Suspected neurological conditions

Consultation on draft guideline - Stakeholder comments table
07 August 2017 – 19 September 2017

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Action for MdDS	Full	General	General		
Action Cerebral Palsy	Full	19	19	Issues with attention and concentration are sensory difficulties that can affect children with CP. ACP would suggest inserting a new point to this section on attention, concentration and memory problems, saying: "Be aware that children with cerebral palsy can experience difficulties registering and processing sensory information, which can result in difficulties with concentrating and paying attention. See recommendation 1.16.1 on registering and processing sensory information in the NICE guideline on Cerebral palsy in under 25s: assessment and management."	Thank you for your comment. If the child already has a diagnosis of CP, they will already be within a network of care and support that would include the recognition and management of the comorbidities to which you refer. In the group of children presenting to a GP with anxieties about sensory difficulties, undiagnosed CP would be astonishingly rare. So although the Guideline Committee understands your concerns, we think this is unnecessarily small print for a guideline aimed at generalists.
Action Cerebral Palsy	Full	22	28-32	Hypotonia in children can also be one of the early motor features in the presentation of cerebral palsy. ACP would recommend inserting a new point after line 28, saying: "recognise that abnormalities of tone, including hypotonia, can be an early motor feature in the presentation of cerebral palsy, and consider referral to a child development service for an urgent assessment. See recommendation 1.3.3 and 1.3.4 on looking for signs of cerebral palsy in the NICE guideline on Cerebral palsy in under 25s: assessment and management." This should be inserted before the fourth point ("if the infant is otherwise developing well, consider referring for community physiotherapy") as this referral should take place urgently and CP ruled out before referral to a generic physiotherapy service.	Thank you for your comments. We have amended the recommendations and link to evidence table to provide some help in recognising weakness, as opposed to simple hypotonia, in an infant.
Action Cerebral Palsy	Full	25	2-20	We feel that this section on tics and involuntary movements in children does not reflect the attention that should be paid to abnormalities of movement that could be a sign of CP. This is particularly relevant as children with CP are also commonly diagnosed with autism and/or epilepsy, which this section does cover. Recommendation 1.3.3 of the NICE guideline on cerebral palsy in under 25s: assessment and management notes that "unusual fidgety movements or other abnormalities of movement, including asymmetry or paucity of movement" should be recognised as possible early motor features in the presentation of CP. 1. Therefore, if a child presents with an involuntary movement it should equally be determined whether the child does or does not have CP, in the same manner that point 1.17.19 of the NICE guidance on cerebral palsy in under 25s urges professionals to "Ensure that dyskinetic movements are not misinterpreted as epilepsy in children with cerebral palsy."	Thank you for your comments. A child who already has a diagnosis of CP will have a network for care including physiotherapist and paediatrician who would be assessing abnormal movements. The Guideline Committee thinks that is unlikely that a child with CP would present to GP with involuntary movements or that a child with undiagnosed CP would present with involuntary movements as the initial problem. Therefore, the Guideline Committee did not feel that a recommendation should be made about this.
Action Cerebral Palsy	Full	26	22-31	Action Cerebral Palsy (ACP) agrees with the findings of the Neurological Alliance's report – that people with a neurological condition have to repeatedly raise their concerns with a primary care physician before being referred to a specialist – and are pleased to see this acknowledged in this draft guidance. It is our experience that when diagnosing cerebral palsy (CP) in babies and young children, GPs often tell parents to "wait and see" whether a developmental issue, which could be a sign of CP, resolves itself. This "wait and see" attitude can be unintentionally harmful for the child if they do have CP, as a delay in diagnosis can prevent crucial early interventions from being applied and tackling the symptom in question, such as physiotherapy for limb weakness. While we appreciate it is not possible for all GPs to be well acquainted with the symptoms of all	Thank you for your comment.

				neurological disorders, CP is the most common motor disorder in childhood, and we hope that this guidance will allow GPs to better understand when they should refer a suspected case of CP to a specialist.	
Action Cerebral Palsy	Full	General	General	We hope that the points raised in this response emphasise that GPs should be aware of several things: • That CP is the most common motor disorder in childhood, with a range of antenatal, perinatal and postnatal risk factors. CP therefore should not be considered a rare disorder that GPs do not need to have a general awareness of. • The key symptoms of CP as identified by the NICE guidance on cerebral palsy in under 25s, particularly the most common delayed motor milestones in children with CP, including not sitting by 8 months; not walking by 18 months; and early asymmetry of hand function before 1 year, all corrected for gestational age. The need to refer to a child development service with urgency if a child is suspected of having CP, with parents' concerns about their child's development taken seriously, to ensure that early identification and intervention can be taken forward.	Thank you for your comment. The Guideline Committee agrees with you about the importance of early recognition and referral of children with CP. This is reflected in the recommendations that the committee has made.
Action Cerebral Palsy	Full	General	General	**1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** ACP recognises that it will be a practical challenge to ensure that all GPs have the knowledge to realise which neurological symptoms may be signs of CP, and the confidence to elevate investigation of these symptoms through referral to a child development service, given the vast areas of medicine and health that GPs are required to manage. GPs may feel uncomfortable in making these referrals if a problem identified is at an early stage of a child's development and so could resolve itself, and so adopt the "wait and see" attitude described at the beginning of this response. However, this attitude can be to the detriment of the child with CP and their family if it means that identification and intervention is delayed, and so should not prevent these guidelines from suggesting consideration of CP.	Thank you for your comment. This guideline and the CP and spasticity guidelines give GPs guidance on when to refer and routes of referral. It is likely that it will be the less severely affected child, who has not already been referred and is presenting to their GP with motor developmental delay or comorbidities. It is unlikely to result in a significant increase in referrals overall or an increase in costs.
Action Cerebral Palsy	Full	General	General	**2. Would implementation of any of the draft recommendations have significant cost implications?** The costs of implementing the draft recommendations in full would be limited to ensuring that GPs receive sufficient training on recognition of neurological conditions before qualifying, although ACP is not able to comment on the exact cost implications of the provision of this training. It is our belief, though, that the related costs would be significantly outweighed by the benefits for children with CP and their families in receiving early identification and intervention. Diagnosing CP can ensure that specialist physical therapies or speech and language interventions are used from the earliest possible stage, preventing later, costlier interventions such as surgery to correct physical issues or referral to a SEND school, which is both costly to the taxpayer and may have considerable impact on the child's upbringing and quality of life.	Thank you for your comments. This guideline and the CP and spasticity guidelines give GPs guidance on when to refer and routes of referral. It is likely that it will be the less severely affected child, who has not already been referred and is presenting to their GP with motor developmental delay or comorbidities. It is unlikely to result in a significant increase in referrals overall or an increase in costs.
Action Cerebral Palsy	Full	General	General	**3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)** For CP, NICE's existing guidelines on cerebral palsy in under 25s are an extremely valuable resource for identifying CP and the intervention pathways that should subsequently be followed.	Thank you for your comment.
Action Duchenne	Short	18	6 - 16	Attention deficit disorder can be a symptom of Duchenne muscular dystrophy. If attention deficit disorder presents along with limb weakness, motor developmental delay, speech and language delay, and postural distortion or any combination of these, the patient should be given a CK test and if the results indicate muscular dystrophy patients should be 'urgently referred'. The CK test is low cost and is not challenging to implement. However, the physical symptoms of Duchenne muscular dystrophy and their progression may be challenging to discern in young children. Therefore Action Duchenne strongly advocates a new-born screening programme along with counselling and support for parents, as outlined in Example 2.	Thank you for your comments. Screening is the responsibility of a separate group (the National Screening Committee) in the NHS. The Guideline Committee agrees that attention and concentration problems exist in Duchenne Muscular Dystrophy (DMD) but the prime purpose of this guideline is early diagnosis and referral of boys with DMD. The Guideline Committee

					considered that presentation of DMD, as ADHD alone would be very unusual..
Action Duchenne	short	24	23 - 27	We are concerned that the recommendation to 'refer' boys with motor developmental delay is inadequate for patients with Duchenne muscular dystrophy because of the resulting delay in diagnosis. Currently there is frequently a prolonged diagnostic process, often lasting 2.5 years, giving a mean age of diagnosis of around 4.5 years, **a figure which has changed little over the last 3 decades**. This recommendation is unlikely to improve that situation. Delay in diagnosis can impact on the age of starting treatment. This applies to current steroid treatment and to new and emerging treatment options. 'There is a clear correlation in Duchenne between the level of function and the subsequent loss of motor activities and ultimately respiratory insufficiency and death. Therefore, initiating treatment at an early age – when function is at a higher level – can be expected to confer significant longer term advantage in terms of health outcomes' (Muscular Dystrophy UK 'Next Steps on Newborn Screening for Duchenne muscular dystrophy'). New and emerging treatments increase the already urgent need for early diagnosis to avoid muscle degeneration as far as possible – in particular, potential effective single administration treatment is in development which would require the earliest possible diagnosis; Children with Duchenne muscular dystrophy therefore need to be 'referred urgently'. However, given that 95% of boys presenting with motor developmental delay do not have Duchenne muscular dystrophy, this symptom is not a sufficient indicator of Duchenne muscular dystrophy and urgent referrals for all presenting with this symptom will not be cost-effective. The recommendation to consider a CK test would be challenging to implement. The common symptom set of Duchenne muscular dystrophy - limb weakness, motor developmental delay, speech and language delay, attention deficit, and postural distortion or any combination of these – may be challenging to discern in young children. Furthermore, most GPs rarely if ever see a case of Duchenne muscular dystrophy and, on the principle that 'if you hear the sound of hooves, assume it's a horse not a zebra' will consider Duchenne muscular dystrophy to be extremely unlikely and may therefore not necessarily routinely to do a CK test on all boys presenting with motor developmental delay. To overcome this challenge, Action Duchenne strongly advocates a new-born screening programme for the condition, along with counselling and support for parents. The significance of new-born screening is outlined in van Ruiten HJ, Straub V, Bushby K, and Guglieri M 'Improving Recognition of Duchenne Muscular Dystrophy: a retrospective case note review' (ArchDisChild 2014 Dec,99(12): 1074-7 doi:10.1136/archdischild-2014-306366). Since that publication in 2014 a highly sensitive and specific CK-MM blood-spot test has been developed (Clinical Chemistry, doi:1373/clinchem.2016.268425) and new and emerging treatments increase the already urgent need for early diagnosis to minimise muscle degeneration – in particular, potential effective single administration treatment is in development which would require the earliest possible diagnosis. In addition, parents and related prospective parents need to be able to make informed family planning choices; and the overall cost of managing Duchenne muscular dystrophy is reduced if families are able to plan from their child's infancy. The implementation of the draft recommendations as they stand is unlikely to reduce the cost of managing Duchenne muscular dystrophy both for the NHS and for families living with the condition, and is likely to continue to incur unnecessary cost to the NHS through delayed treatment. These costs should be set against the relatively low cost of routine new-born screening for Duchenne muscular dystrophy along with counselling and support for parents.	Thank you for your comments. The Guideline Committee agrees with your concern about the delay in diagnosis of Duchenne Muscular Dystrophy (DMD). Responsibility for national screening policy lies with the UK National Screening Committee, not with NICE. We believe that highlighting the awareness of DMD, and suggesting CK as a first test will improve thinking about the condition without overwhelming secondary care services.
Action Duchenne	short	24	6 - 8	Duchenne muscular dystrophy is a complex and severe neurological condition which can initially present as limb weakness, motor developmental delay, speech and language delay, attention deficit, and postural distortion or any combination of these. If limb weakness is presented alongside any of the following symptoms - motor developmental delay, speech and language delay, attention deficit, and posture distortion – practitioners should do a CK test and if the results indicate muscular dystrophy patients should be 'urgently referred'. The CK test is low cost and is not challenging to implement. However, the physical symptoms of Duchenne muscular dystrophy and their progression may be challenging to discern in young children. Action Duchenne strongly advocates a new-born screening programme along with counselling and support for parents, as outlined in Example 2.	Thank you for your comments. The Guideline Committee agrees with your concern about the delay in diagnosis of Duchenne Muscular Dystrophy (DMD). Responsibility for national screening policy lies with the UK National Screening Committee, not with NICE. The Guideline Committee believes that highlighting the awareness of DMD, and suggesting CK as a first test will improve thinking about the condition without overwhelming secondary care services.
Action Duchenne	short	24	4 - 5	Progressive limb weakness is a symptom of Duchenne muscular dystrophy. However, its progression may be challenging to discern in young children, who typically plateau in their strength up until the age of seven. Therefore this recommendation will be challenging for practitioners to implement in the case of Duchenne muscular dystrophy. Delay in diagnosis until the time that limb weakness progression may be more obvious incurs all the problems listed in Example 2 above. These problems include the increased cost to the NHS and to families of treating and managing	Thank you for your comments. The Guideline Committee agrees with your concern about the delay in diagnosis of Duchenne Muscular Dystrophy (DMD).

				hitherto untreated Duchenne muscular dystrophy. To overcome these challenges, Action Duchenne strongly advocate a new-born screening programme, along with counselling and support for parents, as outlined in Example 2 above.	Responsibility for national screening policy lies with the UK National Screening Committee, not with NICE. The Guideline Committee believes that highlighting the awareness of DMD, and suggesting CK as a first test will improve thinking about the condition without overwhelming secondary care services.
Action Duchenne	short	25	1 - 12	The section on posture distortion should also refer to abnormal gait, a classic symptom of Duchenne muscular dystrophy. A child with a waddling gait, particularly in combination with motor developmental delay, speech and language delay, and attention deficit, should be given a CK test and if the results indicate muscular dystrophy patients should be 'urgently referred'. The section should also refer to the Gower's manoeuvre, a classic symptom of core muscle weakness caused by Duchenne muscular dystrophy. Any child presenting with this symptom should be given a CK test and if the results indicate muscular dystrophy patients should be 'urgently referred'. The CK test is low cost and is not challenging to implement. However, the physical symptoms of Duchenne muscular dystrophy and their progression may be challenging to discern in young children. Therefore Action Duchenne strongly advocates a new-born screening programme along with counselling and support for parents, as outlined in Example 2.	Thank you for your comments. The Guideline Committee agrees that there are many associated symptoms along with muscle weakness in Duchenne Muscular Dystrophy (DMD). This guideline cannot give a comprehensive list of all the possible symptoms and signs. We believe that within the topics of motor developmental delay, abnormalities of gait, and weakness, the child with DMD will be referred as appropriate.
Action Duchenne	short	27	1 - 13	Information processing disorders, presenting as abnormal speech and language development, are a common symptom of Duchenne muscular dystrophy. If abnormal speech and language development presents along with limb weakness, motor developmental delay, speech and language delay, attention deficit, and postural distortion or any combination of these, the patient should be given a CK test and if the results indicate muscular dystrophy patients should be 'urgently referred'. The CK test is low cost and is not challenging to implement. However, the physical symptoms of Duchenne muscular dystrophy and their progression may be challenging to discern in young children. Therefore Action Duchenne strongly advocates a new-born screening programme along with counselling and support for parents, as outlined in Example 2.	Thank you for your comments. The Guideline Committee agrees that there are many associated symptoms along with muscle weakness in DMD. This guideline cannot give a comprehensive list of all the possible symptoms and signs. We believe that within the topics of motor developmental delay, abnormalities of gait, and weakness, the child with DMD will be referred as appropriate.
Action for M.E.	Full	14 (and 77)	18-26	In the further notes relating to the referred section (which are on p78 under *Recommendations 36-37 – Chronic fatigue syndrome, fibromyalgia and functional neurological disorder*) the draft guideline states that "functional symptoms that are not primarily explained based on physical or physiological abnormalities. They are likely to have an emotional basis. They may mimic neurological disorders." This statement wrongly says that patients with CFS/M.E. experience functional symptoms. The statement furthermore assumes that the symptoms experienced by CFS/M.E. patients are emotionally based, both of which directly contradict WHO's classification of the condition as neurological. On the basis of this assumption the guideline states that patients "may benefit from an explanation that functional symptoms are commonly accompanied by problems with concentration and memory, and that this may reduce the overall load on clinical services." Not only does this statement erroneously say that CFS/M.E. symptoms are functional, but translates this assumption into guidance that will result in patients being dissuaded from accessing services, which contradicts NICE's own condition-specific guidance for CFS/M.E., CG53.	Thank you for your comment. The Guideline Committee has amended any wording which might be taken as suggesting that CFS/ME is a functional neurological disorder. The purpose of this Guideline is to consider the appropriate referral of specified presentations rather than diseases, and it does not address the causation of CFS/ME or any other condition.
Action for M.E.	Full	14 (and 77)	18-26	As stated in comment 1, WHO's ICD-10 classifies CFS/M.E. as a neurological disorder; a classification that is mandated across the NHS since ICD-10's implementation in 1995. In the further notes on p78, which accompany recommendations 36 and 37 on p14, the *Suspected neurological conditions* guideline states that people with CFS/M.E. should not be referred for a neurological assessment "unless the cognitive difficulties have a significant impact on everyday life." Given that CFS/M.E. is classified within the NHS as a neurological condition, and in practice people with CFS/M.E. are treated within	Thank you for your comment. We have amended the wording to make the intended message clearer.

