that produced the Wish report, says that a lot has happened in the past year and that the outlook has changed."If we are entering a new era of molecular diagnosis and treatment – even if we only see small effects – the approach will be different," he says. "This is about shifting the focus from the behaviour [of those with dementia] and how to manage it, to brain function and how to treat it. It means shifting from therapeutic nihilism to therapeutic optimism. Nihilism is widespread." Wednesday 6 January 2016 14:41 BST*	Thank you for your comment. The guideline will cover assessment tools and investigative tests that can be used by non-specialists to aid decision-making about whether referral is appropriate. The use of diagnostic tests and treatments in specialist care will not be covered.
Royal College of Psychiatrists			From the perspective of the Academies within the Royal College, there is a need to consider within the NICE scope the role of Psychiatry, as a medical speciality dealing with a particular set of brain disorders and the psychological shaping physical symptoms (e.g. pain, fatigue). Specifically, what is expected in undergraduate education and the training needs of psychiatrists with respect to the evidence-based assessment of neurological symptoms and signs, including the use of clinical tests (electroencephalography and neuroimaging). Will the guidelines consider unmet areas of biological psychiatric research to improve understanding and management of conditions the interface between neurology and psychiatry?	Thank you for your comment. The issues you have raised are beyond the scope of this guideline, which deals with the recognition and referral of suspected neurological conditions by non-specialists.

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SUDEP	2	47	**Question 4:** The scoping document states conditions which already have guidelines won't be covered but that recognition of symptoms covered in other guidelines will be cross referred. The current Epilepsy Guidelines reference 'referring to specialist services following a first/suspected seizure', though no specific guidance or information regarding the recognition of symptoms is given to primary care health professionals to assist with this. The health professionals who refer to this new document may well come to it in the first instance upon a patient presenting with a possible neurological conditions. Considering some of the larger neurological conditions may well end up being the final diagnosis, it is vital that they are not neglected from this new guideline and that the recognition of their key symptoms is covered in general terms so as to point professionals in the right direction for appropriate and swift referral. Our charity has had experience from our bereaved families where their loved ones were mis-diagnosed or symptoms not recognised to prompt a referral within primary care settings for specialist investigations, in some instances resulting in their loved one's death (later confirmed as due to epilepsy/Sudden Unexpected Death in Epilepsy during inquest). So it is concerning that epilepsy may be missed out of this new document and not considered in at least general terms considering the title is 'neurological conditions'.	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. This guideline will cover the recognition and referral of symptoms suggestive of a neurological condition, before a diagnosis has been made. Conditions that are already covered by NICE guidance will therefore not be excluded, but the existing guidance will be cross-referred to where there are already recommendations that cover the recognition and referral of symptoms. We have amended section 1.3 of the scope to make this clearer. The guideline committee will consider implementation issues (such as recognition of symptoms) in collaboration with the NICE implementation team. However there is a certain amount of assumed knowledge that even non-specialist health professionals will be able to recognise symptoms that patients present with. It will not be the role of this guideline to go into detail about how to recognise specific symptoms.

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SUDEP	7	160	It is not just the 'uncommon' disorders that can be initially misdiagnosed. Appendix G of the NICE Epilepsy guideline estimates misdiagnosis rates of between 20-30%, stating this is 'probably underestimated' and clearly shows a 'significant' burden on the NHS due to wasted resources and funds. Providing information and guidance to primary care health professionals who are often the first port of call to help them accurately put their patients on the right path for diagnosis can not only help reduce this burden but has the potential to save some of the potentially avoidable deaths from neurological conditions which occur each year.	Thank you for your comment. We have amended section 3.2 and removed the word 'uncommon'.
SUDEP	7	176-178	It would be useful to add in at the end of this first paragraph something like: 'Information for both professionals and patients with suspected or diagnosed common neurological conditions is also provided by many specialist charitable bodies.' Could there be a hyperlink or resource linked to this document where the contact details of these key organisations are mentioned? If this document becomes the first place some professionals go for information, this could prove valuable in helping them and their patients if they are signposted to specific, specialised information as needed throughout the early stages of the referral/diagnosis process.	Thank you for your comment. The section you refer to is about relevant legislation, regulatory frameworks and statutory or professional guidance from professional bodies. Information for the public is usually published alongside the guideline, and this often includes further sources of support and information for patients and their families and carers.
SUDEP	General	General	**Question 1:** Providing specific guidance and information for those in primary care setting whose patients present with suspected neurological conditions is a challenge, but one which vitally needs addressing. Compared to the diagnosis and care of	Thank you for your comment and for highlighting these issues. The aim of this guideline is indeed to increase awareness among non-specialists of

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 recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

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			people with cancer, diabetes or heart conditions for example, neurology is often stuck in their shadows and not seen as a priority in need of addressing or much attention. However, there are a significant number of deaths each year due to neurological conditions, along with mis-diagnoses and emergency-admission rates continuing to rise. We have often heard from GPs their concerns and lack of confidence in understanding epilepsy and how best to help their patients who have already been diagnosed with the condition; for many, their knowledge of the condition is limited, and if this is the case across the UK then their ability to recognise symptoms requiring referral may be even more so. Providing them with robust guidance to assist in this is a step to building conference in primary care settings regarding neurological conditions and helping patients access the diagnosis and care they need swiftly and correctly. It would be a challenge to encourage standardised uptake/use of these guidelines, but there are those who would be immediately pleased for the assistance.	symptoms suggestive of suspected neurological conditions, including the rarer ones.
SUDEP	General	General	**Question 3**: The new proposed title removes the option for some to view the guidance as 'not relevant to them' due to them not believing it is their responsibility to play a part in the diagnosis of those with (suspected) neurological conditions. Anecdotally, amongst the health professionals, there can be a lack of accountability and responsibility for the various stages and roles involved in the care pathway for people with	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'. The guideline committee will consider the point about clarity of roles and responsibilities during the referral

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			(suspected) neurological conditions. By providing clear, specific guidance of the recognition of key symptoms, what to do upon recognition and specifically who is responsible for this stage of the process; this would start the ongoing process of improving care and standards for people with neurological conditions, potentially saving the lives of those who get trapped in the system or never correctly diagnosed until it is too late.	process when reviewing the evidence and making recommendations.
The Brain Tumour Charity	Question 1	106, 108	The two main outcomes that we think would have the biggest impact on practice and be the most challenging to implement for recognition and referral of brain tumours are as follows: • <u>Time to diagnosis</u> – The median Total Diagnostic Interval (TDI) (from appearance of first symptoms to diagnosis) for childhood brain tumours in the UK, as measured through the HeadSmart campaign, was found to be 6.7 weeks in 2013. The challenge will be to help non-specialists (especially in primary care) to recognise symptoms earlier and reduce the TDI further, to five weeks so that average diagnosis times for brain tumours are among the best in the world. • <u>Positive predictive value of symptoms</u> – We are concerned that using PPV alone may serve as a barrier to non-specialists such as GPs referring patients with symptoms that may be caused by a brain tumour for crucial tests, such as MRI and CT scans, possibly delaying diagnosis of brain tumours. Individual brain tumour symptoms often mimic those of other common	Thank you for your comment. The aim of the guideline is to support non specialist to make appropriate and timely referrals for suspected neurological conditions to specialist care. All diagnostic accuracy outcomes, including positive predictive value, will be used to inform the guideline committee of the utility of particular signs and symptoms.

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			conditions which is why the use of PPV is not the best method to use as a basis for referral decisions.	
The Brain Tumour Charity	Question 4	General	Adult brain tumours are missing from the list. Although we note that 'Brain cancers' are included in the consultation document's list of guidance that will be cross-referred to, it is not clear whether consideration has been given to low-grade (non-cancerous) brain tumours.	Thank you for your comment. The guideline committee will consider the information you have provided when confirming the list of conditions that will be used in the literature search strategy. It is important to note that this guideline will be developed on a symptom basis and therefore we are not excluding any specific conditions. However existing NICE guidance will be cross-referred to where there are already recommendations that cover the recognition and referral of symptoms.
The Brain Tumour Charity	Question 2	General	One national initiative that would help to overcome the challenge of working towards the time to diagnosis goal is the *HeadSmart: be brain tumour aware* campaign to reduce diagnosis times of childhood brain tumours. Brain tumours are the leading cause of childhood cancer deaths in the UK. Around 500 children and young people in the UK are diagnosed each year. Diagnosis times of childhood brain tumours are longer in the UK than in many other countries. The UK-wide campaign aims to raise national awareness of the common signs and symptoms of a brain tumour in children and young people by equipping parents, the public and healthcare	Thank you for your comment. The guideline committee will take this information into consideration during guideline development.