				neurological services [Action for M.E., *Spotlight on specialist services*, 2017], the guideline ought to recognise that a referral can be appropriate without the caveat regarding a threshold of cognitive difficulties that needs to be met. In drawing a distinction between people whose symptoms have a significant impact on their everyday life, and people who do not meet this threshold, the guideline's recommendation will result in inconsistent referrals for people with M.E., where those who are considered to be impacted significantly by their clinician will be referred while others will not receive this treatment despite each having the same condition.	
Action for M.E.	Full	17 (and 96-97)	38-39	Recommendation 72 says "Be aware that functional neurological disorder is the most common cause of minor word-finding difficulties in adults." In the further information for this recommendation on p96, the draft guideline additionally states that "functional symptoms that are not primarily explained based on physical or physiological abnormalities. They are likely to have an emotional basis. They may mimic neurological disorders." The further information on p97 concludes that "word-finding difficulty causes undue distress in some cases, and the committee decided that a recommendation to raise awareness of functional disorder as a common cause might help GP's reassure patients and prevent some inappropriate referrals." People with CFS/M.E. experience cognitive symptoms that result in speech and language problems, including difficulty finding words [NICE CG53, 1.2.1.2, 2007]. Therefore the guideline should acknowledge that word-finding difficulties can be a result of a neurological condition, rather than its current position that the symptom is functional and may only mimic a neurological disorder.	Thank you for your comment. The guideline refers to speech disturbance in the context of functional neurological disorders (FND) rather than CFS/ME The guideline cannot specify every potential cause, but recommendation 1.13.1 emphasizes that some causes of speech disturbance require urgent assessment. The guideline makes clear that FND is the commonest cause – it does not say that it is the only cause. Please also note that the linking evidence to recommendations table was amended to acknowledge that not all word-finding difficulties are a symptom of a functional disorder and may be the result of a neurological condition.
Action for M.E.	Full	19 (and 106)	10-12	Include statement that concentration and memory difficulties are common in children with CFS/M.E.	Thank you for your comment. The guideline is based on type of presentation rather than conditions, and is not intended to cover every cause of a particular presentation. CFS/ME is covered in a separate NICE guideline.
Action for M.E.	Full	20 (and 115)	14-15	Include statement that postural hypertension is a common feature of CFS/M.E.	Thank you for your comment. CFS/ME is the subject of a separate NICE guideline.
Action for M.E.	Full	24 (and 140)	4-5	Include statement that sleep disturbance is a common feature of CFS/M.E.	Thank you for your comment. CFS/ME is the subject of a separate NICE guideline (CG53).
Action for M.E.	Full	29	28	*Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management*, CG53 August 2007, to be included as a related NICE guideline, as it is referred to elsewhere in the draft guideline on p78 under Recommendations 36-37.	Thank you for your comment. We have added it to the list of related guidance.
Action for M.E.	Full	General	General	All references to 'M.E.' and/or 'CFS' as a 'functional' disorder should be removed, including statements that patients with M.E. or CFS experience functional symptoms. Myalgic encephalomyelitis (M.E.) and chronic fatigue syndrome (CFS) are not functional disorders. Both are indexed under G93.3 in World Health Organisation's ICD-10, under *Diseases of the nervous system*. The NHS was required to implement the ICD-10 in 1995, and as such that includes the classification of CFS/M.E. as a neurological condition. In addition, the UK Government has consistently stated that it accepts the "World Health Organization's classification of the illness as a neurological condition of unknown origin." [Lord O'Shaughnessy, Parliamentary Under-Secretary of State Department of Health, column 781 in Hansard Volume 783, 4 July 2017] The assumption within this guideline that CFS/M.E. is not neurological is further concerning given that current practice is moving towards treating CFS/M.E. within services for medically unexplained symptoms (MUS). The NICE guideline for the condition makes it clear that specialist services	Thank you for your comments. The Guideline Committee has amended all instances in the guideline to remove the suggestion that CFS/ME is a functional neurological disorder. The purpose of this Guideline is to consider the appropriate referral of specified presentations rather than diseases, and while it recognises that certain

				for CFS/M.E. are likely to be needed by significant number of people with the condition [NICE CG53, 1.5.1.2, 2007]. It is likely that the approach offered by MUS services would be inappropriate in many cases. Therefore it is essential that the *Suspected neurological conditions* reflects WHO's position that CFS/M.E. is neurological in order to provide clear guidance on the classification of the condition, as this will also impact on service commissioning and clinical practice. In so doing, the guideline would also be in line with a growing body of evidence that CFS/M.E. is neurological [Institute of Medicine, *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an illness*, February 2015]. Comments 2 and 3 below address two specific examples where CFS/M.E. has been stated to be, or is implied to be, a functional disorder.	symptoms might have a functional basis it does not address the causation of CFS/ME or any other condition.
Action for M.E.	Full	General	General	CFS/M.E. also affects children, and has a significant impact on their health and wellbeing. Research has shown that the condition is the leading cause of long-term sickness absence in schools [Dowsett EG & Colby J., *Long Term Sickness Absence due to ME.CFS in UK Schools: An Epidemiological Study with Medical and Educational Implications*, 1997], and children frequently tell us that the condition can leave them feeling isolated both from their peers and through the lack of awareness and understanding from professionals. Therefore it is imperative that this guideline enables clinicians and other health professionals to be aware of CFS/M.E. in children and respond appropriately. Comments 7-9 below address some specific areas where the draft guideline ought to acknowledge the possibility of CFS/M.E. when considering symptoms in children.	Thank you for your comment. This guideline is designed to guide practitioners on the need for referral, rather than the diagnostic processes which might take place after referral. There is a separate NICE guideline on CFS/ME providing guidance on recognition and diagnosis.
Action for MdDS	Full	General	General	First up, would it be OK if NICE didn't use value judgements by commenting on what does/doesn't count as 'significant' conditions in this draft about guidelines/guidance re suggested neurological conditions/problems? That's like being told, as I was during my diagnosis with Mal de Debarquement Syndrome (MdDS), to think myself 'lucky' that I didn't have Meniere's disease and it's not OK. The first neurologist I saw also wrote that he didn't think I had a 'significant' neurological condition and never apologized even though it was also clear that his knowledge of MdDS was substandard. But, more importantly, it is society that creates different levels of disability and makes some disabilities significant and others not. Being on the receiving end of that is not fun, wherever someone is on the scale (ref ATOS/Capita/the DWP re removing benefits/mobility vehicles from people who have the capacity to represent at the Paralympics, which ATOS sponsored – go figure). Also please reference today's society in the UK regarding the inhumane treatment of people with medical conditions, as reported by the UN. Language matters. Please use it wisely, not divisively. Thank you. When, by chance, I saw the call for patient feedback re the NICE draft guidance and guidelines for suspected neurological conditions (or 'problems' as NICE seem to refer to them), I was in the process of writing an article that I intended to pitch to either the BjoGP or the BMJ (who have previously published my writing). The working title was 'Why giving or relying on a 'functional'/'MUS' diagnosis may be the worst action you can take for your patients'. So I've used some of the ideas and references I'd gathered for that article for this feedback and to prompt my comments/questions/suggestions. Unless otherwise stated, these comments/questions/suggestions are mine and should not be taken as representative of Action for MdDS UK. They are offered from the perspective of my patient journey which includes (but is not limited to): a remarkably swift and accurate diagnosis of Mal de Debarquement Syndrome (MdDS) given by a man who was very unpleasant and, according to his assistant, 'like that with everyone'; subsequent years of mismanagement in the NHS including an attempt by a neuro-psychiatrist to reframe MdDS as a 'functional' condition; being re-diagnosed with MdDS but still having to work hard to get shot of the 'functional' label in primary care; being removed from a primary care practice on the basis of issues I'd raised having been invited to submit a complaint against them; having to discriminate against my last doctor on the grounds of his gender to get shot of him after he made it clear that he still believed – entirely illogically - that there were 'underlying psychological causes' for motion-triggered MdDS; being on the receiving end of some world-class management speak gobbledygook following a complaint I was invited to put in against the neuro-psych and a neurologist following the 'functional' reframing attempt; reading my medical records and subsequently re-naming MdDS as Mal de Debacle Syndrome and, most significantly, having nieces and nephews who run the risk of developing MdDS. My feedback spans several areas of medicine including balance conditions, rare conditions, misdiagnosis and resulting trauma (very common in rare conditions) and my experiences in both primary and secondary care. Fortunately I have had relatively low symptom levels during the time I've written this so have been able to do more than type with my eyes shut. As such I have been able to include links people have sent me and some general questions they've raised.	Thank you for your interest in this guideline and for your comments. The Guideline Committee has read these carefully and we note the difficulties you have encountered at various times in your interaction with the NHS. We are sorry that you have experienced these disappointing consultations and are glad that you are now under the care of a Consultant and team who understand your condition and are helping you with this. At several points in your submission you ask us to comment on specific events which you have experienced, and this suggests that we need to explain what NICE can and cannot do. The primary functions of NICE are to assess new treatments for use in the NHS and to produce guidance on the management of specified conditions or symptoms. This guidance can only be couched in general terms, and it is up to individual practitioners to apply NICE's recommendations to the particular circumstances of each patient. It is not NICE's role to monitor the performance of Health Care Practitioners, a function carried out by other agencies such as the Care Quality Commission, General Medical Council, etc. We therefore cannot comment on the care given to you by

				This feedback is fuelled by embarrassment regarding how far behind the UK is with respect to research into MdDS, disgust at how long it can take people with MdDS to get a diagnosis (and the high costs they encounter in the process), anger at the way many patients are treated in parts of the NHS, concern that the draft seems out of date and potentially harmful, bafflement that the Louise L Hay notion that emotions/thought patterns form the basis for physical symptoms seems to be considered as mainstream rather than woo woo and extreme distrust of scientists who use euphemisms and publish papers/produce podcasts etc that are riddled with negative value judgements about patients and doctors. It is also fuelled by the optimism that results from currently receiving world-class care within the NHS (at long last), engaging with the rare conditions communities, being part of the positive changes within the balance world and contact with many fine medical students, bright junior doctors, dedicated senior doctors/consultants and outstanding Professors and researchers. It is also fuelled by gratitude to NICE for facilitating this process for me, specifically via Jill Peacock and Ben Doak. Most of all it is fuelled by gratitude to my family. I am crying as I type this but, amongst the MdDS community, I am considered to be 'lucky' because my middle sister had MdDS-like symptoms for two years, so always believed me. No one would wish these symptoms on anyone just as no one would want to experience the well-understood social epidemiology of 'living rare'. Yet unswerving support from family members is rare, particularly for people with balance conditions and many other invisible conditions, including migraine. I am aware that parts of my feedback might be hard for you to follow or understand. But that's OK because the same goes for me re the NICE draft re 'neuro problems'. Re balance conditions, let's hear from a professional first: *"The results of mismanaging, misunderstanding or ignoring (dizziness and vertigo) can be life-threatening and debilitating," says Kimberley Bell, a physical therapist who specializes in vestibular disorders. "The resulting mental health overlay is devastating."* Many patients report feeling overwhelming relief when one of their clinicians acknowledges that the devastating mental health overlay is the result, not the cause, of their symptoms. This is often the case even if they have still not received a formal diagnosis so don't know if they have a central or peripheral cause for their symptoms or a treatment plan. I am sending this feedback to NICE at the start of Balance Awareness Week and am grateful to have been reminded by a fellow campaigner that last year a man in the UK was diagnosed with BPPV after 49 years of severe symptoms. Yes, you read that right – 49 years. He was angry because so much of his life had been adversely affected and that this could have been avoided. We were angry because the twitter conversation that revealed this delayed diagnosis also had a thread about the UK ethos around some balance conditions which is that 'acceptance = better quality of life'. Do NICE agree that this gentleman would have had a better quality of life if he'd been diagnosed and treated sooner? The symptoms of many neurovestibular/vestibular conditions are enough to destroy people's lives on their own. If they are mismanaged and misunderstood – or blamed on the patient via the UK 'functional'/'anxiety disorder'/'it's caused by your thoughts' paradigm – the effect on the long-term prognosis can be profound. The knock-on effect to relevant research may also be hindered by this approach. Does NICE want to tell the researchers into MdDS, Meniere's, Vestibular Migraine etc etc that they are wasting their time, because 'dizziness' symptoms are still viewed as being 'functional'/the result of an 'anxiety disorder'/caused by patients' emotions in some parts of the world? Or does NICE want to put their efforts into encouraging these researchers to develop treatments for these and other conditions and, simultaneously, indicate that they are up-to-speed with current thinking? I am also grateful to the members of MdDS UK who were well enough to read the draft and submit their comments/questions/suggestions to me. One question some members asked was what 'functional' means and what 'functional illnesses' are. Which I was unable to answer since I've had	individuals. It is also not NICE's role to carry out primary research and we therefore cannot perform the trial of SuperBetter that you suggest. NICE commissions its guidance with a specific remit for each piece of work. In this case, the National Guidelines Centre was asked to produce a guideline on referral to neurological services. This is an unusual topic for a guideline in that it does not cover treatment, nor does it cover details of diagnosis (although in deciding whether a referral is appropriate it is not possible to ignore the potential diagnoses which might present with a particular symptom).This is a broad remit, and the Guideline Committee could not cover every possible symptom. One of its earliest tasks was to decide which symptoms to include and the committee did this based primarily on whether the symptom is currently managed adequately or not, and secondly, on how common the symptom is. It was not possible to cover every conceivable presentation within the time available for production of the guideline. We are summarising this process here (it is described in more detail in the Full Guideline) because it answers some of your questions. It accounts for the omission of functional movement disorders to which you refer, and for the absence of anything about genome sequencing. It is also why there are no recommendations for treatment for MdDS or of treatment for any other conditions. One of your main points is to criticise our assumption that symptoms may have a functional aetiology. We do not agree that the concept of functional illness should be abandoned. There are people who develop physical symptoms for psychological, subconscious or emotional reasons, and their symptoms

				confusing and conflicting answers to that question from almost every health professional I've asked. The subsequent question was along the lines of 'how can doctors diagnose someone with something when they can't even explain what it means?' The only answer to the question about what 'functional' means that rang true to me was from … drum roll please … a Bristol neurologist who said that a 'functional diagnosis' is 'lazy psychological profiling'. Which is a long way from 'a change in function, not structure' which is what a neural-ophthalmologist told me she thought it was generally taken to mean. Even with that explanation a 'functional' diagnosis is unlikely to be useful because unless doctors and patients know why the function has changed, they are unlikely to be able to do anything about it. Before I encountered the neuro-psychiatrist I was completely oblivious to the 'functional'/'MUS' paradigm other than as (by other names) a thing of the past that we'd said 'good riddance' to a long time ago. It was stunning to find out that this wasn't the case. It still is. So this feedback is also fuelled by gratitude to doctors like Emma Reinhold and to the editor of the BJoGP who selected her 'MUS to DEN' letter as the editor's choice in April 2017. Because 'functional' and 'MUS' seem to be used interchangeably in parts of the NHS, I'd extend her title so it reads: <u>'Functional'/'MUS' to DEN and PUN</u> (I have no idea what 'MUS', means other than euphemistically, but DEN stands for Doctors' Educational Needs and PUN stands for Patients' Unmet Needs.) "'Functional' is horrible and enough to distress anyone." This is a quote from my middle sister after I was told by the neuro-psychiatrist that it would be 'worthwhile' to 'explore a functional model' for the symptoms of Mal de Debarquement Syndrome (MdDS) in 2012, 6 years after I was accurately diagnosed with motion-triggered MdDS. I'd tell you what my retired GP/medical journalist Dad (may he walk in peace) said about 'functional' but it involves a derogatory-to-men swearword, so I won't. When I researched 'functional disorders' I noticed that it isn't a 'model' because it can't be used to predict outcomes, so I dismissed this label a priori. However I did go on to read up about 'functional' since my (then) primary care doctors did not dismiss this label and repeatedly tried to re-refer me to the neuro-psych involved whilst refusing to make rational referrals (e.g. to the Eye Hospital). They also went to great lengths to challenge me to accept the 'functional' diagnosis and even wrote it in a referral note for an entirely unnecessary MRI scan. NICE, please note, 'normal neuroimaging' does not infer a 'functional' diagnosis as per your Point 7 on page 56 of your draft re 'neuro problems'. See Dr Jon Stone's 'Bare Essentials' paper and others for info about neurological conditions that don't show up on an MRI. It's worth noting that when my first MRI came back as normal the diagnosing consultant said 'There, you can stop panicking that you've got a brain tumour now.' He'd already told me the MRI was a 'ruling out test' and that he expected a normal result so I hadn't been concerned about it at all and found his attitude distressing and demeaning. It was only much later that I realised that 'normal' or 'negative' MRI results could, illogically, be used to confirm a 'functional' label. NICE – would you like to estimate the percentage of rare conditions patients who have ruling out scans/tests (which come back 'normal', as you'd expect) only to have these results used against them? To get rid of the 'functional' label I had to get re-diagnosed with MdDS (at vast expense to the NHS and my family, who fund me, bless them) But getting re-diagnosed wasn't easy and the emotional scars from the 'functional' labelling process remain to this day. Not least because the neuro-psychiatrist who tried to give MdDS this label said that she knew about MdDS at the start of both our consultations but later admitted that this wasn't true. She also sent the largely inaccurate 'mental state report' paragraph to my (then) GP but not to me, despite writing 'copy' on the notes I received. I discovered this through a clerical error made when I requested an electronic copy of the clinical notes and was sent the complete version. Initially (via the notoriously psychologically damaging NHS 'complaints procedure') I was told that this part of the notes isn't sent to patients because they might not understand the language used in it, which is not in keeping with Health 2.0 and is a blatant example of dumbing down and/or a clear training need for the people who write these reports. Later, after I accessed the hand-written notes from the neuro-psych (which took several months to achieve and didn't happen until 2017), I was told that this part of the notes wasn't sent to me because it was of no therapeutic value. If	can be helped by recognising this and managing the problem appropriately. If recognised at an early enough stage these cases are not necessarily best served by a referral to neurology, and the Guideline Committee therefore felt obliged to offer some help to Primary Care practitioners for identification of functional illness within this Guideline. We note your assertion that emotions are always caused by physical symptoms, not the other way round. However, you also state that anger can affect the immune system, which if true is a clear instance of an emotion having an effect on a biological system. We agree that the symptoms of rare diseases can sometimes be misdiagnosed as functional (in fact, symptoms of rare diseases are also commonly misdiagnosed as being due to other common diseases). This is a concern, but it does not mean that everyone with a functional diagnosis has an undetected rare disease. You mention the term "MUS" in several places and you state that we equate this to "functional". The guideline does not use the term "MUS". The committee also disagrees that "functional = mad". The committee has not said that, nor did theyi imply it. You also ask some additional specific questions: • You ask why dizziness is a Red Flag symptom in children but not adults. The significance of a symptom or sign in children can be very different from adults. Children do suffer stress but the symptoms it produces vary depending on the age and maturity of the child. Throughout the guideline when writing recommendations for children, the committee drew on evidence and clinical experience