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			professionals with information they need. This is achieved through the distribution of symptom cards and posters to raise awareness of symptoms, and the promotion of a clinical guideline and training module for health professionals (1). The HeadSmart campaign aims to reduce brain tumour and brain cancer diagnosis times to under five weeks, on par with the best countries in the World. Before the launch of HeadSmart, average diagnosis times for children with brain tumours in the UK was 13 weeks. After publication of the guidelines for healthcare professionals in 2011, this was reduced to 9.1 weeks. Following the public launch this was reduced to 7.5 weeks in 2012, 6.9 weeks in 2013, and most recently 6.7 weeks (2).	
The Brain Tumour Charity	Question 3	General	We would support the change to the title of this guideline, as it would bring the scope of the document in line with the recently published NICE Guidelines on Suspected Cancer: recognition and referral.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
The Dystonia Society and Warwick Clinical Trials Unit	**2**	41	The guideline refers to "referral to specialist care" being within scope. It would be useful to understand how widely this might be understood, as there is an issue around access for people with dystonia to other health care professionals (beyond neurologists), particularly to help with the on-going management of 'non-motor' symptoms such as pain, anxiety or depression. We asked participants in our survey whether they had received an onwards referral to 'emotional or psychological support'.	Thank you for your comment. Decisions about referral to other specialist services would usually be made by neurologists. The primary aim of this guideline is to focus on referral to specialist care for further neurological assessment, following initial assessment by non-specialists. The guideline committee may consider referral to other specialist services outside of neurology where appropriate.

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			Around a fifth (20%) had been referred for this sort of support, 11% said that they were not referred, but would not have wanted it, but 66% said that they would have wanted this support but were not offered it. Given this we would recommend that consideration be given to whether the onward referral to other key healthcare professionals (for example psychologists, physiotherapists etc.) could also be included in the guideline scope. *RECOMMENDATION: Consider how scope could include referral to other healthcare specialists such as those offering emotional / psychological support.*	
The Dystonia Society and Warwick Clinical Trials Unit	2	42	We welcome the focus in the guideline scope on "information, support and initial management advice". It will be helpful if this can include information about patient advocacy organisations like the Dystonia Society, as well as wider NHS services. Our online survey asked what sort of information would be most useful for people when they are diagnosed with dystonia and the most common responses were around the wider impacts of the condition on quality of life, pain, changes to lifestyle etc.. This suggests that early information about support networks for those with suspected neurological conditions would be important. RECOMMENDATION: "Information, support and initial management advice" should routinely include links to patient advocacy organisations.	Thank you for your comment. Information for the public is usually published alongside the guideline, and this often includes further sources of support and information for patients and their families and carers.

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The Dystonia Society and Warwick Clinical Trials Unit	**2**	45	The Dystonia Society believes that a guideline with a broader scope could be hugely beneficial for dystonia. As such we would prefer the "assessment, diagnosis and management of suspected neurological problems after referral to specialist neurological services" to be within scope for the guideline. We recognise, however, that this would involve a significant shift from the current scope, and believe that this would most likely be best addressed through an additional specific guideline on dystonia.	Thank you for your suggestion. It is correct that this is a significant shift from the proposed scope. The scoping group has considered all issues raised by stakeholders at consultation and have considered the prioritisation of clinical areas to be included against the resources available. We believe that a general guideline based on recognition of general neurological symptoms rather than specific conditions would be most beneficial.
The Dystonia Society and Warwick Clinical Trials Unit	**3**	77	While we believe that a specific guideline on the treatment of dystonia is needed, we are very pleased that NICE has committed to produce this guideline around the recognition and referral of neurological conditions. Our information suggests that diagnosis of dystonia still takes on average more than two years, and in some instances much longer. As such the issue of diagnosis and referral remains a hugely important issue for people with dystonia. From our online survey the length of time between reporting symptoms to receiving a diagnosis ranged from three weeks, to more than 30 years. Additionally around two thirds of respondents (65%) said that their condition had at some point been misdiagnosed. As such we welcome the proposed focus of the guideline on assessment tools and tests for non-specialists, although this is particularly challenging for a condition as variable as dystonia. We are pleased to see dystonia prominently listed within the planned literature searches.	Thank you for your comment and for sharing the results of your survey with us. The aim of the guideline is indeed to increase awareness among GPs and other non-specialists of symptoms suggestive of neurological conditions, including the rarer ones.

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			The comments received back through our online survey highlighted the enormous difference that swift identification and referral from GPs can have. For example, talking about the length of time to be referred to a specialist one respondent said that referral took: "6 years from first symptoms" but that "after seeing a different Dr he referred me on first visit and it took about a month for appointment". We asked respondents to our online survey to rate the support that they received from their GP from when they first presented with their symptoms, to the point of diagnosis. The responses were varied, but more than half (55.5%) rated the support 'poor' or worse, 15.5% rated it 'satisfactory' and 29% rated it 'good' or better. This significant level of variation, and significant dissatisfaction with support suggests that for people with dystonia clear guidelines for non-specialists to ensure that the right referral is made early on could be very important. We are pleased that this is reflected in the suggested literature searches. The Dystonia Society's best practice guide also includes some information in this area (http://www.dystonia.org.uk/images/Best_Practice_Guide.pdf) It is clear that awareness among GPs is a key determining factor in prompt diagnosis of dystonia – we would therefore suggest that consideration is given to "What can be done to increase awareness and understanding of rarer neurological conditions	

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			among GPs" This should perhaps also be a key question to help develop the guideline. *RECOMMENDATION: "What can be done to increase awareness and understanding of rarer neurological conditions among GPs" should also be a key question for the guideline.*	
The Dystonia Society and Warwick Clinical Trials Unit	4	112	We are pleased that 'quality of life' and 'patient satisfaction' feature in the main outcomes suggested. Availability and quality of information should also be considered as an outcome. RECOMMENDATION: Availability and quality of information should also be considered as an outcome.	Thank you for your comment. This is not a definitive or exhaustive list as the final outcomes will be determined when the clinical questions have been formulated and discussed with the guideline committee. The guideline committee will consider your suggestion.
The Dystonia Society and Warwick Clinical Trials Unit	5	124	As well as being a variety of different individual conditions, dystonia can also occur alongside other conditions – for example, significant numbers of people with cerebral palsy or Parkinson's may also have dystonia. Early recognition and subsequent targeted management of dystonia alongside another condition can make a very significant difference. It would therefore be helpful to ensure that these links with other conditions are properly recognised in the cross-referencing with other guidelines.	Thank you for your comment. Dystonia, as a presentation, would be identified as a sign and symptom of a suspected neurological condition.
The Dystonia Society and Warwick Clinical Trials Unit	General	General	The Dystonia Society works with thousands of people affected by dystonia every year, whether that is through our dedicated helpline, through our network of local groups, or through the hundreds of thousands of people who visit our website for information each year. In order to inform our response to the draft guideline scope we conducted a short online survey to	Thank you for your comment. Management of people with a confirmed diagnosis of dystonia is outside the scope of this guideline.

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			gather views and experiences on the process of being diagnosed with dystonia and the effect(s) this has on both the person affected and their family. We also sought views on what would be important information for family/carers, to help understand and manage living with the condition. We are submitting this response jointly with the Warwick Clinical Trials Unit at the University of Warwick, with whom we have been working on a research project. Dystonia is a neurological movement disorder that affects around 70,000 people in the UK. It is an incredibly varied condition that can range from genetic 'primary dystonia' that can affect the entire body and generally begins in childhood, to very specific adult-onset 'focal' dystonia that affects just one part of the body. As well as the physical impact, dystonia can have a huge impact on quality of life. It is not 'curable' and the most common form of treatment offered in focal dystonia is Botulinum toxin injections. Our members report huge variation in the support and treatment that they receive for the condition. In addition there is a growing weight of evidence around the 'non-motor' symptoms of dystonia, which can include anxiety, depression, pain and problems with sleep. However, the medical support provided to support these non-motor symptoms is at present incredibly varied.	