				that is true, I am left wondering why the 'mental state examination' was done at all. And why the resulting report was sent to my old primary care team, along with the rest of the clinical letters which are largely inaccurate but demonstrate extreme specialism bias on behalf of the neuro-psychiatrist. Either way, lying to patients by telling them they are receiving a 'copy' of their notes when they are not isn't ethical. There must be loads of patients who are entirely unaware that this happens and I think they should be told. This practice may have stopped now, via the changes to the NHS Constitution, but patients who have been subjected to it in the past need to be told, retroactively, and as a matter of urgency. I doubt this can come under the remit of this draft but would welcome input from the NICE committee regarding how this deceptive practice can be exposed so it never happens again. I encountered the neuro-psychiatrist when I was referred to 'the sleep clinic' and thought I was safe in the hands of scientists. I didn't sleep much for nearly a year after I went for a CBT assessment (in an attempt to find out what 'functional' meant, since the neuro-psych hadn't been able to explain, other than by saying it meant 'medically unexplained symptoms', refusing to answer when I asked her what that meant and telling me I would have to find out more via CBT) and was directed to Dr Jon Stone's site. When I read the content of the neuro-psych's notes again after reading the 'functional' diagnostic paper on that site, I began to despair, became traumatised and felt a strong suicide ideation for several months. It didn't help that spending so much time on the computer trying to work out what 'functional' meant triggered a migraine which, in turn, triggered a very bad episode of MdDS. I doubt that long period of insomnia and trauma is likely to have a positive impact on my long term health and so do my family, who are likely to have to pick up the pieces. Again. I had a partial breakdown as a result of the 'care' I received at 'the sleep clinic' and other mistreatment within the NHS and still get flashbacks. Knowing this trauma is common amongst patients and results from institutionalised belief systems is also traumatising. I didn't die from the 'MUS' label, but I am aware that others have if their primary diagnosis was missed or side-lined. As they often are once these labels are given to patients. I am very grateful to one of the lead researchers into MdDS who told me that 'labels can be very dangerous' and advised me to challenge the one I'd got. She said that if I was labelled with anything that might have a negative impact on my future health-care it would have to be after a formal assessment against set criteria, which it certainly wasn't. The 'functional' label harmed me more than MdDS ever could. MdDS took away my primary career and my secondary career, my plan to take a PhD and my transatlantic marriage (flights being one of the worst triggers for me). The 'functional' label resulted in extreme difficulties in primary care, destroyed my trust in the medical profession for a long time and led to a long delay before I got diagnosed with vestibular migraine, POTS and a-typical Dysautonomia. The neuro-psych should have been able make the migraine dx on the basis of blood test results and the known association between migraine and MdDS. But apparently she was too busy using her incomplete and inaccurate understanding of my psyche to fill the gaps in her medical knowledge. (DEN) So, I repeat, the 'functional' label harmed me more than MdDS ever could. That people are paid vast sums of money to harm other people (especially in a health care setting) is mindboggling. That it takes someone across the Atlantic to spot issues around blood pressure fluctuations and diet via email – and be able to give the relevant treatment intel – all of which that neuro-psych failed to notice, despite the evidence in front of her, is also mindboggling. She (the neuro-psych, not the researcher) missed it (despite me flagging up the blood pressure issues prior to and during our first consultation and again during our second consultation) along with serious malnourishment and physical exhaustion. And, as before, she missed the obvious migraine dx too. That's not health and care excellence, is it? I have no idea how, but – never having examined her or taken a medical history or even spoken to her – this neuropsychiatrist also managed to diagnose my Mum's epilepsy as 'non-organic'. So much for leaving it to the experts as my old primary care team advised. It was only when I asked why I was there, during my second consultation with the neuro-psych that I began to realise that my trust in her was misplaced. She told me it was so that she could supervise me through CBT and	rather than extrapolating from adult practice • You ask about audio versions of the guidance. NICE does not produce these • You ask about links to 3rd party websites. NICE policy is not to provide such linkage however meritorious the site appears to be. This is because NICE cannot control the quality of other sites and the content may change after publication of the NICE guidance. Regarding Thank you for your comments about an economic model,. tThere is not an economic model supporting this guideline. There is a cost analysis that can be found in appendix N: this examines costs associated with neurology appointments and the impact on changes in the number of appointments on NHS costs. There is not any economic modelling to calculate the specific costs for people with neurological conditions, to which costs for misdiagnoses or delayed diagnoses would be relevant. The committee has, however, noted that misdiagnoses and delayed diagnoses give rise to costs (to the NHS as well as to patients), and so agrees that actions that reduce these problems will be very worthwhile. Many of the recommendations in this guideline aim to reduce misdiagnoses and delayed diagnoses, and this is noted in the discussions related to individual recommendations where relevant. Thank you again for your comments.

				that some of her patients had 'achieved a cessation of their symptoms' through CBT. At the time there was no trialled treatment for MdDS and therefore no chance of a cure and at the start of that consultation she'd told me that she didn't think there would be a cure for MdDS for 30 years. To then tell an untreatable, incurable patient that CBT could cure the symptoms was confusing and unbelievably cruel. This was recognised and acknowledged by the representatives who were present at the 'local resolution meeting' which was part of the 'complaints procedure'. All except the neuro-psych. She did, however, agree that thoughts and feelings do not create long term physical symptoms and seemed to acknowledge that a 'functional' label would, as Dr Wade had told me, cause the 'certainty' of prejudice in primary care. I doubt this will stop her trying to slap this label on other people and conditions though, since her livelihood seems to depend on it. While his colleagues in my old primary care practice were telling me to trust the experts, repeatedly, one GP had warned me that if I went to the 'sleep clinic' they'd make mincemeat of me. But I was desperate and didn't trust that he wasn't saying that just to get out of having to pay for the referral (which was part of his reputation, along with dismissing physical symptoms in favour of quasi psychological ones). However this begs an important question for NICE. Why are there departments in the NHS whose job it is to make mincemeat of patients? It's interesting to note that I was removed from that primary care practice shortly after getting re-diagnosed and shortly after buying my medical record, which was heavily redacted, including one entire record being given the black pen treatment. (I've had that redaction lifted now, but it took my current GP several years to achieve that). By chance I spoke to the CEO of one of the excellent UK Migraine Charities (some links to them might be useful in your guidance since their guidance on migraine management is clearer than yours) one day. She kindly talked me through one of the papers on MdDS with respect to migraine and then asked me about my experiences in the NHS. So I told her about the 'functional' debacle, the redactions, the high level of inaccuracy in my medical record and being removed from a practice and she said 'oh, that's all too familiar to me'. Do NICE think that people with migraine being booted out of their primary care practices is Health and Care Excellence? What about the inability of many doctors to follow the GMC guidelines regarding note-taking? (This is possibly beyond the scope of any one set of NICE guidelines but it is a major and common problem which causes a lot of wasted time and distress for patients and doctors alike. So probably should be listed in DSM.) What about my former primary care team who told me that they were aware that redactions in notes were stressful for patients but then went ahead and redacted mine anyway, in the full knowledge that stress isn't good for people with MdDS (or any other medical condition, as far as I can tell)? Do NICE view that as Health and Care Excellence? Fortunately I now have the medical 'dream team' for someone with a rare condition and no longer list 'doctors' as one of the worst symptoms of MdDS. My GP is a gem as is my local neurologist who's done loads of work for Team MdDS UK. My osteopath is a genius – people with MdDS often experience extreme symptom hikes when in enclosed spaces and he's fixed that for me as well as reducing the influence of barometric pressure changes which can also hike symptom levels. £43 per session, though, so I don't go very often. The Genetics Prof in Bristol is also a genius which is good because, as before, my middle sister had MdDS symptoms for two years, my eldest sister had migraine and my Mum has epilepsy (drug controlled but audio triggered, which is fascinating to me since audio vibrations have a massive influence on MdDS symptom levels for me, both in a good way and a bad way, depending on the frequency.) But if my adult nieces and nephews develop MdDS and get labelled as having an 'anxiety disorder' or 'functional symptoms', rather than being offered access to trialled treatments, I will not be a happy punter. The backstory re how hard it was for me to get a referral to the Genetics Prof is mindboggling. But I'd be glad to tell NICE about it because it has a happy ending. I am now an e-patient, thanks to Findacure. Thanks to the funding I get from my family I will be joining Prof Floris Wuyts (Euro MdDS superhero) at the next Cambridge Rare Diseases Summit on 23rd October and hope that someone from NICE will be there – I went last year, to network, and found it inspirational on many levels but mostly because of their #patientsincluded #patientsinvolved ethos. I am grateful for the opportunity to give feedback re the NICE draft 'neuro problems' guidelines and guidance, not least because it mentions 'functional' and 'MUI' (which I generally refer to as 'MUS') several times and seems to reinforce the notion that if patients have been given these labels once they are unlikely to be able to shed them in favour of a rational diagnosis. (see Point 7 on page 56) I am concerned that this NICE draft	

				doesn't mention DEN (doctors' educational needs) or PUN (patients' unmet needs) so appears not to be up to speed with GPs such as Dr Emma Reinhold who are reframing the 'MUS'/'functional' space to reflect emerging conditions which are frequently misdiagnosed as 'MUS'/'functional'. Despite not fitting the current criteria (the neuro I saw said it always takes ages for the criteria to catch up with the reality of patients' symptom patterns), I have also been diagnosed with Vestibular Migraine and recently read the NICE guidelines for migraine. They're a bit confusing and contradictory but I was relieved to see no mention of 'MUS' or 'functional' in them so wonder why they are mentioned in the draft 'neuro problems' guidance and guidelines. Can you explain, please? When I last saw the neuro-psych I was able to comment on her training aid for when to diagnose 'MUS' and point up the many flaws in it. I would send it to NICE but it disappeared from the internet shortly after that meeting. Which is a shame because it demonstrates a) her specialism bias b) a distinct lack of understanding that untreated physical symptoms may not abate spontaneously and c) how poor the neuro problems clear up rate is - and why these issues are interconnected and inappropriate for modern medicine. But the fact that it disappeared so rapidly probably tells you everything you need to know. However I have a paper copy. Would NICE like to see it? I have also been diagnosed as having 'mild to moderate intellectual under functioning' and am aware that I also have symptoms consistent with cognitive/vestibular interactions. This includes word loss and difficulty with word finding (nearly the same thing, but not quite) which is not 'functional' at all, although this draft infers that it is. Regarding difficulties with word finding/word loss, the same can be said of many people with migraine, cog-fog from chronic pain, any form of ataxia, M.E, MS, Parkinson's ('we can't walk and talk at the same time'), Meniere's Disease (more women than men report being told that the symptoms of MD were caused by depression, which delayed their diagnoses, thereby causing psychological damage and damage from inappropriate medications), any other balance condition you can think of, dementia, head injuries etc etc. The list is a long one, unfortunately, and word loss/word finding problems can also be the result of medications. Which, if they were discovered to be inappropriate due to misdiagnosis, could increase the psychological damage. That the draft 'neuro problems' guidance and guidelines ascribe word loss and problems with word finding as being 'functional' (Point 72, page 95) gives me cause for concern because it demonstrates a lack of understanding from NICE re the physical causes. [The Brainless Blogger is hilarious on the topic of memory/word loss etc. if you need to pause for a giggle at this point.] Two questions arise. The first is 'Word loss and difficulty with word finding are also signs of stroke (along with the well-known word-slurring). Would NICE be willing to flag this up, in the relevant section?' And the second question is 'why do NICE think that word loss and difficulty with word finding is 'functional'?' I was grateful that the neuro psychologist who did the cognitive testing told me that the 'functional' model had been largely discredited but I see no sign of this via this draft 'neuro problems' guidance and guidelines. However it was good to read the part of the draft that says 'sensory migraine aura may be associated with speech and language difficulties' but a link re cognitive/vestibular interactions would also be very helpful for all balance conditions patients and their doctors. As would a link that explains the sympathetic/parasympathetic system in relation to balance conditions, which can often be overlooked by doctors. Ditto re a link to the connection between balance and the limbic system, which is also often overlooked. Also there are some good mnemonics which can help patients and doctors when consulting about balance conditions so links to those would be helpful too. The language in the So Stoned one is archaic ('photo*phobia*"? What century is this again??) and the 'stoned' connotation is unfortunate, but it's still very helpful. Slightly off topic but I live in Bristol and am disappointed to note that there seems to be only one local Stakeholder registered re this draft. My care via the North Bristol Trust (NBT) is now exemplary so I might have wanted to submit my feedback via them but I can't because they're not a registered Stakeholder. I might have also considered submitting via the National Hospital for Neurology and Neurosurgery (where I was re-	

				diagnosed) but the adult audio-vestibular clinic has now moved to the National Throat, Nose and Ear Hospital and my consultant there told me that they haven't been asked to give feedback re this draft. MdDS is thought to be a malfunctioning of velocity storage in the Vestibular Ocular Reflex so it doesn't sit comfortably with me to not be treated in an Eye and Ear Hospital so I have discharged myself from the National Throat, Nose and Ear Hospital. Thankfully no one in any of these hospitals (other than Frenchay, which is part of the NBT) has ever suggested to me that MdDS is 'functional' or due to 'MUS'. It's interesting to note that the glossary of terms in the draft doesn't include what 'medically unexplained illness' is or the associated risk factors of this label (death, in some cases). Neither does it give an explanation of what 'functional' means or mention the harm this diagnosis can cause. In the literature from Dr J Stone (Bare Essentials, Functional symptoms in Neurology) it states that patients who are given a 'functional' diagnosis often experience anger when they receive a non-organic diagnosis. It is recognised that anger is not good for the immune system. So direct, physical harm ensues from this diagnosis. Dr D Wade told me that patients with a 'functional' diagnosis face the 'certainty' of prejudice in primary care and Prof Carolyn Chew-Graham demonstrates that doctors find their stomachs churning and their hearts sinking when faced with patients deemed to have 'MUS'. This isn't healthy for anyone. 'Functional' (the rebrand of 'psychogenic') may be falling out of favour as the term used for symptoms for which doctors have been unable to find the cause, which feels like progress. The explanations for why 'functional' was used demonstrate that neurologists are willing to try and hoodwink patients by using a term that maps onto an understanding of modern imaging techniques. This is deliberately duplicitous. Dumbing down is also in evidence, from the notion that 'functional' is a term that's easy to use with patients. Using this term is neither respectful to patients, their GPs or to neurologists, since apparently the evidence required to prove a 'functional' diagnosis is a normal or 'negative' MRI scan. Given that the 'functional' literature also demonstrates that not all neurological conditions show up on an MRI, doctors and patients should not be pressurised into accepting this diagnosis on the basis of 'negative' MRI scans and neurologists – and NICE - should know this, as before. If 'functional' is taken to mean 'a change in function, not structure' then a snapshot from an MRI isn't going to prove anything. Further dumbing down is in evidence when patients are told that 'functional' means 'medically unexplained symptoms' since it doesn't. Let's try it. 'After the carburettor was fixed, the vehicle was fully medically unexplained symptoms'. It doesn't work, does it? Or let's try another example: 'Before the symptoms of EDS became severe, Jane was fully medically unexplained symptoms. But as the symptom severity increased, she struggled to continue her training to be a doctor.' Still not working, is it? Or, totally pertinent to this draft, try substituting 'MUS' for the word functional in the second sentence of the Introduction part of this useful article and see if it works: http://journal.frontiersin.org/article/10.3389/fsurg.2016.00032/full Doesn't make sense if you do that, does it? 'Functional' is a euphemism and therefore not appropriate for use in a scientific field. When patients ask what 'functional overlay' means they are often told that it's just one person's opinion and they are entitled to another one. So they ask again what it means and why their notes say it was discussed with them, when it wasn't. Doctors nearly always look shifty when asked what 'functional' means and usually preface their response with something like 'none of the terms are perfect' which doesn't inspire confidence in either the doctors or the terms. Answers vary and honesty is hard to come by but patients have reported being told that they have emotional/mental health issues that are either causing or exacerbating their symptoms. Given that usually no pre-morbid formal or informal assessment of their emotional/mental state has been made, this encourages patients to believe that their doctors are making snap judgements rather than thorough scientific enquiries about their presenting symptoms. The 'functional' diagnosis may also rely on the Hoover's test. Oh how I laughed when, in one of Dr Jon Stone's podcasts, he said that this has been used to try and 'catch the patients out'. Is that Health and Care Excellence? He disapproves of this 'catching out' practice and I can't believe he's the only one. Yet he lets himself down in his papers and elsewhere in his podcasts etc.	