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			Qualitative evidence collected by the Dystonia Society, from both people with dystonia and medical professionals in the dystonia community, suggests that **a NICE guideline specifically relating to the treatment and on-going management of dystonia would be the best way to improve consistency of treatment and outcomes for patients**. Working with leading medical professionals, the Dystonia Society has produced 'best practice' guidance that could usefully inform a formal NICE guideline. This can be found here: http://www.dystonia.org.uk/images/Best_Practice_Guide.pdf *RECOMMENDATION: The Dystonia Society believes that achieving the best and most consistent patient outcomes in the treatment of dystonia necessitates expanding the currently planned guideline scope and considering the development of* ***a NICE guideline specifically relating to the treatment and on-going management of dystonia.***	
The Neuro Foundation	2	40	It is important that GPs and those in secondary care are aware of the possibility of NF in anyone presenting with the features in the scope below. There should be a low threshold for investigation of symptomatic individuals with NF who are more likely to have an underlying neurological complication if they present with symptoms. Brain cancers. (Gliomas and ependymomas in NF1 and NF2, malignant meningioma in NF2)	Thank you for your comment. The guideline committee will take this into consideration when reviewing the evidence and making the recommendation.

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	2 “ “	40 “” “”	Dysembryoblastic neuroepithelial tumour in NF1 ☐Epilepsy. (NF1 and NF2) ☐ Migraine. (NF1 and NF2) Cerebrovascular disease (NF1 and NF20 Aqueduct stenosis (NF1) ☐Cognitive impairment (NF1) ☐ Multiple sclerosis. (NF1) Superficial siderosis related to surgery Cranial nerve schwannomas Optic pathway glioma Spine Spinal cord compression and pain related to tumours NF1, NF2 and schwannomatosis or to severe kyphoscoliosis. (NF1) ☐ Peripheral nerve Peripheral nerve deficit due to tumours (NF1, NF2 and schwannomatosis) Neuropathy (NF1 and NF2) Neuropathic pain. (NF1 and NF2 and schwannomatosis) Malignant peripheral nerve sheath tumour (NF10	
The Neuro Foundation	8	45	We note the draft SCOPE of the above guideline that is out for public consultation. We also note that, whilst much of the scope is very relevant to the potential modes of presentation of individuals affected with neurofibromatosis, no mention is made	Thank you for your comment. The guideline committee will consider the information you have provided when confirming the list of conditions that will be used in the literature search strategy. It is important to note that this guideline will be developed

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			of these conditions. Please include mention of neurofibromatosis in the scope for the following reasons: Neurofibromatosis 1, Neurofibromatosis 2 and Schwannomatosis are inherited conditions that have a major impact on the nervous system. NF1 affects 1/2500; birthmarks and freckling may be the only presenting manifestations in children, particularly if they have no family history (>50% are de novo). However, NF1 is associated with potentially life-threatening complications including nervous system tumours, cerebrovascular disease and cord compression. NF2 and schwannomatosis are uncommon diseases but have significant neurological symptoms. NF2 often presents with brain tumours or spinal tumours causing neurological deficit or pain. Schwannomatosis is characterised by peripheral nerve or spinal nerve root tumours that cause severe pain and neurological deficit.	on a symptom basis and therefore we are not excluding any specific conditions unless there is existing NICE guidance that covers the recognition and referral of symptoms.
The Neuro Foundation		6	Families' wider support needs are often addressed by charitable organisations dedicated to serving people affected by specific neurological conditions. The benefits of this support in improving treatment outcomes; condition management and improved quality of life outcomes is significant.	Thank you for your comment. Information for the public is usually published alongside the guideline, and this often includes further sources of support and information for patients and their families and carers.
The Neuro Foundation	76	3	Care is nationally commissioned for people with Complex NF1 (unusual or potentially life-threatening complications) at GSTT and CMFT. All NF2 care in England is nationally commissioned	Thank you for your comment. It is beyond the scope of this guideline to consider care arrangements for people with a confirmed diagnosis of a neurological condition.

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			in four centres (CMFT, GSTT, Cambridge and Oxford). All centres offer telephone advice and clinic assessment	
The Walton Centre NHS FT		General	The issues in secondary care are rather different and perhaps guidance needs to be split for primary / secondary care? In secondary care there are two main issues; 1) acute neurological presentations (recognition, early management, referral to neurology outreach services) 2a) acute exacerbations of existing long term conditions (MS, PD, epilepsy etc); 2b) Management of long term neurological condition during admissions for other reasons eg a pt with PD admitted with #hip)	Thank you for bringing this to our attention. Presentations in secondary care will be covered within the scope of this guideline. The guideline committee will bear the first issue in mind when discussing the evidence and making recommendations. Regarding the second issue, this guideline will cover the recognition and referral of symptoms suggestive of a neurological condition, before a diagnosis has been made. The management of people with confirmed diagnosis of a long-term neurological condition is therefore outside the scope of this guideline, but may be covered within existing guidance for specific conditions.
The Walton Centre NHS FT	2	44	Excluding areas already covered by NICE guidance seems problematic; existing guidance are largely based on diagnoses, rather than clinical presentations (see comment 1). So any new guidance is bound to overlap with existing condition guidance, and I assume would 'refer on to them for further info' etc	Thank you for your comment. This guideline will cover the recognition and referral of symptoms suggestive of a neurological condition, before a diagnosis has been made. Conditions that are already covered by NICE guidance will therefore not be excluded, but the existing guidance will be cross-referred to where there are already recommendations that cover the recognition and referral of symptoms. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. We have amended section 1.3 of the scope to make this clearer.

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The Walton Centre NHS FT	7	154	Functional disorders are so common, they should be included in some way; even if only to consider in the differential diagnosis. There is a comment in the workshop feedback that these can only be diagnosed 'by ruling everything else out first'. This is incorrect and suggests a fundamental misunderstanding of these disorders, which cross every branch of medicine though are probably more common in neurological practice. There are various flags / pointers which can suggest these as a likely diagnosis either from the current presentation or past history.	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. Because of this, no specific conditions (including functional disorders) will be excluded from the guideline. The guideline committee will take this into account when reviewing the evidence and making recommendations.
The Walton Centre NHS FT		General	It is vital that any guidance is based on 'symptom complexes' or 'clinical presentations' rather than diagnoses; this mistake has been made in all sorts of guidelines in the past. For example, pts do not present with 'stroke' they present with 'acute onset neurological deficit' (which has various causes). Pts do not present with Parkinson's, they present with tremor and/or akinetic-rigid syndrome (which has various causes) etc etc. This is particularly true for guidance aimed at primary care.	Thank you for your comment. This guideline will be developed on a symptom basis, rather than by condition. The list of conditions will be used to guide the literature search. Specific symptoms are not highlighted in the scope, but will be determined through literature searches and in collaboration with the guideline committee.
The Walton Centre NHS FT		General	If the guidance is mainly about recognition & early management (and ? referral) of certain symptom complexes, the question is how (or whether!) an organisation such as NICE can achieve this. Can it train GP's & general physicians in how to take a good neurological history in 10 minutes? – probably not. A tutorial on how to do a brief but useful neurological examination? –possibly eg online video. It is probably possible to define a reasonably small number of the most common symptom complexes, and for each one develop guidance for history features, examination findings and initial investigations that would help initial	Thank you for your comment. Early management is outside the scope of this guideline. The NICE implementation team will work with the guideline committee to consider these issues when developing the implementation support materials for this guideline.