				If no physical examination has taken place, which is often the case, a 'functional' diagnosis should not be given. When it is (without an examination) it seems to be based on what some neurologists refer to as 'clinical instinct'. This also encourages patients to believe that due processes have not been followed and that, instead, they are being judged. This is not surprising, given that Dr Jon Stone advises neurologists not to avoid giving the 'functional' diagnosis because someone seems 'normal'. Normality is a social construct that changes over time so is an unreliable basis for giving or not giving any diagnosis. He also advises neurologists not to make a 'functional' diagnosis because someone has 'an obvious personality disorder'. Diagnosis of a personality disorder is not in the skill-set of most neurologists. But making snap judgements may be. The overarching impression I had after reading the notes from the neuro-psych was that I'd been in a kangaroo court with no witnesses and no jury since they are full of statements such as 'she admitted' this 'she denied' that etc. Mostly inaccurately recorded, as usual, and with little clinical relevance. But deeply unpleasant and disturbing. Although probably not as unpleasant and disturbing as the history of a woman aged 24 (at onset) who developed MdDS after a flight back to the UK, where she lives. A neurologist told her (via his clinic letter that was sent to her GP) that she was too young to have MdDS and that, therefore, she was making up the symptoms for medical attention and that this meant it was 'likely' that she had a 'personality disorder'. Does NICE agree that some UK neurologists don't need retraining, they need sectioning? [This, fortunately, was the opinion of this patient's GP, who had to pick up the pieces after this unproductive consultation.] Does NICE understand that when what many patients want to do is highlight and disseminate good practice, calling out the not-so-good practice gets in the way of this? The diagnosis of 'functional' symptoms may also be based on previous medical history. Dr Jon Stone advises neurologists to ignore the information in the 'physical' notes because they may be wrong. He suggests that a panic attack may have been misdiagnosed as asthma or that an appendix or uterus may have been removed when perfectly healthy. However he doesn't provide the misdiagnosis rates for asthma as a panic attack (or vice versa) or for the removal of a healthy appendix or uterus. This pick and mix approach to a patient's previous medical history, without checking back regarding these earlier diagnoses, is disrespectful to the people who made them and to their patients. Undermining confidence in other medical professionals via this approach isn't healthy for anyone either. Neither is it healthy to suggest using humour when discussing whether patients are/are not thought to be 'mad'. Some patients and most doctors know that any of these labels ('MUS'/'functional' or whatever is trendy at the time) are short for 'merely mad, not really ill', which is no laughing matter. When patients reject or question the 'functional' or 'functional overlay' diagnosis they are often told that they are doing this because they are prejudiced against people with psychiatric diagnoses. This may be the first they've heard that it is a psychiatric diagnosis so this approach is often unproductive and can be distressing for patients and doctors alike. Especially if the patient is still undiagnosed and is aware that although they and their doctors may not know the name of their bio-medical condition yet, any further delays in the diagnostic odyssey is also going to delay their ability to access evidence based treatments. Sometimes, illogically, this distress in the patient is then taken as being proof of the 'functional' diagnosis. Remember, the one that causes anger and therefore damage to the immune system? If they have the strength, patients then have to have a discussion with their doctors about ableism, power hierarchies, well-being, the value of neuro-diversity and the difference between prejudice and discrimination in medicine. The gender agenda (aka Medical Misogyny) may come up and the patients may wonder what century we're in, whatever their current gender identity is. Whilst involving patients in diversity training for doctors is crucial, doing it on a one to one basis, and during consultation time, isn't cost effective and is just more pro-bono work for the patients. Interestingly, when Dr Jon Stone discusses 'personality disorders', he states that patients with 'psychotic' diagnoses rarely have 'functional' symptoms. But the patients may not be aware of this when they are told that 'functional' means 'psychiatric' (which brolly covers 'psychotic'). Apparently their doctors are not aware of this either. OK, I know the committee won't have seen this because it's only just come out. But would it be OK if NICE acknowledged that neuroscience is moving faster than they are, in this draft? Or, to reframe that in a more positive light, that neuroscience research is an on-going process – thank heavens. But if NICE negates it via the assumption that neurological symptoms and conditions devolve from emotions and/or that they are	

				'functional', that is unlikely to be helpful to patients, doctors or researchers. https://privatemedical247.com/psychotic-teenager-misdiagnosed-as-bipolar-had-a-curable-autoimmune-disease/ Are NICE aware of Dr Jon Stone's advice to neurologists re what to say if someone challenges the 'functional' diagnosis? I haven't looked at any of his recent stuff but it used to be to say 'I believe you. Why don't you believe me?' What is wrong with this picture? Can anyone at NICE convince themselves that referring to neurology in terms of a game of Top Trumps is sensible? (See the 'mimics' paper which helps explain why the NICE recommendation 7, on page 58 is completely the wrong way around. Physical symptoms of 'dizziness' or imbalance mimic assumed 'functional disorders', not the other way round. So the recommendations 52-53 are also inaccurate in this respect. Yes, I know Dr Jon Stone has it the other way around in his paper. He's a good guy in many respects but his career depends on people buying into his stuff.) It's interesting to note that this 'mimics' paper says that 'functional symptoms is a card that neither doctor nor patient wishes to hold'. True that. How do you feel about doctors using the assessment as treatment for 'functional' symptoms? Doesn't that contravene medical ethics since patients are not able to research the diagnosis and therefore are unable to give informed consent, prior to treatment? (See the 'using the assessment as treatment' paper). NICE - is it clear from that paper when the diagnosis is given? The impression I get is that it's been made before the patient has even walked through the door, possibly on the basis of inaccurate or misleading referral letters which may not have been seen by the patients. Or possibly on the basis of confirmation bias regarding the assumed rate of 'functional'/'MUS' symptoms in neurology which is hanging around like a bad cliché. I'd like your views on this, please. What about the notion of neurologists practicing the treatment that is said to aid recovery from 'functional' symptoms (which is giving a clear and simple explanation of the symptoms) as they would skiing or cooking? (See the 'Bare Essentials' Paper) Patients and/or the treatment of symptoms are not hobbies – proper training and accreditation should be sought for any form of treatment. Likewise patients should be empowered by being given data showing the success rates of this treatment, prior to giving consent. If it was that simple to cure people of 'merely mad not really ill'/'MUS' symptoms, would Dr Lisa Steen still be alive? When I read her posthumous blog I got to the part where she said that her symptoms were hard to describe and thought 'oh no, I know where this is going' because the literature about 'functional' (I think this is in Dr D Wade's leaflet) suggests, completely illogically, that if symptoms are hard to describe in detail, the main symptom is more likely to be 'functional'. Please can you tell me where this myth comes from and what NICE are going to do to get rid of it? Given that even the experts find 'functional' hard to describe, could 'functional' be 'functional'? How does NICE feel about 'functional' being included in the ICD? This was done partly so that doctors could be paid for making this diagnosis. Incentives like that may increase the rate of diagnosis, thereby causing more harm to patients. Are you OK with the misdiagnosis stats for 'functional disorders' not being independently verified? There are many problems with these stats but that's the most obvious one. What about the part in the 'functional' literature where neurologists are advised to build trust with their patients because this could lead to a disclosure of a 'life event'? That's not Health and Care Excellence, that's grooming. And entirely unnecessary since the 'functional' diagnosis can be given in the absence of life events anyway. Some of the literature on 'functional' mentions that symptoms are more likely to be 'functional' if they seem to derive from more than one organ. So it's not surprising that balance conditions (which can involve eyes, ears and proprioceptive system as well as the brain) are frequently misdiagnosed as 'functional' or that getting a diagnosis with, say, vestibular migraine or Meniere's can take even longer than the average time it takes to get a rare conditions diagnosis.	

				Likewise some of the 'functional' literature suggests that the more symptoms a person has, the more likely it is that the main symptom is 'functional'. Most rare conditions, including MdDS, EDS, Friedrick's Ataxia and many others are multi-system, multi-symptom so it's also not surprising that rare conditions patients are frequently misdiagnosed as having a 'functional' disorder. Dr D Wade says that it is important for patients to realise that no other diagnosis (other than 'functional') will ever be found. Rare conditions patients have proved him wrong, many times. But the challenge of getting a rational diagnosis once a patient has a 'functional' label remains. Please, NICE, make it stop. It's interesting to note that the symptoms you list as being 'functional' (e.g. the fleeting sensations of 'twitches', 'buzzing sensations' or 'electric shocks') are migraine symptoms and my neurologist tells me that non-epileptic attacks/seizures are also a feature of migraine – IE not 'psychogenic' at all. (She also noticed I had a tremor and was concerned about Parkinson's. But since one of the MdDS researchers I met has seen this in her patients, I'm not concerned.) As the main goal of the 'functional' world seems to be to 'draw the line under further investigations', scientific research re these and other symptoms is halted. If these symptoms are recognised they can be treated but the treatment offered for people deemed to have 'functional disorders' won't help and could make the symptoms worse. I doubt that's what NICE wants but found this lack of understanding about reasonably common migraine symptoms in the guidance very worrying. What if someone doesn't have a good neurologist, as I do? What about new GPs? If they read your current draft they could misdiagnose someone, which will delay their access to effective treatment. It is also interesting that NICE only lists a few symptoms at this point in the draft. Dr Stone advises neurologists to 'show familiarity' with all 24 symptoms at one point but then raises it to 28 later. So either NICE are missing something, or he is. And it is very interesting to note that NICE doesn't list symptoms associated with 'functional movement disorders' (fairly recently rebranded from 'psychogenic') at this point in the draft, although you may do elsewhere. Apparently 'functional' movement conditions can be diagnosed via the Hoover's test and don't respond to treatment via a simple explanation of the symptoms as other 'functional' symptoms are supposed to do. Does this mean that NICE accept that the symptoms of so-called 'functional movement disorders' are not 'functional' since they are not listed at this point in the draft? Even if they are listed elsewhere, do NICE accept that since 'functional movement disorders' don't respond to the simple explanation of symptoms treatment, they are not 'functional'? Interesting too that the NHS Choices blurb on 'MUS' still lists ME, Fibro and IBS as having 'functional' components. These conditions are only 'MUS' until you meet a doctor who has them. Once these conditions leave this list, what will be left? Will it be repopulated with conditions such as Meniere's/BPPV/Inter-cranial hypotension/CSF leaks etc. – all of which can cause 'dizziness'? If so, how will that help these patient populations? [Off topic but it's great to see the coverage of Endometriosis – often misdiagnosed as IBS – in The Times and The Guardian. Apparently the NICE guidelines on this – and the comment from NICE in The Times – are being welcomed, with the caveat that unless diagnosis rates improve significantly, the guidelines won't have worked.] Meanwhile – and to repeat - the biggest risk factor for diagnosis with 'functional' disorders still seems to be a previous diagnosis of a 'functional' disorder. This NICE draft doesn't help remove this risk factor; instead it reinforces it. For a short while I joined the UK 'FNDHope' group (to discuss misdiagnosis) and found their misdiagnosis risk factors covered the problems for people with rare conditions very well. I had to leave, though, because it was too upsetting to read about patients with 'functional' labels going to their doctors and being asked 'So, what do you get out of being ill, then?' as if it is some kind of lifestyle choice which brings benefits to the patients. That's not health and care excellence; that's abuse. I think there was going to be a survey in that group about how many patients with the 'functional' label didn't go to their doctors when they needed to, possibly because of this type of abuse. That this question needs to form part of a survey tells you everything you need to know about the 'functional' label. As the woman who (having herself been misdiagnosed with a 'functional' disorder when she had a bio-medical, organic condition, obviously) founded the FNDHope group told me, 'functional' symptoms were not discovered in a laboratory or under a microscope. The word was coined at a conference. Yes, I know some people take comfort from the 'functional' diagnosis. But if Dr Stone could be persuaded to rename his site, patients with recognised neurological conditions might not stumble upon it accidently, read his diagnostic paper and be put off from seeing a neurologist. What name change would NICE suggest? "Word we coined at a conference in an attempt to hoodwink patients dot org"? Or "'Tiresome' patients who make GPs' stomachs churn and their hearts sink dot org"? Or "None of the terms are perfect and there's no agreement between patients and	

				doctors re what 'functional' means but we're going to use it anyway unless we use 'MUS' or 'MUPPETS' instead dot org"? Or "Conversion disorders are a 'relic' from the Freudian era, according to Dr Jon Stone, but we still think they exist dot org"? Or "Let's patronise/confuse patients, GPs and NICE etc. by telling them that normal neuroimaging via an MRI infers 'functional' symptoms at the same time as explaining that normal neuroimaging is common across a wide range of neurological conditions, including some of the rare ataxias, MdDS etc. dot org"? Regarding 'conversion disorders' the following is useful: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4000178/ Hilarious (not) that the author mentions neurological conditions and medical conditions as if they are two separate things – any idea where that's coming from, NICE? It's caused me some personal problems recently because my gem of a neurologist was trying to get me some psychological support (due to the flashbacks etc.) and couldn't because apparently neurology isn't part of the medical directorate at that hospital. This means that none of her patients with Alzheimer's, Dementia or Parkinson's (etc.) can access this support either. Utterly bonkers but apparently there's nothing that can be done to instate neurology as medical, unless their up-coming merger with the muscular-skeletal directorate works in this respect. Fingers crossed it does. Meanwhile here's an extract from an email I wrote to the guy who sent me the above link. *'Conversion disorder' has to be the most woo woo diagnosis ever. Even Dr Jon Stone calls it a 'relic' yet it's still on his site as if it's a thing. How do they think that works with children? Are they suggesting these children are converting emotions from a previous life into physical symptoms in their current life? Just plain ridiculous, as it was when they tried that one on with Jenn Brea. I do those 'patient narrative' meetings with trainee doctors and one of them tried it on me, re MdDS. I could see it coming a mile away from his line of questioning but it was still very unpleasant. Thankfully the rest of his cohort laughed at him and two of them suggested that medicine might not be the right field for him when he could be a really great astrologist. One of them has EDS and gave him a thorough ticking off.* [FYI, in case you don't know this already, Jenn Brea is one of the leading campaigners in the M.E. field.] So my question re 'conversion disorder' misdiagnosis (since this happens in neurology and audio-vestibular medicine far too often – and ditto in the rare conditions world) is 'Does NICE think that every patient who has ever been given a 'conversion disorder' misdiagnosis (IE all of them) needs urgent recall to ensure that they haven't been so traumatised that they don't go and see their doctors when they need to?' Also NICE should know that the abuse I mention above isn't limited to people diagnosed with 'functional' symptoms (or 'conversion disorder' or 'illness behaviour' (ref EDS/JHS) or whatever other term is trendy at the time). More than one UK Meniere's patient has reported being told 'we see a lot of bored housewives, I think you're one of them.' Some of the reports I hear from Team MdDS UK are also horrific. Sometimes it's just about the massive admin wastage in the NHS when we're passed from ENT to Neurology to Neuro-otology to audio-vestibular, to neural-ophthalmology (if we're lucky and the consultant understands MdDS, which happens occasionally) and back again, with referral letters getting lost or duplicated etc. at almost every turn. But mostly it is verbal abuse from doctors, consultants and, very occasionally, physiotherapists. I try to call it out whenever I witness it but it has to stop because this takes up far too much of my time, which should be spent getting the NHS to diagnose and treat patients with MdDS/vestibular migraine/POTS/Dysautonthanks etc. etc. Sometimes it's worth it if the highly-paid people apologise – and I did get an apology from the neuro-psych's CEO after the 'functional' debacle. But apologies are meaningless without amends. I got no apology from the neuro-psych, or my old neurologist, though, which is telling. Sometimes what we hear from doctors can be entirely surreal. For example one chap with MdDS noticed that a consultant had recorded 'vertigo' as his diagnosis. He said 'I don't have vertigo' to which the consultant replied 'what would you rather I wrote then? 'man boobs'?' Thankfully this chap has a sense of humour and shared the joke. I have his permission to share it with you. So that was the past (I hope), this is the future. The approach to a 'functional overlay' label from some physiotherapists is a good one. They don't read the referral notes before they see their patients because any mention of 'functional overlay' might colour their view of their patients and they don't want to work that way. Some of them now report that when they do read 'functional overlay' in the referral notes afterwards, they feel it says more about the person who wrote the notes than it does about their patients.	

An even more positive approach is exemplified in the Editor's choice letter to the BJoGP by Dr Emma Reinhold from April 2017 which I mentioned before. 'MUS to DEN' is a major advance on the 'psychogenic to functional' rebrand. Not surprisingly, this letter is getting great reviews in groups like the 'Dizzy Me – Light on Balance' group and the former patient co-author of this book sent it to VEDA recently. Tania, the co-author with Prof Wuyts, went undiagnosed with a vestibular condition for 15 years. During that time she received many misdiagnoses and, therefore, the wrong treatment. Spend some time in the migraine sites or the Meniere's Awareness Project site and you'll see plenty of evidence that this is not an unusual situation.

Your guidance and guidelines could go a long way to speed up the diagnostic process for neuro/neurovestibular/vestibular conditions. But not if they are rooted in the past re 'functional' 'anxiety disorders' etc.

I haven't been able to read the entire draft. But I did notice that NICE mention 'emotional' factors maybe being the cause of assumed 'functional' disorders. They are not. Our emotions change from moment to moment and are not strong enough to sustain physical symptoms for more than a short time (for example, laughter, tears, sweat from fear etc. – although sweat may be absent for people with some forms of Dysautonothanks and/or people with Ectodermal Dysplasia). Also 'functional' symptoms are considered to be more disabling than organic symptoms and cause distress for patients. So if they exist (which I doubt very much) the patients would learn, very quickly, to shift their emotional states to get rid of the symptoms. That they are unable to do this is proof that emotions do not cause symptoms, 'functional' or otherwise.

Would NICE suggest that cancer is caused by patients' emotions and is, therefore, 'functional'? Or the Zika Virus? If not, why do so re neurological/neurovestibular/vestibular conditions?

CSF leaks can cause 'dizziness' and patients with these – and those with inter-cranial hypotension - report similar symptoms to those of MdDS/VM. Are these leaks caused by emotions? They can be treated, but not if they go undiagnosed. How does NICE feel about patients with these conditions potentially being side-lined into the 'functional' world, via these guidelines?

Train of thought but one of my contacts is in hospital in London receiving treatment for a CSF leak. His comment on this draft was 'the reliance on the 'psychogenic' dx is getting so tired'. Unfortunately this made me laugh so hard I did the nose trick with my drink and got a symptom hike. And hiccups.

I think it is unlikely that Chiari Malformations have an emotional basis. What does NICE think?

How about gluten ataxia?

How about Susac Syndrome?

Many people with these conditions (some of which, not coincidently in my view, affect the balance system) – and many others – are often told initially that they have 'functional' symptoms or 'psychological/psychogenic' symptoms and these labels may stay in their records, even after they get a rational bio-medical diagnosis. Many patients may also be entirely unaware that they have been labelled with 'functional' (etc. etc.) disorders or 'functional overlay' because these opinions are often written in referral letters that they don't see. Which is worrying since formal diagnoses are often made, at least in part, on the basis of the referral letter/notes. So mistaken opinions that creep in to referral letters can't be challenged by patients, simply because they don't know they are there. It is only when they are compounded by a formal diagnosis that the harm can be undone and by then it is often too late.

What about conditions people are born with, such as squints? Are they 'functional' symptoms resulting from emotions carried over from a previous life? Some people (including me) who have to co-exist with MdDS have squints and/or no binocular vision and/or convergence insufficiency so this interests me particularly. We're told repeatedly that 'functional' symptoms turn up in all areas of medicine (except psychiatry, apparently) so what about Cerebral Palsy? Is that 'functional' too? (Interesting to note that a contact I have with CP feels better when he's in motion – see below re MdDS and motion).