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			management and referral decisions eg 'headaches' 'dizziness' 'impaired mobility' 'loss of consciousness' 'limb weakness' 'speech or swallowing problems' etc etc. You could also do this for the acute presentations to secondary care, some of these would be the same as primary care but some would be different.	
The Walton Centre NHS FT	General		I agree on re-naming the guidance as suggested.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
Tourettes UK	2	27 -30	The inclusion of children (over the age of 28 days) in the guideline will present a challenge to the guideline development process, and the guideline committee should consider whether a separate guideline relating to the recognition of paediatric neurological conditions should be developed. However as Tourettes syndrome is a childhood onset condition this is vital to good diagnosis and lifelong care and so it essential that this problem is overcome.	Thank you for your comment. This guideline will cover children, young people and adults. There will be many issues that are the same to all age groups. Where there are differences, the guideline committee will identify issues that are specific to each age group and will consider the best way to present the recommendations.
Tourettes UK	2	57 -68	It will be a challenge to ensure that the guideline complements and supports existing NICE guidance relating to specific neurological conditions. However, as there are no existing guidelines for the majority of neurological conditions this difficulty needs to be addressed and overcome. Given that the guideline will focus on the initial assessment of people without a confirmed neurological diagnosis, it should not explicitly exclude any neurological conditions, as many initial signs and symptoms will be common to a wide range of conditions. In addition, existing NICE guidance focuses more strongly on treatment and ongoing management of neurological conditions, rather than on the pre-	Thank you for your comment. It is important to note that this guideline will be developed on a symptom basis, rather than by condition. This guideline will cover the recognition and referral of symptoms suggestive of a neurological condition, before a diagnosis has been made. Conditions that are already covered by NICE guidance will therefore not be excluded, but the existing guidance will be cross-referred to where there are already recommendations that cover the recognition and referral of symptoms.

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			diagnosis phase. Therefore, this guideline is an opportunity to complement existing condition-specific guidelines relating to neurology.	We have amended section 1.3 of the scope to make this clearer.
Tourettes UK	4	108	Gathering evidence on the outcomes and measures listed in this section may be challenging, as there is limited available data relating to neurological conditions. Although the Neurology Intelligence Network (NIN) has begun to compile, publish and analyse available data on neurological conditions, it has only been in operation for around18 months. Consequently there is less collated data at the national level for neurology than for other condition and service areas. It may be necessary to convene patients, clinicians and other key stakeholders to consider some of the outcomes and generate additional evidence.	Thank you for your comment. We agree that it may be difficult to find data on some of these outcome measures. This is not a definitive or exhaustive list as the final outcomes will be determined when the clinical questions have been formulated and discussed with the guideline committee.
Tourettes UK	general	general	Regarding the condition categories suggested above as a focus for literature searches: the guideline committee should refer to the categories of neurological conditions developed by the NIN in 2015 for classification purposes, in order to ensure that all categories are sufficiently represented. These categories are available via: http://www.yhpho.org.uk//resource/view.aspx?RID=207314. The NIN categories include a number of categories not currently included in the list above, including sleep disorders, inflammatory disorders and developmental disorders.	Thank you for your comment. The guideline committee will consider the information you have provided when confirming the list of conditions that will be used in the literature search strategy.
Tourettes UK	general	general	We support the aim of developing a guideline to support better initial assessment, recognition and referral of people presenting in non-specialist settings with symptoms suggestive of a	Thank you for your comment. The aim of the guideline is indeed to increase awareness among

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			neurological problem. Patient experience data suggests that this stage of the pathway is not currently working well for people with suspected neurological conditions, with 40% of patients waiting over a year between first onset of symptoms and referral to a specialist (http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report). It is therefore essential that primary care practitioners are supported to assess people presenting with neurological conditions and refer them in a timely manner. This is particularly pertinent for people presenting with suspected Tourettes Syndrome as GPs are genereally unaware of the specifics of the condition and are unsure of where to refer patients for diagnosis.	non-specialists of symptoms suggestive of suspected neurological conditions, including the rarer ones.
Tourettes UK	general	general	Existing practical resources and initiatives to note for the development and implementation of this guidance include: - The information and data provided through the NIN, available via: http://www.yhpho.org.uk/default.aspx?RID=198139 - Neurological Alliance patient experience data drawn from almost 7,000 people living with neurological conditions, available at http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report - NHS England's current project scoping models of community care and support for people diagnosed with neurological conditions	Thank you for your comment. The guideline committee will take this information into consideration during guideline development.

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			- The Primary Care Neurology Society http://www.p-cns.org.uk/, a network of primary care professionals with an interest in neurology which collates useful resources.	
Tourettes UK	general	general	We agree with the proposed title change to "Suspected neurological conditions: Recognition and referral" as it reflects the symptom-led approach of the guideline and the fact that the guideline refers chiefly to primary care settings where a confirmed diagnosis has not yet been made.	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.
UKMSSNA	2	38	A challenge to implementation in this instance would be the short consultation time in general practice. History taking and examination of individuals presenting with neurological conditions requires a longer appointment to be carried out effectively. This will have economic and opportunity costs that need to be factored in to the impact analysis.	Thank you for your comment. The guideline committee will bear this in mind when reviewing the evidence and making recommendations.
UKMSSNA	2	42	We endorse the need to support people with suspected neurological problems while they await diagnosis. Some of our members have had experiences of individuals with suspected MS being referred to them as MS Specialist Nurses for support – only to find at a later date that the individual concerned has a different diagnosis of for example muscular dystrophy or motor neurone disease. We would therefore suggest that caution should be advised in referring to Specialist Nurses prior to a diagnosis. Generic help and information may be more appropriate during this waiting period. For example practical support and information regarding the investigations being planned or "Getting the best from neurological services" a booklet produced by the Neurological Alliance.	Thank you for your comment. The guideline committee will take this into consideration when making recommendations.

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04 December 2015 – 08 January 2016

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UKMSSNA	2	46	It is likely to be some weeks after referral that a diagnosis is made and the individual may need further assessment or management after referral but prior to diagnosis. We suggest that this sentence be changed to "Management of neurological problems after assessment or diagnosis by specialist neurological services."	Thank you for your comment. We have amended section 1.3 of the scope to reflect that patients' information and support needs will continue past referral until a diagnosis has been made. Information and support needs post-diagnosis are not within the scope of this guideline.
UKMSSNA	3	60	Although there is a NICE Guideline for MS it would be appropriate to consider the presentation of MS in children and those under the age of 16 years in this guideline. Children and young people often present in a different way or are not diagnosed until adulthood because of the failure of primary care clinicians to recognise the need to refer to specialist services. It is estimated that between 5-10% of people living with MS experience their first symptoms under the age of 16 years. It is therefore justifiable to include children and young people with MS as one of the groups to be included in the literature search.	Thank you for your comment. This guideline will cover children and young people with suspected neurological conditions.
UKMSSNA	5	134	We think this will be a very useful tool but consideration will need to be given to how the use of this can be supported and facilitated in primary care. Effective systems of delivery will enhance the impact of the guidelines on practice.	Thank you for your response. The NICE implementation support team will work with the guideline committee to ensure effective implementation of this guideline and encourage take up of the recommendations.
UKMSSNA	7	154	A barrier to the successful reduction in the number of individuals with functional symptoms being referred to specialist neurology is the lack of alternative provision for these individuals. Although there are tests and investigations that will enable the referrer to establish if there is a functional element to the patient's presentation in primary care other referral pathways are	Thank you for highlighting this issue. The guideline committee will consider this when reviewing the evidence and making recommendations.

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			often limited. Mental health services for example are reluctant to become involved until a consultant neurologist has ruled out a rare condition. There are some excellent multidisciplinary clinics – such as the one at the National Hospital Queen Square (UCLH) under the clinical leadership of Dr Mark Edwards- that effectively manage and treat functional conditions but in the absence of this type of approach individuals often end up being referred to many different neurologists and falling between the services offered by physical and mental health.	
UKMSSNA	General	General	We welcome the development of this guideline to support primary care practitioners in the recognition of neurological symptoms and guide them in making appropriate referrals on for diagnosis.	Thank you for your comment.
UKMSSNA	2	general	Implementation of the guidelines may be hampered by lack of systems to support it within general practice. One way to facilitate effective implementation of the guidance would be to ensure the information was easily accessible in primary care perhaps by embedding the "NICE Neuro pathway in a "Neuro knowledge portal" on all GP computers. The portal could also contain quick links for referrals and a "Neuro mail" function for advice from local Specialists who agree to support the initiative. This could provide a useful time efficient one stop resource.	Thank you for your comment. The NICE implementation team will work with the guideline committee to inform the implementation support activities for this guideline.
UKMSSNA	General	general	We support the proposed change in the title of this document to "Suspected neurological conditions: recognition and referral" as	Thank you for your comment. The title is now 'Suspected neurological conditions: Recognition and referral'.

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			this makes the purpose of the document much clearer and will enable the content to be focussed appropriately.	