				Bottom line – either NICE needs to demonstrate that all conditions are 'MUS' or that none of them are. Which is more likely, that medical science is incomplete or that people are able to manifest physical symptoms from sustaining their emotions for years on end to this effect? Even if this was possible, who would do that? IE choose to be ill? No-one. The interesting flip-side to this is that if neurologists were empowered to be less cue-blind to emotional content in consultations, holistic outcomes might improve. http://www.msbrainhealth.org/treatment-decisions/article/making-space-for-emotions-a-continuing-challenge-for-neurologists Many patients would like to spare their GPs from having to pick up the pieces by making space for our emotions during their much shorter consultation slots. So would NICE be willing to flag this up as a training need for neurologists instead, somewhere in this draft? Our mental health services are already overwhelmed and unable to provide services for those in desperate need. If the neurologists extended their remit to cover the emotional fall-out of living with conditions such as MS, MdDS, migraine, EDS etc. etc. this would take some of the pressure off the mental health teams – and our GPs. GPs and mental health teams are already having to support claimants who are turned down for health benefits – and even those that are not – so anything that can be done to prevent them having to do yet more work would be hugely beneficial, especially given the wait times and the further hell that is coming with the roll out of Universal Credits. Regarding specific questions about the implementation of the 'neuro problems' guidelines and guidance the main one from the MdDS UK members is 'How will these guidelines stop people with MdDS being told that their symptoms are caused by depression and anxiety, even after they've been accurately diagnosed with MdDS?' This is probably best exemplified by one of the scenarios I'll be using at the Cambridge Rare Diseases Network Summit in October as a competition for the students. I have the patient's permission to use her story and have written the scenarios in the second person to facilitate the 'walk a mile in my shoes' deal. Spoiler alert – this story has a happy ending. *4. You are female and were diagnosed with MdDS in 2002 when you were 30. Each time you ask your GP about your symptoms he tells you that they are caused by anxiety and depression, no matter how many times you mention MdDS. The years go by and you stop mentioning MdDS and gradually come to believe your doctor. You have to leave your £20k per annum job in banking because no accommodations are made for you regarding cognitive impairments, lighting, computer use etc.* *In 2017 you are working part-time in a playschool and now earn £6K per annum. You are admitted to hospital where you stay for a week, during which time you are diagnosed with Hemiplegic Migraine. You have been transferred to a new GP and manage to call her despite having high symptom levels. You do not mention MdDS but ask if your health problems since 2002 could be all due to migraine. Your new GP tells you that she's looked back through your notes and that she feels you have two things to deal with, migraine and MdDS. This is the first time a GP has mentioned MdDS to you and you feel a huge sense of relief that someone finally believes you/the original diagnosis. What's more, your doctor seems to understand the diagnosis and is aware of the link between MdDS and migraine. Your new GP tells you that she's going to do all she can for you. What actions do you take?* Think about it, NICE, that's 15 years of gas-lighting. See any sign of Health and Care Excellence there? Other than from this woman's new doctor? I imagine the same question about symptoms being ascribed to 'anxiety' and/or 'depression' (minus the accurate diagnosis part) could be asked by people awaiting diagnosis with vestibular migraine (which can take up to 30 years). Likewise those with Wilson's Disease, Hughes Syndrome (please note the main presenting symptoms – my old doc wondered if I had this on the basis of my symptoms but that's probably because he was in denial re the MdDS dx at the time), Meniere's Disease (which is also linked to vestibular migraine now), minor brain injuries, concussion, MS (which might not show up on a scan for 5 years) etc. etc. Regarding patients with balance conditions, I'd like to ask why NICE link 'dizziness' to 'anxiety disorders' when it is well established that any anxiety is the result of the 'dizziness', not the cause? One of my earliest MdDS contacts was a woman who was a former rocket engineer and the factory manager. Hardly a candidate for an 'anxiety disorder'. One of the lead researchers into MdDS had a short episode of it herself and is a top level scientist – another unlikely profile for someone with an 'anxiety disorder'. Another new researcher has active MdDS and is a lecturer in anatomy. She does all sorts of fun stuff like running neuroscience fairs for kids and also has a full teaching load on top of her research activities, which are undertaken between her university in Australia and the one in Antwerp where Prof Wuyts works. Not the anxious type at all. These are only	

examples from the MdDS world but there are highly professional, non-anxious people all over the world with balance symptoms (including 'dizziness') that result from Parkinson's, Ataxia, Migraine, etc.

Once each patient understands that constantly feeling off balance is bound to feel physically threatening (balance being an evolutionary necessity) and can knock the sympathetic/parasympathetic system out of whack, the secondary symptoms (including anxiety) can be much easier to manage and understand. That can help with keeping any POTS symptoms under control too. (This is good because my old doctor didn't want to refer me for POTS/Dysautonomia testing because the medications are expensive. I promised him I wouldn't take the meds so he did refer me, but I fired him anyway for being obstructive and knowing nothing about MdDS).

It is true that the vicious circle between balance conditions and 'anxiety' is well-documented. But whenever yet another paper is published on this topic and gets posted in groups such as the Meniere's Awareness Project, the responses are usually along the lines of 'Der, really?? Why is it that these researchers don't understand the difference between correlation and cause? How about they put their fine minds to developing a treatment rather than telling us stuff we already know?'

NICE, do you understand the difference between correlation and cause, with respect to 'dizziness' in adults and 'anxiety disorders'?

The advice in this draft re telling people thought to have 'functional' dizziness to anticipate a symptom hike when exposed to stress is worrying. If patients are taught to anticipate a hike in symptoms from stress, they may worry about any stressful situation they encounter, thereby increasing their stress levels. Response to stress seems to depend on a range of issues (including how much weed they smoked, apparently) but setting patients up to worry could add to the anger they already feel about the non-organic diagnosis, thereby creating another cycle of stress, trauma and harm to the immune system. NICE, given how over-stretched and underfunded the mental health system is, in the UK, is this wise?

With regards to patients with 'dizziness' who have been traumatised by long diagnostic delays and/or by being told that their symptoms have an emotional basis I'd like to ask if NICE recommends EMDR as a treatment?

I take it NICE knows that the symptoms of Lyme include 'dizziness'. Good luck with telling the adult Lyme crew that their symptoms may result from their emotions or that normal neuroimaging counts for anything.

Train of thought but a link to SuperBetter in your guidance could help a lot. And/or a trial to assess its efficacy compared to CBT (the type that doesn't include bio-feedback, that is.).

MedicalExpress have recently reported that dancing can reverse the signs of aging in the brain, as if this is something we didn't know already. A lot of the 'functional' diagnosis is made on the basis of 'distractibility' of symptoms but when people with Parkinson's dance or ride bicycles their symptoms often reduce or abate completely. Yet no one would say that Parkinson's was 'functional' just because when different neural pathways are in use, the symptoms abate.

MdDS is interesting in this respect too. For many patients the rocking symptoms abate when we are re-exposed to passive motion because of the different neural pathways involved. I can also switch off the symptoms of MdDS by using a TENs machine. Many people with MdDS have periods of complete remission from all symptoms (other than some residual cog-fog occasionally) and this, for me, was always like an on/off switch. The neuro-psychiatrist who tried to slap the 'functional' label on MdDS could not explain these features of MdDS via her medical models ('functional'/'MUS' etc.), which discredits her and them completely.

If MdDS is useful for one thing and one thing only, it is that.

I note with interest that when dizziness occurs in children, the NICE guidelines refer to this as a Red Flag. And stress is seen as a potential trigger. But in adults dizziness is often viewed as 'functional' or caused by having an 'anxiety disorder'. That's not OK. If it's a Red Flag in children, why isn't it a Red Flag in adults, especially because fall frequency is a reasonably good predictor of early and unnecessary death? Is blaming the patients for feeling 'dizzy' going to help prevent falls?

				With respect to patients who are labelled as having 'MUS' I'd like to ask NICE why the diagnosis rates of 'MUS' are not going down as medical knowledge increases? Does NICE think this due to confirmation bias? I'd also like to ask if NICE recognises that many so-called 'MUS' result from inappropriate medications? You mention 'psychogenic' tremors in this guidance. Does this mean you haven't read Carolyn Wilshire's paper 'Psychogenic explanations for physical illness; time to examine the evidence'? The rebuttal she got from Carson was 'they don't understand clinical instinct'. Which tells you everything you need to know about Carson and/or the approach of some neurologists. Patients don't want 'clinical instinct'. They want a credible explanation for their symptoms and evidence based guidance re their treatment options. Or maybe you haven't read this paper, which discusses misdiagnosis of a form of parkinsonism and decades of delays in accurate diagnosis https://www.researchgate.net/publication/50908491_Decades_of_delayed_diagnosis_in_4_levodopa-responsive_young-onset_monogenetic_parkinsonism_patients ? It's only just reached my radar (via a response to Dr Emma Reinhold's 'MUS to DEN' tweet) but it was published in 2011. Another response to that tweet is about the psychiatrisation of CFS/ME which has been well-documented and well-contested. Please, NICE, don't make the same mistake with neurological/neurovestibular/vestibular conditions via your draft. This would push progress back by 10 – 20 years at least, as happened with CFS/ME. All the brilliant neuro research that's been done recently would be lost (some of the MdDS research is based on space flight science so we're standing on the shoulders of giants, for sure), patients would be stigmatised (as happened during the PACE trial debacle) and gazillions would be wasted on the wrong kind of treatments. I couldn't find anything in the draft about the value of genome sequencing, which could help determine which medications will work and which won't, thereby saving the NHS a fortune and preventing harm to patients. Why is that? When I posted about this draft on faceache Anne Lawlor, who was a recent rare honouree via Global Genes replied by saying #thinkgenetics. I agree – do NICE? Regarding so-called 'somatoform disorders' I'd like to ask what "'dry out' the physical symptoms" means? And why new symptoms or an increase in the severity of symptoms should be seen as 'an emotional communication' rather than manifestation of a new disease? Here's the relevant link:https://www.nbt.nhs.uk/clinicians/services-referral/neuropsychiatry-clinicians/management-somatoform-disorders Are NICE OK with the highly controlling behaviour of the clinicians who 'manage' patients with assumed 'somatoform' symptoms/diagnoses? Are you/we/us (I've lost track re who's who re the pronouns, partly because of all that 'we/us' stuff in your confidentiality agreement) able to explain how this apparent manifestation of symptoms as a form of emotional communication applies to episodic conditions? IE is it possible for patients to be completely OK one day, but then apparently be unable to communicate their emotions after periods of remission, so have to manifest symptoms again? How does that work for the relapse/remission MS crew? Or the MdDS crew? The woman who sent me this link was threatened that if she didn't accept the 'somatoform' diagnosis she would be removed from her primary care practice. Are NICE OK with that? In one of the podcasts about 'functional' disorders it says something like "really clever doctors call 'functional' disorders 'somatoform disorders'". Does this 'management' information look like it was written by someone 'really clever' to NICE? Back in the realm of rare/underdiagnosed conditions, the following blog gives an excellent insight re the diagnostic odyssey. Although it's not about a neurological condition, it's understandable that neurologists were involved in the diagnostic process. What may be less understandable is why one of them started asking the author questions about family relationships and diagnosed him with a 'somatisation disorder'. http://www.findacure.org.uk/cant-see-the-wood-for-the-trees/?platform=hootsuite Please draw your own conclusions regarding the author's response to the implications of the inaccurate diagnosis made by that neurologist. Regarding rare conditions, I'd like to ask 'How will these guidelines stop the main barriers to diagnoses with rare conditions which Rare Diseases UK report as being that patients are not being believed and/or are told that their symptoms are 'psychological'?' I understand that not all rare conditions are covered by the neurological remit but enough of them are to make this a very important question for me.	

If mental health comes under ‘neuro-problems’ I’d like to ask how the guidance and guidelines will reduce the higher than average rates of anxiety and depression recorded in people with rare conditions?

Suggestion: A non-condition specific set of NICE guidance and guidelines for rare conditions that is congruent with the UK Rare Diseases Strategy could be very useful. However this would mean duplicating work so it might be easier to signpost the Strategy in all your guidance and guidelines since rare conditions turn up in all fields of medicine.

I’d also like to ask if the ‘neuro problems’ guidelines will address the specific problems faced by female patients, as is discussed regularly on the invisible disabilities sites, the migraine sites and many others, including the rare conditions sites. Although it is not about a neurological condition, this blog by a student doctor raises this issue very clearly (for the quick read scroll down to the second bullet point):
http://www.kevinmd.com/blog/2017/07/patients-can-teach-doctors-rare-diseases.html

I also have permission to share this account from a patient with EDS. Yes, this happened in America but the same line of questioning and attack is reported in the UK.

I have EDS and autonomic dysfunction. Prior to proper diagnosis I was treated as having fibro and CFS. At the time (years ago) lidocaine injections into trigger points were a recommended method of pain management. I called different pain specialists to see if any of them could do this. I spoke directly to one and he sounded very empathetic over the phone and said he'd help me. But once I got in his office his personality did a 180. He spent an hour interrogating me about my relationships and my sex life, and then moved on to verbally abusing me and suggesting that the only thing I needed was to do an hour of aerobics everyday so I could lose weight and get a boyfriend, because then I wouldn't be so depressed. When I defended myself he threatened me with corrupting my medical records and blacklisting me from my current doc and every other pain management specialist in the area. I tried to file a complaint with the hospital but they defended his interrogation techniques as "his right" and then denied any culpability because he was not technically on their staff...allegedly. I later found out he was their chief of anaesthesiology. I didn't see a doctor for years after that, even when symptoms were life threatening. I'm still scared of doctors, especially pain specialists. The current war on chronic pain patients hasn't helped.

I had other experiences of sexism like one doc saying that fibro is something women who can't handle life end up with. But that anaesthesiologist was the last straw for me at the time. I gave up trying to get help for a long time. It delayed proper diagnoses for almost twenty years.

More than half the questions the neuro-psych asked me were intrusive and irrelevant but I trusted her because she said she knew about MdDS and I was also desperate for help, so felt obliged to answer. (My (then) primary care team had made it very clear to me that they would not look kindly on any research I did into MdDS and told me to ‘trust the experts’, so when I thought I’d met one I was very relieved. But my trust was based on her deception and at no point did she inform me about her specialism bias.) I did try to put a boundary around discussing my relationships but she broke that boundary twice. I also tried to put a boundary around discussing my spiritual life and she broke that, too. If I’d understood she was using what I now call ‘the Dr Jon Stone script’ (which includes doctors having the courage to draw the line under further investigations) I would never have gone near her. Are NICE OK with clinicians who waste NHS time on irrelevant and intrusive questions that leave patients feeling like they’ve been through a quasi-psychiatric assessment that’s not measured against formal criteria?

We have a family friend who is a judge and he noticed a profound change in me after these consultations. He said it was likely that my human rights had been compromised but that it would be very difficult to prove. The validation he gave me helped to heal the trauma but a patient being traumatised by a neuro-psych is not health and care excellence. The funny part is that she recorded most of my answers inaccurately anyway and there are major discrepancies between her hand-written notes and those she dictated to her secretary which were sent to me.

As I’ve mentioned, I have only been able to access her hand-written notes very recently and it took many months before they were provided for me. But I am glad I persevered as they are very revealing and demonstrate her specialism bias (‘MUS’/’functional’) very clearly. At one point during our first consultation she asked me if I’d had any other health issues that might have affected my sleep and I told her that I’d had back pain on and off and had received physiotherapy which had been successful. She asked me if the physio had diagnosed the cause and I replied by saying that he wasn’t sure what had caused what out of my history of injuries (whiplash, falls etc.) but had been able to treat me effectively anyway. In her

				handwritten notes she recorded these incidences of back pain as 'MUS' and in her clinic notes she wrote 'she stated that they had been unable to elucidate the cause of the symptoms'. Erm, no I didn't, but I find it hugely entertaining, retrospectively, that she elected to put florid language into my mouth, possibly in an attempt to back up her 'MUS'/'functional' theory re MdDS and to influence my former primary care team to do the same. It nearly worked. Possibly for the same reason she decided to report a skiing accident that resulted in a helical leg fracture as an 'illness'. Ooops. She got the timing of that accident wrong, too. Ooops again. This can't have been a mistake since we discussed it as some length. To repeat, the inability of some health care professionals to write accurate notes is systemic, causes major problems for patients and doctors and these problems probably should be considered as a mental health condition and included in DSM. The ability to make stuff up out of thin air and/or deliberately miss-record patient data is not limited to neuro-psychiatrists – neurologists do it to and I wish they'd stop. Unreliable narrators are great fun in fiction. But not in health care. Do NICE agree? Would NICE care to comment on the mental health of the neuro-psych I saw, on the basis that she told me the MRI ordered by her colleague in neurology would come back as 'normal' whether I was in episode or remission but then wrote that she would await the result 'with interest' when she already knew what it would be? That made me hoot with laughter initially, before I realised the implications and experienced the consequences of my 'care' in her clinic back in primary care and elsewhere. It makes me laugh again now. But that's only possible because I got re-diagnosed, despite her insistence that no further tests were necessary. If she'd had her way, I would never have got tested at the Bristol Eye Hospital either and the resulting intel re MdDS would never have been established. Ditto re cardiology testing. Ditto re cognitive impairment testing. Ditto re genetic testing. Are NICE OK about neurologists/neuro-psychs or anyone else who attempt to block research via 'the Jon Stone script' or for any other reason connected with the 'no further tests are necessary' paradigm? A couple of years ago some 'rare' patients in the UK got together and re-wrote the Jon Stone script from the patient perspective. It's pro-bono work, as usual, and probably needs updating but would NICE like to read it? The questions I've asked about the 'functional'/'MUS' labels etc. are not rhetorical. To them I add this question 'Are NICE OK about young patients deemed to have 'medically unexplained physiological/psychological symptoms' ('MUPPS') being encouraged to refer to themselves as 'MUPPETS'?' http://www.swpc.org.uk/Exeter2017SWPCProgramme.pdf These are young patients with M.E. or C.S.F. so the 'MUPPS' label is inappropriate anyway. The attempt by the psychobabble merchants to land-grab M.E. is well-documented and has failed. When I read this NICE draft I thought 'oh no, here we go again, more land-grabbing by the 'functional' mob which means that primary symptoms will be left untreated and people may be forced to go for CBT, do GET and be given the wrong medications.' I did note that the draft mentioned that a high level of expertise was necessary to diagnose 'functional' disorders. It isn't and I'm stunned that NICE don't know this. Oh what fresh hell is this? Shame on me but I don't read all the posts from the various M.E. groups but have just found out that – on top of having to live with the ghastly symptoms of M.E. – UK patients with this condition are now being asked to write to their MPs to get the NICE guidelines on M.E. revised. (Their ref: EDM 271). Please, NICE, don't let this happen again re the suspected neurological conditions guidelines. Or, in the form of questions 'NICE, what are you going to do to ensure that we don't have to hassle our MPs regarding any future guidelines you produce?' and 'If it turns out that we do have to do this, please can NICE co-ordinate it nationally, rather than patients having to go via their local neurological alliances (if they exist and have any spare capacity for campaigning)?' Each time I think I can finish this pro-bono work, something else crops up that necessitates another additional question. *Sigh* This time the question is 'since the guidelines NICE came up with for M.E. resulted in people with that condition having to lobby their MPs to try to get them changed, how much confidence do you think I have with this draft re suspected neurological conditions?' On a more cheerful and pragmatic note, I'd like to see some hyperlinks in the guidance and guidelines to symptom checkers such as Isabel and the 'findzebra' app. Signposting patients and clinicians to VEDA would help and I also recommend Dr Tim Hain's site too, especially with respect to gold standard vestibular testing (e.g. don't use the air caloric test, it can give 'false positive' results). Sending every doctor in the UK a copy of the	

				English Edition of Dizzy Me – Light on Balance probably isn't possible, but mentioning it in the draft would help a lot. The field of balance in medicine is expanding rapidly so of course the authors couldn't include all balance conditions or even all the up-to-date information about the ones they did include, but this book is a welcome addition to the literature. The comments on it by doctors are priceless and often run along the lines of 'why didn't anyone tell me about all this when I was training?' I doubt the draft can include links for rare conditions such as MdDS but if it can, I recommend Dr Dai's public sites http://labs.icahn.mssm.edu/dailab/mdds/?fref=gc and http://mdds.nyc/?fref=gc Dr Cha's information is also useful and can be found via the Laureate Institute. The understanding of 'vertigo' in the draft seems very limited. IE it only seems to refer to rotational or 'true' vertigo. The rocking, bobbing, swaying symptoms of MdDS (often described as 'the feeling of being on a boat, when you're not') are also mentioned by people with dystonia and many people with vestibular migraine. Someone called Sophie who is a member of one of the VM groups just posted that she 'desperately wants to get off this boat' and has had loads of responses saying the same thing and discussing the many misdiagnoses people have received. Note to self, thank bleep I'm not on suicide watch in this group. Please add something to the draft to cover non-rotational vertigo so that these symptoms gain recognition and validation and so that patients can get an accurate diagnosis more easily. This recent blog by one of the lead researchers into MdDS will help explain why this is important: https://thedoctorweighsin.com/mdds-makes-you-feel-like-you-are-still-on-the-boat/ When MdDS isn't being misdiagnosed as 'a panic attack' – sigh - it is still frequently misdiagnosed as one of the many spinning vertigo conditions such as Meniere's or Labrynthitis because doctors misinterpret the symptoms as 'vertigo' no matter how many times we tell them we don't have 'vertigo'. (NB some people with MdDS have more than one condition so may have BPPV or other conditions that cause spinning vertigo too). This leads to the wrong medications being prescribed which is costly to the NHS and potentially damaging to patients. Likewise doctors often want to do the Epley manoeuvre on us and this can be harmful for people with MdDS and/or vestibular migraine. So getting a good description of non-rotational vertigo into your guidelines will save money for the NHS and help patients avoid being misdiagnosed and mistreated. The link below is an old article but demonstrates the problems people face when they become 'dizzy', especially when seeking a diagnosis. It also demonstrates a lack of understanding amongst medics of non-rotational vertigo and so makes it understandable why many patients with different balance symptoms/conditions are frequently misdiagnosed with BPPV, labrynthitis etc. Understandable, but not good, either for the patients or the NHS. https://www.theguardian.com/society/2008/oct/14/health-healthandwellbeing Unfortunately I have seen little in the way of improvement in services since then, although the establishment of balance clinics (set up by the 'spin doctors') has helped a bit. All the same, public confidence in the relevant specialist services is not great and there are still many reports of delayed diagnosis and mistreatment, in all senses of the word. A quick look at the comments section of this 'patient powered petition' will give you a world-wide view of this situation. Those of us involved with it were delighted when several heavyweight consultants signed and left comments, as did other health care professionals. But the comments from patients and their family members make it clear we have a long way to go and a lot of work to do. https://www.change.org/p/world-health-organization-who-vestibular-patients-for-smarter-doctors-and-better-patient-care Regrettably I feel the current content of the NICE guidelines and guidance on suspected neurological conditions will make this work even harder due to the references to 'functional disorders' and the notion that physical symptoms have an emotional basis. My sister's question about this is typically direct 'Aren't NICE meant to help people, not harm them?' Please let me know your answer and I'll pass it on to her. She could be a member of Team MdDS UK and/or Action for MdDS UK, but she doesn't do Facebook and wants to focus on her good health now, rather than her previous health issues for which she was never given a diagnosis. In the small print of the draft NICE make an excellent point regarding the need to differentiate between peripheral vestibular symptoms and symptoms that derive from the CNS. Would you be willing to write this in large print, repeatedly, throughout the guidance and guidelines? It is the key to a successful diagnosis for many patients and could save a fortune for the NHS.	

				Please can you also add information about 'silent' migraine, preferably near to where you mention Vestibular Migraine? Is there anything in the draft re the fun science around mitochondria and neurological conditions? There might be but without a search facility it won't be easy for me (or anyone else) to find it. Too tired to check but I think the draft mentions sensory processing conditions which are also interesting re CNS conditions that have an impact on the vestibular system. My grown-up nephew has synaesthesia and would like to see more information in the guidelines about this, if possible. Is there an audio version of the 'neuro problems' draft? I know there's an accessibility button on the NICE site but I couldn't find it there. Getting my access needs met to give feedback hasn't been easy but I appreciate the efforts that have been made by NICE in this respect. Do you think your outreach to patients has been effective? I saw my GP recently and she wasn't aware of the draft or the opportunity to give feedback so the same question applies regarding outreach to primary care doctors. For me, access issues also encompass being able to understand the language used in guidance and guidelines/policies, whether they are from NICE, the Specialised Services crew, NHS England or any other body committed to health care. My Masters comes from a school of Language, Linguistics and Literature and I was awarded a Distinction (Fortunately I only had one short episode of MdDS during the second year of this part-time degree). Yet understanding parts of this draft from NICE was completely beyond me, even with low symptoms levels prevailing. Yes, dumbing down isn't fun, but neither is feeling that I can't comprehend something that may have a great deal of influence over doctors and patients. This draft wins my 'sticky toffee pudding' of the year award, by a long way. Maybe GPs all speak the NICE language but our family GP looked at some of it last week and said it gave her a headache trying to figure out what parts of it meant. Other than the question about what 'functional' means, the main inquiry that derived from consultation within the MdDS UK group was about section 2.1.7. Here's one version of that inquiry: 'As I'm sure you and others will have already flagged up, section 2.1.7. of the draft suggests that a combination very common in MdDS (IE 'dizziness' and 'anxiety') is likely to point to a 'functional illness' and, as such, requires no further investigation. This would, in effect, prevent patients with MdDS from getting any recognition or support let alone a diagnosis and relevant onward referrals for testing or treatment. It should be advised that MdDS and other vestibular/neurovestibular conditions, including vestibular migraine, would need to be ruled out before a 'functional' diagnosis was considered and further investigations blocked. This can be done via a thorough examination of the patients' histories including, in the case of MdDS, onset triggers, presence of cognitive/vestibular interactions (aka 'cog fog' or 'brain fog'), reports of rocking/bobbing/swaying symptoms, light sensitivity etc. and the common experience of the abatement of symptoms when patients are re-exposed to passive motion.' To this commentary we added the following questions: 'Do NICE accept that unless this part of the draft is changed, diagnoses of MdDS and other vestibular/neurovestibular conditions may be delayed or missed? Do NICE also accept that the symptoms of many balance conditions (often described by doctors as 'dizziness' and 'anxiety') could also be missed – or, worse, misdiagnosed – as a result of section 2.1.7?' It is worth noting that I have rarely encountered a patient with a rare condition who doesn't have symptoms of imbalance or 'dizziness' either as part of their primary condition or as secondary – but frequently reported – symptoms. Would NICE advise all patients who experience imbalance or 'dizziness' not to report these symptoms in the UK, because of the risk factor of diagnosis with a 'functional disorder' or an 'anxiety disorder' and the subsequent blocking of further investigations/referrals? Alternatively, would it be better for NICE to acknowledge that some of the testing kit for vestibular/neurovestibular function has improved greatly over the last few years but that unfortunately not all the hospitals can afford the best kit? [When I got re-diagnosed the kit was so good that something actually showed up as 'broken' – the irony that this was a huge relief to me is not lost on my current GP or neurologist.] If so, would NICE consider that it would be useful to re-open 'cold cases' IE those where no diagnosis has been given – except possibly a 'functional' one – or where there may have been a misdiagnosis as a result of the paucity of the testing kit?	

				I gather that there is an economic model that supports the NICE draft guidelines re suspected neurological conditions. I have not been able to access this yet and won't have time to do so before the deadline for commentary on the draft. But it would be useful to know if it factors in the costs associated with misdiagnoses and/or delayed diagnosis, which are far too common for patients with vestibular and neurovestibular conditions. Yes, much of this cost – including the resultant mistreatment – is borne by the patients. But if symptoms are misdiagnosed and/or mistreated/mismanaged it is considerably harder for these patients to be economically active/productive. Having said that I also gather that I am now considered to be your 'colleague', which is great. Please can you tell me what my starting salary will be, what I can expect in the way of career progression and what support I will get regarding my access needs at work? Also, since many others have contributed to this commentary, please let me know how your job-share scheme works and/or if I am on a zero hour contract. OK, I'm kidding about this, but thanks for the laugh. As co-founder of Action for MdDS UK, my final question re the draft guidance and guidelines on suspected neurological conditions is 'Given that there is evidenced based treatment for MdDS (opto-kinetic stimulation and trans cranial stimulation), how will the implementation of the NICE guidance and guidelines on neurology ensure that these treatments will be made available on the NHS so that MdDS patients are empowered to achieve parity with patients diagnosed with Visual Vertigo?' My favourite part of the draft guidelines and guidance for suspected neurological conditions is where it discusses clear communication with patients and says that jargon shouldn't be used. 'Functional' and 'MUS' are jargon. So please don't use them unless you want to contravene your own guidance. Before I go back to watching kittens on the internet/having a laugh with Team MdDS UK about the perils of ironing when symptomatic/looking at the brains of deceased NFL players/doing Laughter Yoga/pressing the angry emoji on yet more reports of medical misogyny/generating some new neurons in the hippocampus/hanging out with my neighbour who, like my Mum, has just turned 90 (all possible when symptom levels are low), I leave you with a verbatim report of a consultation that was doing the rounds a few years ago. It's hilarious. Dr Stone got one thing completely right. Patients with neurological conditions can often be remarkably cheerful. The patient in this dialogue has Multiple Sclerosis and is one of the funniest people I know. Doctor: And, of course, you're feeling anxious and that's going to make your symptoms worse. So we need to treat the anxiety. Patient: (mildly amused that the doctor had referred to himself as 'we' for the third time) Fortunately I don't suffer from anxiety and even if I did I'd prefer it if you treated the primary symptoms rather than those – including anxiety – that may result from them, for some members of this patient population. Doctor: Oh, lots of our patients who have anxiety say that they don't. Patient: And you're ignoring this collective information because …? Doctor: Well, it's like when you have a headache, worrying that you might have a brain tumour could make the headache worse. Patient: I note that you didn't answer my question. Meanwhile fortunately I don't get headaches very often. When you get a headache, do you worry that you've got a brain tumour, doctor? Doctor: No, of course not. Patient: Yet you assume that I would. Interesting. What other assumptions do you make about patients, doctor? Doctor: (very agitated) Are you accusing me of making assumptions about my patients? That's like saying I'm prejudiced. Is THAT what you're accusing me of? Is it? IS IT? Patient: (getting up to leave) Wow, that escalated fast. Bye now. Doctor: No, wait, we just want to help you. Patient: (giggling) Getting paid a lot of money to disregard information from your patients and then shouting at one of them is your idea of helping, is it? Doctor: Why are you laughing at me? Patient: You're right, it's not a laughing matter. But you keep saying 'we' and there's only one of you, so I can't help but think that you may be delusional. Like I say, not a laughing matter at all. Bye now.	

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Association of British Neurologists/ Society of British Neurological Surgeons		3		There is this caveat which is welcome 'The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and, where appropriate, their carer or guardian' given the breadth of this document, this one sentence needs to be made much more explicit. Several commented that the document was too prescriptive and fear that it will add to the overall pressure on neurology OPD services in terms of triaging, where even neurologist would be quite wary of triaging referrals and ending up accepting everything just because some GPs have the backing of a "guideline". Greater emphasis should be made on what GP should be able to manage themselves; investigations they should do prior to referral to a neurologist, e.g. basic bloods, ECGs etc.; consider and treat relevant co-morbidities, e.g. Diabetes Mellitus, depression / anxiety; medication that may be causing / exacerbating symptoms, e.g. anticholinergics causing cognitive problems, chemotherapy causing neuropathy; and consideration as to when a referral to another specialist may be more appropriate.	Thank you for your comments. The guideline aims to facilitate referral when appropriate. The Guideline Committee has attempted to achieve the best balance between encouraging appropriate referral and discouraging inappropriate referral. The investigation and treatment of neurological disorders, including what should or should not be undertaken in primary care, was outside the scope of this guideline. Where some investigations in primary care are appropriate, they have been indicated in the guideline. Please also note that the 'do not refer' recommendations were changed to 'do not routinely refer' to acknowledge that there may be exceptions.
Association of British Neurologists/ Society of British Neurological Surgeons		67 68	 13	NICE recommendation 5.4: Gait unsteadiness: 1. TSH should be undertaken, alongside B12 and folate, in primary care. 2. Agree that progressive ataxia should be referred urgently (2WW), as immediate MR (or CT) imaging is usually mandatory. 3. Atypical brain infections including sporadic (and familial) Creutzfeldt-Jakob disease are probably more frequent than PML and Whipple's. It thus remains questionable as to whether these should be included in a guideline primarily aimed at primary care. There is no mention of Parkinson's disease which is a much commoner cause of gait unsteadiness 4. Paraneoplastic cerebellar degeneration normally necessitates a CT of chest/abdomen/pelvis, and sometimes total body FDG-PET (but this should be for specialist request only as these guidelines are aimed at primary care) Gluten sensitivity (or the identification of ataxia +/- neuropathy in the presence of anti-TTG antibodies) is a contentious subject. Overt vitamin deficiency (including of vitamin E) may not always be present. Most experience is in Sheffield, and it is true to say that the experience in other centres does not match. Many find that closer scrutiny reveals alternative (or additional) explanations for ataxia, e.g. MS, alcohol excess. Indeed, recent data from Sheffield suggests that alcohol (and other toxins?) may cause cerebellar degeneration through gluten sensitisation, so "gluten sensitivity" may be an epiphenomenon of a wider immune-mediated mechanism of progressive cerebellar damage.[1] I don't know how true the statement that this entity "is one of the most common treatable causes of sporadic gait ataxia" is. In the Sheffield series, it accounted for 302/1500 cases, but no data were available on what proportion were reversed by strict adherence to a gluten-free diet (however impressive individual reports are, based on the normalisation of spectroscopy etc.).[2] The arguments for testing and treating gluten sensitivity in progressive ataxia patients should be more nuanced, to reflect these uncertainties and breadth of experience, and referral for secondary care etc. should not be delayed pending receipt of these antibodies. References: 1. Shanmugarajah, P *et al*. Cerebellum & Ataxias (2016) 2. Hadjivassiliou, M *et al*. JNNP (2016)	Thank you for your comments. 1. The Guideline Committee agrees that it is reasonable to recommend assessment of thyroid function in primary care in these circumstances and therefore we have amended the recommendation. 2.The Guideline Committee's view was that progressive ataxia merited urgent (within 2 weeks), but not immediate referral. 3. The Guideline Committee has amended that Linking Evidence To Recommendations table to remove references to extremely rare conditions by name and have substituted the phrase 'other rare conditions' in where necessary. 4. The Guideline Committee agrees, but this is out of scope for this guideline. The Guideline Committee agrees with your comment and has explained it in the recommendations and link to evidence table .Testing for gluten sensitivity in this context, is to enable gluten sensitivity to be identified in primary care, as it may need management by a clinician other than a

					neurologist. The diagnosis of gluten ataxia would remain the responsibility of a specialist. This guideline does not attempt to mention every possible cause of each presentation, and Parkinson's Disease is covered by a separate guideline.
Association of British Neurologists/ Society of British Neurological Surgeons		72		24. Advise adults with Bell's palsy that the rate of improvement is variable and maximum recovery can take several months. This recommendation is accepted, however if there are atypical features (eg progressive symptoms and/or failure to improve within 4 weeks) then referral to neurology may well be appropriate. If a referring clinician has reasonable clinical concerns or diagnostic uncertainty, they should refer.	Thank you for your comment. The recommendation covers only presentations where the clinician is confident to diagnose Bell's palsy, but the presenting symptoms have now been elaborated in the recommendations and link to evidence table .
Association of British Neurologists/ Society of British Neurological Surgeons		72		25. Consider referring adults with a previous diagnosis of Bell's palsy who have developed symptoms of aberrant reinnervation (including gustatory sweating or jaw-winking) 5 months or more after the onset of Bell's palsy for neurological assessment and possible treatment	Thank you for your comment. The comment quotes a recommendation and the Guideline Committee is unsure what the stakeholder is referring to.
Association of British Neurologists/ Society of British Neurological Surgeons	11	13		Dizziness in adults – the term dizziness is used loosely to describe a problem with balance, dizziness in clinical practice has meant anything from memory loss, losing consciousness to vertigo, we are assuming that the guideline is trying to address vertigo which is a better term. This is better described on 57 (line 32- ie "Dizziness is a term used to refer to a subjective sensation of spinning (vertigo), to a more vague sensation of unsteadiness and sometimes to a feeling of light-headedness or pre-syncope.	Thank you for your comment. The Guideline Committee agrees that the term 'dizziness' is vague, and has added the definition of 'dizziness' in the glossary. The recommendations in the section on dizziness are not intended to apply only to vertigo.
Association of British	full	15	33	anti-gliadin antibodies –we don't think of it as a first tier screen for peripheral neuropathy.	Thank you for your comment. In this context, testing for gluten sensitivity should be undertaken to demonstrate coeliac disease which would then

Neurologists/ Society of British Neurological Surgeons					require referral to a non-neurological service rather than to diagnose non-coeliac gluten sensitivity (which would be the responsibility of the neurologist). Standard serological testing for coeliac disease is now widely available.
Association of British Neurologists/ Society of British Neurological Surgeons	full	26	21	Introduction There is a description of the range of neurological maladies and state that a high proportion are functional; then state that often there is delay in referral and in the same paragraph say that many do not need to be referred. This paragraph is confused and needs rewriting. Given the variation in experience that individual non-specialists will have of neurology, this is an opportunity to make a more explicit statement that a decision to refer a patient from primary care to neurology may well be more nuanced than could be put in a lengthy guideline.	Thank you for your comment. We have amended the introduction to reflect the complex nature of the decision to refer to secondary care.
Association of British Neurologists/ Society of British Neurological Surgeons	full	50	3	5.1 Blackouts in adults Blackouts - there is a separate guideline covering blackouts and yet this is covered whereas headache is not clearly. This section would benefit from being more specific about which features indicate epilepsy and having an emphasis on considering investigations for cardiovascular (ECG) causes prior to referral to neurology. If patients have severe learning difficulties many CCGs have Learning Difficulty (LD) services which can manage seizures as well as their other needs. There is discussion of LD services in the under 16 guidelines but no mention with reference to adults.	Thank you for your comments. The NICE Headache guideline covers diagnosis and management in primary care, and therefore does not need to be included in this guideline, although the Guideline Committee has added a clear link to the Headache guideline. In contrast the NICE TLOC guidance (which covers blackouts) is not specific about specialist referral for uncomplicated syncope, and we have therefore clarified this here We have now included in the recommendations and link to evidence table a list of symptoms which may indicate epilepsy.

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Association of British Neurologists/ Society of British Neurological Surgeons	full	66		Recommendation 12 – Facial pain with abnormal neurological signs Accepted As stated dental/ sinus disease are common causes. Recommendation 13 – Trigeminal neuralgia Accepted Recommendation 14 – Temporal arteritis Accepted. Should state ESR should be done prior to referral if temporal arteritis suspected.	Thank you for your comments. The Guideline Committee considered that ESR is not necessarily a test which needs to be undertaken in primary care before referral in these circumstances and local practice varies.
Association of British Neurologists/ Society of British Neurological Surgeons	full	68	7	Recommendation 16 – Rapidly progressive unsteadiness of gait Why do they even mention ADEM/Whipples which are extremely rare, and by mentioning them will lose the attention of a generalist audience	Thank you for your comment. The Guideline Committee has revised the recommendations and link to evidence tables to rationalise references to rarer conditions.
Association of British Neurologists/ Society of British Neurological Surgeons	full	70	7	Recommendations and link to evidence (consensus statement 17 to 21 in Appendix S) “Ask adults who have difficulty with handwriting that has no obvious musculoskeletal cause…“ should be alteration in the wording, to read “Ask adults who have noted a change in handwriting that has no obvious musculoskeletal cause”.	Thank you for your comment. The Guideline Committee has elaborated the recommendations and link to evidence table to clarify. We do not think that your suggested wording can be adopted into the recommendation because people may find that their handwriting changes naturally over time.
Association of British	full	72		26. Refer urgently adults with rapidly (within hours to days) progressive weakness of a single limb or hemiparesis for investigation, including neuroimaging, in line with the recommendation on brain and central nervous system cancers in adults in the NICE guideline on suspected cancer.	Thank you for your comment.

Neurologists/ Society of British Neurological Surgeons				This recommendation is accepted	
Association of British Neurologists/ Society of British Neurological Surgeons	full	72	5	22. For recommendations on assessing sudden-onset limb or facial weakness in adults, see the NICE guideline on stroke and transient ischaemic attack in over 16s. - This recommendation is accepted but the group note that the NICE guidelines on stroke and transient ischaemic attack in over 16s does not discuss in detail the pathway for patients identified as stroke / TIA mimics.	Thank you for your comment.
Association of British Neurologists/ Society of British Neurological Surgeons	full	72	8	23. Do not refer adults with an uncomplicated episode of Bell's palsy (unilateral lower motor neurone pattern facial weakness affecting all parts of the face and including weakness of eye closure). This recommendation is accepted but wording could be improved to describe uncomplicated Bell's palsy as "unilateral lower motor neurone pattern facial weakness affecting all parts of the face and including weakness of eye closure and *evolving over hours*" This addition seeks to separate Bell's palsy from brainstem events	Thank you for your comments. The Guideline Committee has amended the recommendations and link to evidence table to clarify the time course and premonitory symptoms of Bell's palsy.
Association of British Neurologists/ Society of British Neurological Surgeons	Full	73		27. Refer immediately adults with rapidly (within 4 weeks) progressive symmetrical limb weakness for neurological assessment and assessment of bulbar and respiratory function. This recommendation might be improved by widening the description to "Refer immediately adults with rapidly (within 4 weeks) progressive symmetrical weakness *or bulbar dysfunction symptoms* for neurological assessment and assessment of bulbar and respiratory function" This category seeks to capture Guillain Barre syndrome but also Myasthenia Gravis and since there is no domain for bulbar symptoms in the document there might be value in adding in here	Thank you for your comments. The recommendation has been amended to emphasise that bulbar or respiratory dysfunction represent an indication for urgent referral.
Association of British	Full	73		"28 . Refer adults with slowly (within weeks to months) progressive limb weakness for neurological assessment in line with the recommendations on recognition and referral in the NICE guideline on motor neurone disease. "	

Neurologists/ Society of British Neurological Surgeons				There is no mention of fasciculation in the guidance, given that this guidance is regarding patients with suspected neurological disorders, it is worth mentioning that muscle fasciculation is a common symptom presenting to primary care. For the vast majority of patients, this lies within the spectrum of normal physiology. However fasciculation as a clinical sign in the presence of progressive muscle weakness, particularly with muscle wasting in the context of preserved sensation, warrants prompt referral to neurological services and should be referred in concordance with the recommendations on recognition and referral in the NICE guideline on motor neurone disease. This recommendation is accepted but should include some comment on the patient with fasciculation without weakness	Thank you for your comments. A new recommendation (1.14.6) has been added: *Do not routinely refer adults with small involuntary muscular contractions (fasciculations) unless these are associated with muscle wasting and weakness or muscle rigidity.*
Association of British Neurologists/ Society of British Neurological Surgeons	Full	73		29. For adults with symptoms of compression neuropathy of the radial nerve, common peroneal nerve or ulnar nerve: This recommendation is accepted but wording might be improved to “For adults with *history,* symptoms *and clinical examination typical* for compression neuropathy..” In the accompanying explanation for this recommendation there is note that atypical features should lead to alternative action. The wording suggested here brings this caution into the main text of the recommendation.	Thank you for your comments. The Guideline Committee has amended the recommendation (1.7.9): *For adults with compression neuropathy of the radial nerve, common peroneal nerve or ulnar nerve:* • *refer to orthotic services for a splint* • *review the symptoms after 6 weeks, and refer for neurological assessment if there is no evidence of improvement.*
Association of British Neurologists/ Society of British Neurological Surgeons	Full	73		Recommendations 30-34 are accepted In Recommendation 33 correctly indicates that referrals for suspected Cauda Equina syndrome should be immediate (emergency) and this emphasis should be included in the Summary and also in Recommendation 58 which refers. GPs should refer to the local Emergency Department for assessment and appropriate imaging. The ED and secondary care practitioners should consider performing emergency MRI imaging based on clinical assessment and refer to Neurosurgery or Spinal surgery. In Recommendation 34, (Lumbar canal stenosis) the referral should be to ESP, Neurosurgery or Orthopaedic Spinal surgery.	Thank you for your comments. The pathway for referral will depend on local arrangements and is not specified here.
Association of British Neurologists/ Society of British Neurological	Full	76		Re section on Memory Failure 1. The guideline appears to focus on who **NOT** to refer and generally seems to discourage referral. We suggest that the emphasis should first be on who to refer. It should p**rovide guidance on who to refer first and widen the referral group.** It should include people who might have normal performance on brief cognitive screen BUT have any of the following: 1. Prominent behavioural change (not due to pre-existing psychiatric condition) 2. Progressive speech, language or visual complaints 3. Other neurological signs / symptoms, e.g. gait disturbance or Parkinsonism 4. Inability to cope with daily activities or work 5. Family / carers concerned about progressive deterioration in cognitive function.	Thank you for your comments. The Guideline Committee acknowledges that the age threshold of 50 sits awkwardly with the current arrangements for most memory clinics. The threshold was taken because the existing NICE guideline on dementia seemed to be aimed primarily at an older population.

Surgeons				2 The threshold for referral seems to be placed at a very high level of impairment when current trends are to diagnose dementia and those with prodromal neurodegenerative conditions early. 3. The guidance is in a section on 'Memory failure' but clearly acknowledges and discusses cognitive problems that are not associated with memory complaints. The section would be better entitled 'Cognitive problems' to encompass people with behavioural or atypical (e.g. language or visual) presentations. The guideline refers specifically to people under 50, but *does not seem to have guidance for those above this age*. We are unsure why 50 has been taken as a threshold. Most 'memory clinic' services run by psychiatrists and gerontologists would be uncomfortable assessing patients <65 yrs old with cognitive complaints. There should be a low threshold for referral if there is a family history of young onset (under 65) dementia. Family history is not referred to at all in the current draft. Cognitive screening should be performed on a validated screening instrument for use in primary care.	Thank you for your suggested amendments. We have incorporated some of these into the recommendations in this section. We are not aware of a validated screening tool for use in this age group.
Association of British Neurologists/ Society of British Neurological Surgeons	Full	79	5	Recommendation 39 – Single dense amnesia with complete recovery We have significant concerns about this group not being referred, and incorrectly being diagnosed with transient global amnesia. There is also no mention of head injury in this section. Given the small numbers of patients involved, we would suggest that this group should be referred for further assessment. There needs to be a much clearer emphasis on obtaining a witness account for the guidelines for Transient Loss of Consciousness (TLoC) or Memory problems in the neurology clinic It is there on P79 but this should be stated more strongly elsewhere, even if there is reference to the NICE epilepsy guidelines. In addition for Transient Loss of Consciousness- including the ambulance record and the ECG (which are often in the A&E notes) with the referable is desirable. There is no mention of the importance of an ECG in the documentation on guidelines for adults (there is for children) with TLoC.	Thank you for your comment. Head injury is not relevant here as it is not a cause of a single episode of sudden onset amnesia. There is a clear recommendation to review with a witness if possible. The Guideline Committee believe that the definition of transient global amnesia used in this guideline is unequivocal and would not give rise to misdiagnosis. Specialist opinion would therefore have little to offer. The other issues are dealt with in the NICE TLoOC guideline (CG109).
Association of British Neurologists/ Society of British Neurological Surgeons	full	82	1	posture distortion in adults This is a very odd choice of words- abnormal posture in adults is preferred and more closely aligns with the information on Dystonia on NHS choices http://www.nhs.uk/Conditions/Dystonia/Pages/Symptoms.aspx	Thank you for your comment. The reason for this choice of words is to facilitate searching alphabetically for recommendations relating to the condition.
Association of British Neurologists/	Full	84		"Sensory symptoms such as tingling or numbness in adults" - The comments regarding functional symptoms are accepted	Thank you for your comment.

Society of British Neurological Surgeons					
Association of British Neurologists/ Society of British Neurological Surgeons	full	85	Last line	The 1st reference to the NICE guidance on migraine is not until P85 ie "For recommendations on diagnosing and managing migraine with aura, see the NICE guideline on headaches in over 12s. " Given that headache is the commonest reason for referral to a neurologist, there needs to be a much better referencing of other NICE guidance on headache. This would also make it much clearer regarding other headache disorders- such as temporal arteritis and trigeminal neuralgia	Thank you for your comment. The Guideline Committee has added a cross-reference to the Headaches NICE guideline in the recommendations in the Adults section of the guideline.
Association of British Neurologists/ Society of British Neurological Surgeons	full	86	16	anti-gliadin antibodies . This comment was based on "No evidence was identified for this review. These recommendations are based on committee consensus.	Thank you for your comment. The committee decided to retain the existing recommendation based on consensus and on previous guidance on coeliac disease (please see NGC20, rec 1.1.2).
Association of British Neurologists/ Society of British Neurological Surgeons	full	88	1	Recommendation 47 – Migraine aura There is duplication of the sentences *"usually spreads gradually from its starting point to adjacent body parts* *over a period of a few minutes, in contrast to stroke, which comes on very rapidly.* *Sensory migraine aura may be associated with speech and language disturbance."*	Thank you for your comment. The Guideline Committee has now amended the recommendations and link to evidence table .
Association of British Neurologists/	full	88	15	Recommendation 49- Stereotyped sensory hallucinations Stereotyped sensory hallucinations – is the term *hallucination* the best choice of word as a description of a sensory seizure? An alternative phrase example would be stereotyped sensory *phenomenon*.	Thank you for your comment. The Guideline Committee is satisfied with the current wording. A hallucination is the experience or perception of something not present. A phenomenon

Society of British Neurological Surgeons					is a fact or situation that is observed to happen, and is a term inappropriate here.
Association of British Neurologists/ Society of British Neurological Surgeons	full	89	21	Recommendation 57 – Cervical radiculopathy Surgery referral is mentioned in the rationale behind the recommendations but not in the recommendation itself. It may be worth stating therefore when applicable to refer a patient specifying that this is to spinal surgery rather than neurology for clarity. Should be divided into Cervical Radiculopathy with or without Myelopathy. Myelopathy is correctly indicated as an Urgent referral.	Thank you for your comment. The recommendation is based on presentation rather than diagnosis. The pathway for referral will depend on local arrangements.
Association of British Neurologists/ Society of British Neurological Surgeons	full	89	33	Recommendation 58 – Lumbar radiculopathy . The referral of suspected Cauda Equina syndrome should be immediate (Emergency) as indicated in Recommendation 33. Surgery referral is mentioned in the rationale behind the recommendations but not in the recommendation itself. It may be worth stating therefore when applicable to refer a patient specifying that this is to Neurosurgery/spinal surgery rather than neurology for clarity.	Thank you for your comment. The recommendation is based on presentation rather than diagnosis. The pathway for referral will depend on local arrangements.
Association of British Neurologists/ Society of British Neurological Surgeons	full	90	9	5.10 Sleep disorders in adults accepted It is important to state exclusions and also avoid referring patients with poor sleep hygiene e.g. insomnia as a referral criteria and also specify that OSA be referred according to local policy. These two symptoms are frequently referred into the neurology sleep clinic and at present these services do not have the capacity to accept these referrals.	Thank you for your comments. We agree, and believe this is covered in the current recommendations.
Association of British Neurologists/	full	93	3	5.11 Smell or taste problems accepted with the caveat that that there is no mention regarding to consider referring to ENT first as this could be more appropriate.	Thank you for your comment. The Guideline Committee has amended the recommendations and link to evidence table to account for ENT referral to

Society of British Neurological Surgeons					exclude a local cause of sensory loss first.
Association of British Neurologists/ Society of British Neurological Surgeons	full	95	29	5.12 Speech problems in adults accepted with 1 caveat re MND Recommendation 71. Refer adults with progressive slurred or disrupted speech to have an assessment for motor neurone disease, in line with the recommendations on recognition and referral in the NICE guideline on motor neurone disease. This is too dogmatic, there are several other causes of speech problems apart from MND (e.g. myasthenia). GP should also consider urgent SALT referral. Recommendation 72 – again useful to include this symptom (ie functional).	Thank you for your comment. The guideline is not intended to cover every possible cause of disrupted speech, but the Guideline Committee agrees that the focus on MND alone is not optimal. We have made a slight amendment to the recommendation.
Association of British Neurologists/ Society of British Neurological Surgeons	full	96	5	Recommendation 74 Consider referring adults with isolated and unexplained persistent dysphonia to have an assessment for laryngeal dystonia (involuntary contractions of the vocal cords) if hoarseness caused by malignancy has been excluded. The last sentence should be changed to state “therefore consider initial referral to ENT” at the end of this statement for clarity.	Thank you for your comment. The Guideline Committee has amended the recommendations and link to evidence table to account for ENT referral to exclude a local cause of sensory loss first.
Association of British Neurologists/ Society of British Neurological Surgeons	full	98	1	5.13 Tics and involuntary movements in adults Tics and involuntary movements - blepharospasm often managed in eye clinics, so this will very much depend on local service arrangements, may not necessarily be referred to neurology	Thank you for your comment. The Guideline Committee has made this change to the recommendation. It now reads as follows: *Refer adults for neurological assessment if they have involuntary movements of the face, neck, limbs or trunk that cannot be temporarily suppressed by mental concentration. If they have involuntary tight eye closure of both eyes (blepharospasm) that cannot be temporarily suppressed by mental concentration refer to neurology or eye clinic according to local provision.*

Suspected neurological conditions

Consultation on draft guideline - Stakeholder comments table
07 August 2017 – 19 September 2017

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Association of British Neurologists/ Society of British Neurological Surgeons	Full & Short	3	general	The ABN welcomes this guideline as an attempt to provide some guidance on referral of patients with suspected neurological conditions- *however there are significant changes which need to be made before the ABN would be happy to support this document*. Not least, this is essentially two documents combined into one - a guide for adults and another for children. There should be 2 separate documents. To put this in context, the ABN has sought as wide ranging views of ABN members of any NICE consultation- with all advisory groups (AAGs) consulted including acute neurology, stroke, MS and neuroinflammation, cognition as well as all members of the ABN executive and the Service Committee. The common themes are outlined below as an ABN response. 1. Several pointed out that the split between paediatrics and neurology is not clear in this document. It tries to squeeze too much into 1 document, which is why it currently stands at 168 pages. There need to be 2 separate guidelines- one for children aged 16 and under, one for adults 2. The range of conditions covered has been commented on as very strange and somewhat randomly selected; some were not appropriate for a document primarily aimed at a referring GP. For example, Whipples and Coeliac disease are mentioned (which are exceedingly rare), antigliadin antibodies are recommended in peripheral neuropathy, yet there is either no mention of important common referrals to neurology nor links to other NICE guidance (such as for Multiple Sclerosis). For example, there is no section on “disorders of vision” - diplopia, ptosis, papilloedema; however, there is “smell and taste”, which is far less important) 3. Also there is no mention of consideration of treatable rare disorder such as Wilson’s in assessment of a young onset Movement Disorder. This is more common than Whipples’ and more clearly warrants a mention 4. Given that the aim of the document is stated as guide for the non-specialist about referral of 'common and important' neurological presentations- this distracts by other inclusion of conditions that should not be included, and the omission of others. The wording needs to be more nuanced- Do Not Refer sections- there is a very real risk of a reasonable GP being unwilling to refer a patient they have genuine concerns over or unsure of. Although this is stated, it needs to be re-emphasised throughout. Recommendations 52 and 53 refers to Functional symptoms. As a general comment it seems inappropriate to expect the non-specialist to decide if a symptom is functional. The wording in relation to Functional symptoms needs to change recognising the uncertainty and action to be taken when in doubt as well as with persistent symptoms. 5. “The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and, where appropriate, their carer or guardian’ given the breadth of this document, this one sentence needs to be made much more explicit. Several commented that the document was too prescriptive and fear that it will add to the overall pressure on neurology OPD services in terms of triaging, where even neurologist would be quite wary of triaging referrals and ending up accepting everything just because some GPs have the backing of a "guideline”. 6. There is an assumption of a greater level of neurological knowledge than the average (& competent) GP would be expected to possess. As the acute neurology AAG commented “I’m not sure that this document will in any way improve patient care or help create what one might consider to be a "good model" for a neurology service”. For example, under dizziness – a GP may be able to do Hallpike and Epley manoeuvre but how common is HINTS test performed in general practice (P63)? Although it does state “HINTS could still be a good alternative to MRI in excluding central legions in a population similar to that included in the studies and when performed by someone trained in its use and interpretation.” This does not seem to be useful in terms of advice to a GP with a dizzy patient. GP review commented specifically on the directive nature of the document and the unrealistic level of triage and neurological expertise expected by this document. (there is no consideration e.g. of general medical cause of dizziness, e.g. anaemia). There should be clearer definitions of Immediate- ie admit this patient to hospital; urgent- refer to Outpatients urgently with expectation that they would be seen within a set time period; 7. Although NICE describe the difficulty in producing an evidence basis for this work and that much of it was agreed by consensus. That is reasonable if the only way forward but in that case, we would suggest that this makes broad consultation all the more important, and **essential to see a redrafted version of this document following this consultation**.	Thank you for your comments. The references to rare conditions have been rationalised. These appear in the recommendations and link to evidence sections rather than the recommendations themselves, and are intended only to help explain how the GC derived the recommendations. They are not intended as a comprehensive review of any particular presentation. Time constraints meant that not every neurological presentation could be included, and the GC based its decision primarily on whether or not current referral practice could be improved, and secondly on how common the presentation is. In this guideline it is not in general appropriate to refer to diagnosis and management of specific conditions. The guideline is aimed principally at primary care, but the scope also includes those presenting to A&E departments, hence the inclusion of the HINTS test The involvement of the external reference group is described in the full guideline (Section 4.1). Briefly, they were asked to comment on a first draft of the guideline, and then recommendations were re-drafted when the external group voiced substantial disagreement with the draft versions. In response to your specific comments: 1. The guideline will be published in an accessible form (usually viewed online, which will split the paediatric from adult recommendations.) 2.The choice of conditions was decided with extensive input from stakeholders who defined the scope of the guideline.

				8. In the document, it states there were 43 external experts in total consisting of the following expertise: 9 adult 11 neurologists (20.9%), 7 paediatric neurologists (16.3%), 9 general practitioners (20.9%) and 18 12 other professionals including paediatricians, psychiatrists and physiotherapists (41.9%). We are unclear how much consultation with this group there was 9. In summary, there needs to be a much clearer focus on the target audience- which will primarily be primary care. The current draft is inconsistent in the level of information and appears confused at times in terms of target audience.	3. The Guideline Committee agrees and has deleted the reference to Whipple's disease. 4. The wording of each recommendation has been considered carefully to provide straightforward and accessible statements, necessary in a guideline of this type. At no point does the guideline suggest that the diagnosis of a functional neurological disorder should be made by a non-specialist. 5. The place of NICE guidelines in defining good practice is well established, and the Guideline Committee did not think it required reiterating here. 6.Advice is provided both for primary care and for other non-specialist services such as those in A&E. The guideline is clear that a high level of neurological expertise is not required of the non-specialist. 7. NICE guideline development processes must be independent. The consultation process enables a wide range of views to be assimilated in the final guideline, but it cannot be submitted for approval to any external body before publication. 8. The processes involved in devising and editing a NICE guideline can be found on the NICE website. Minutes of all guideline development group meetings are published. 9.The target audience for the guideline is stated in the introduction.
Association of British Neurologists/ Society of British Neurological Surgeons	short	13	12	Do not refer adults with symptoms of cervical radiculopathy that have remained stable for 6 weeks or more unless: Very odd use of English (and this occurs repeatedly) Suggest "Refer adults with symptoms of cervical radiculopathy that have been unstable for 6 weeks or more if…	Thank you for your comment. The term 'unstable' when referring to cervical pathology has a particular connotation here which would be confusing. NICE writes is a specified style which occasionally results in awkward sentence construction, but in this instance the Guideline Committee thinks that the "Do not refer" construction is preferable.

Association of British Neurologists/ Society of British Neurological Surgeons	short	15	27	***1.13 Tics and involuntary movements in adults*** Do not refer adults with tics (involuntary movements that can be 27 temporarily suppressed at the expense of mounting inner tension) unless 28 the tics are severe and disabling. Odd grammar Refer adults with severe or disabling tics for a diagnosis	Thank you for your comments. The Guideline Committee accepts that NICE's standard terminology occasionally results in awkward sentence construction, but in this instance the Guideline Committee thinks that the "Do not refer" construction is preferable. The rationale for the wording is explained in the recommendations and link to evidence table which is to be found in the full guideline.
Association of British Neurologists/ Society of British Neurological Surgeons	short	16	1	1.13.2 Consider referring adults with a tic disorder for psychological therapy if the 1 disorder distresses them. ***Only consider referring those adults with a clear diagnosis of a tic disorder for psychological therapy if the disorder is upsetting them. Most GPs would we suspect be very uncomfortable making a diagnosis of such a movement disorder without some speciality input at the diagnosis stage***	Thank you for your comment. The Guideline Committee considered that tic disorder is sufficiently common that diagnosis would normally be expected to be made in primary care.
Association of British Neurologists/ Society of British Neurological Surgeons	short	26	8	1.6.8 For adults with symptoms of compression neuropathy of the radial nerve, 26 common peroneal nerve or ulnar nerve: 27 □ refer to orthotic services for a splint Recommendation 54 – Carpal Tunnel syndrome – Refer to Neurosurgery or Hand surgery This is inappropriate (and unsafe), we very much doubt that a GP would feel confident about making such a diagnosis in all cases without neurology (and/or neurophysiology assessment first). Possibly change the wording to 'consider referring for a neurology opinion if the history and signs are not typical, e.g. of a Saturday night palsy (in the case of a transient radial nerve lesion)	Thank you for your comments. Clinicians vary in their standard of competence in neurological examination or diagnosis, but where the clinician is confident in the diagnosis the recommendation is appropriate. Both recommendations acknowledge that referral may be necessary. However, the Guideline Committee feels that some primary care clinicians will be confident in these diagnoses.
Association of British Neurologists/ Society of British Neurological Surgeons	short	4	19	We are concerned that this section does not mention the possibility of subacute vertigo, with neurological signs, having a potentially serious cause like multiple sclerosis. See NICE guidelines on MS care, 2003.	Thank you for your comment. The guideline was necessarily limited in scope and had to concentrate on areas where practice was variable or unsatisfactory. The Guideline Committee recognised that subacute vertigo may be a feature of demyelination and require onward referral, but decided that for the most part current practice is satisfactory in this area.

Association of British Neurologists/ Society of British Neurological Surgeons	short	6	11	***Facial pain, atraumatic 10*** 1.3.1 Refer urgently adults with facial pain associated with persistent facial 11 numbness or abnormal neurological signs for neuroimaging Wording needs clarifying although just the short version but this would lead to a lot of unnecessary imaging	Thank you for your comment. The Guideline Committee considered the wording of this recommendation was satisfactory. Pain associated with neurological signs is a rare and serious combination of features and demands urgent imaging.
Association of British Neurologists/ Society of British Neurological Surgeons	short	7	1	Suggest change wording to include a mention of thiamine as per: take an alcohol history and follow the recommendations (such as a consideration for thiamine as in the NICE 1 guideline on alcohol-use disorders: diagnosis, assessment and 2 management of harmful drinking and alcohol dependence	Thank you for your comment. The guideline is intended to cover referral, not treatment. The need for thiamine administration is covered in the NICE guideline on alcohol-use disorders.
Association of British Neurologists/ Society of British Neurological Surgeons	short	7	4	Ataxia associated with coeliac disease is rare; it seems strange such a rare condition is being highlighted here.	Thank you for your comment. Ataxia is an uncommon neurological condition, but can be associated with gluten sensitivity and could be diagnosed in primary care, removing the need for onward referral (and speeding up diagnosis). Moreover, this is in keeping with the existing NICE guidance on coeliac disease.
Association of British Neurologists/ Society of British Neurological Surgeons	short	7	7	1.4.4 Refer adults who have difficulty initiating and coordinating walking (gait 7 apraxia) to neurology or an elderly care clinic to exclude normal pressure 8 hydrocephalus. This should be changed to “1.4.4 Refer adults who have difficulty initiating and coordinating walking (gait 7 apraxia) to neurology or an elderly care clinic. Normal pressure hydrocephalus is frequently over diagnosed on the basis of an over-interpretation of imaging, there are many other valid reasons for referring on the basis of the gait abnormality for a specialty opinion that have nothing to do with imaging	Thank you for your comments. The Guideline Committee understands your point, but felt that some of the recommendations to refer needed explanation since they might not be apparent to some in primary care. These brief mentions of the reasoning are not essential but the Guideline Committee thinks they will enhance take up of the recommendations. The Guideline Committee considered that it was worthwhile emphasising that

					normal pressure hydrocephalus can present in this way as it is potentially treatable. The recommendation does not mention imaging.
Association of British Neurologists/ Society of British Neurological Surgeons	short	8	1	This section should include a specific paragraph on subacute Paraparesis, either due to compression myelopathy, or multiple sclerosis.	Thank you for your comment. Recommendation 1.7.5 covers this type of presentation: *For adults with slowly (within weeks to months) progressive limb or neck weakness:* • *refer for assessment of neuromuscular disorders in line with the recommendations on recognition and referral in the NICE guideline on motor neurone disease or* • *refer urgently if there is any evidence of swallowing impairment or* • *refer immediately if there is breathlessness at rest or when lying flat* *respiratory compromise (breathlessness, breathlessness lying flat, morning headache or recurrent chest infections).* The possible causes do not need to be specified in the recommendation.
Biogen Ltd	Full	127	4	"*if no explanation for the hypotonia is found and the infant is weak, refer urgently to paediatric services….”…* as there are now treatments for some neurological infantile disorders in which earlier treatment results in a better long term outcome. This is especially the case if the infant has tongue fasciculations	Thank you for your comment. The scope of the guideline covers referral, not treatment, and the current recommendation correctly identities the need for urgency.
Biogen Ltd	Full	127	4	*“Children who exhibit floppiness with weakness are much more likely to have an underlying progressive disorder of the nervous system. In this circumstance, an urgent referral is required to avoid a delayed diagnosis…..”* ….Spinal Muscular Atrophy (SMA) is a rare, genetic, neuromuscular disease caused by an insufficient level of functional survival of motor neuron (SMN) protein, which leads to a loss in motor function and to respiratory failure; it is the leading genetic cause of death in infants and children. Patients with SMA can present as floppy and weak and have progressive problems with swallowing and breathing. Therapy now exists that can alter the trajectory of the disease. The earlier these treatments are instigated the better the long-term prognosis.	Thank you for the comment The Guideline Committee agrees with your brief summary of SMA, which is contained in the main text of the guideline rather than a recommendation. The Guideline Committee feels that the current recommendation on hypotonia deals adequately with the need for speedy referral.
Biogen Ltd	Full	128	4	*“if the possible cause of the developmental delay is being investigated before the boy has had a specialist review, consider measuring creatine kinase level to exclude Duchenne muscular dystrophy…..” …*Spinal Muscular Atrophy *(*SMA) is a rare, genetic, neuromuscular disease caused by an insufficient level of functional survival of motor neuron (SMN) protein, which leads to a loss in motor function and to respiratory failure; it is the leading genetic cause of death in infants and children. Patients with SMA can present as weak and have progressive problems with swallowing and breathing. Therapy now exist that alter the trajectory of the disease. The earlier these treatments are instigated the better the long term prognosis.	Thank you for your comment. We agree with your brief summary of SMA, which is contained in the main text of the guideline rather than a recommendation. The Guideline Committee feels that the current

					recommendation on hypotonia deals adequately with the need for speedy referral.
Biogen Ltd	Full	131	5	*"if the possible cause of the developmental delay is being investigated before the boy has had a specialist review, consider measuring creatine kinase level to exclude Duchenne muscular dystrophy….."* …For children with motor developmental delay or regression associated with reduced exercise tolerance or muscle weakness consider referral to Paediatric neurology. In tandem, also consider referral for the SMN1 gene deletion test.	Thank you for your comment. This test would not be appropriate for primary care, but the Guideline Committee agrees that it would be considered after referral. This guideline's remit covers referral, not management thereafter.
Biogen Ltd	Full	131	5	*"Motor developmental delay can indicate muscular dystrophy, cerebral palsy, global developmental delay…."* or other progressive neuromuscular disorders.	Thank you for your comment The Guideline Committee has amended the recommendations and link to evidence table .
Biogen Ltd	Full	131	5	Spinal Muscular Atrophy (SMA) is a rare, genetic, neuromuscular disease caused by an insufficient level of functional survival of motor neuron (SMN) protein, which leads to a loss in motor function and to respiratory failure; it is the leading genetic cause of death in infants and children.	Thank you for your comment.
Brain & Spine Foundation	Full Version			The Brain & Spine Foundation welcome the Guideline entitled 'Suspected neurological conditions: recognition and referral, for health professionals in primary and secondary care, neurology departments, people using services, their family members and carers, and the public. As an organisation we are responding to the adult section of the guideline. Overall we have concerns regarding the complexity of the draft guideline and isolating the adult assessment to 14 signs and symptoms, which do not include symptoms such as headache, visual disturbances, bowel and bladder dysfunction. We understand they are included in other guidelines, but this fragments the information and makes the format less cohesive for the non-specialist user. Our question is will the NICE Pathway being developed alongside this Guideline, include other symptoms in an algorithm for ease of use?	Thank you for your comments. Time constraints meant that not every neurological presentation could be included, and the Guideline Committee based its decision primarily on whether or not current referral practice could be improved, and secondly on how common the presentation is.
Brain & Spine Foundation	Full version		General	From the experience of our users not all GP surgeries have permission to request MRI scanning due to budgetary restrictions. This will have an impact on the implementing some of the sections within the draft guideline	Thank you for your comment. We agree that access to neuroimaging varies. However, the vast majority of the recommendations within the guideline do not depend on, or even refer to, direct GP access to neuroimaging.
Brain & Spine Foundation	Full version	104-105		The Guideline is entitled Suspected neurological conditions: recognition and referral, but the Information and Support section discusses 'neurological conditions', which is post diagnosis and the action people should take. More information should be given as to why a GP has referred the person to a neurologist and what a neurologist's role is. Psychological support is greatly needed whilst the person is waiting to see a specialist. This section needs to be clarified, for although safety is of the utmost importance when driving, contacting DVLA when undiagnosed can have a huge impact on the person's ability to work. Informing their employer when undiagnosed can have a detrimental effect on the person's career and until the person receives a confirmed diagnosis, (which can take many months) they are not required to inform their place of work.	Thank you for your comments. The recommendation on information and support refers to 'suspected neurological conditions' which the Guideline Committee considered appropriate. The guideline is designed to clarify under what circumstances specialist clinical review should be sought. The Guideline Committee agrees that psychological support may be needed especially before there is certainty about the potential diagnosis. The recommendation says that informing an employer should be considered if symptoms are affecting

					the ability to work. Whether this is done or not will, of course, depend on the particular circumstances of each person. The Guideline Committee agrees that DVLA notification is primarily about safety. The DVLA regulations on driving are independent of this guidance.
Brain & Spine Foundation	Full version	56	Point 5	The Guidelines are dependent on the health professional's experience in identifying neurological signs and symptoms. From our users experience the Epley manoeuvre and Hallpike manoeuvre are not performed widely within primary care to assist with diagnosis. There is no mention of ENT referral which has a faster referral time than neurology, or suggestions of vestibular rehabilitation exercises. Will there be support for further training to implement these procedures?	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned. The pathway of referral is not specified in this guideline, but the Guideline Committee considered that where specialist referral was requested, a referral to neurology would usually be the most appropriate, as pathology of the brain rather than the ear, nose or throat, was often in question.
Brain & Spine Foundation	General			The Guidelines aim is to reduce the number of people being referred inappropriately to neurology clinics and has recognised 14 signs and symptoms, but many people have complex and rarer conditions which may have several symptoms and we feel this is not reflected in this guideline.	Thank you for your comment. The aim of the guideline is covered in the introduction. The guideline cannot cover every possible neurological presentation but the Guideline Committee has tried to concentrate on those where current referral practice is sub-optimal.
British Academy of Childhood Disability	Full	117	Table 15	head size should read 'increasing head size'	Thank you for your comment. However, the Guideline Committee does not agree that the issue is only increasing head size. Small head size as well as big but static head size are predictors of some cause of headache.
British Academy of Childhood Disability	Full	139	7.12.14	Should this mention that recurrent night terrors several times a night are more likely to be a seizure disorder than single episode night terrors?	Thank you for your comment. The Guideline Committee has included night terrors to the recommendations and amended the recommendations and link to evidence tables.
British Academy of	Full	145	Squint	Urgent referral should be recommended for new onset paralytic squint even without vomiting, ataxia or headache. (This is suggested in the discussion but not made very clear in the recommendation).	Thank you for your comment. The Guideline Committee has added the following recommendation (1.30.3):

Childhood Disability					"Refer urgently children with paralytic squint for neurological assessment, even in the absence of other signs and symptoms of raised intracranial pressure".
British Academy of Childhood Disability	Full	19	Point 96	'Be aware that acute confusion in children can be a symptom of meningitis, encephalitis or poisoning'. It suggests checking blood glucose. In my experience acute confusion in children may be more likely to be due to hypoxia or low blood pressure secondary to shock and I would recommend checking oxygen levels, pulse and blood pressure immediately too. 2.	Thank you for your comment. The Guideline Committee considered what extra a GP should do over and above standard clinical practice. A low blood glucose level would allow the possibility of additional first-line treatment whilst awaiting urgent ambulance transfer to hospital.
British Academy of Childhood Disability	Full	19	Point 90, line 21	This recommends urgent referral for 'neurological assessment'.. It should be clarified whether this is intended to be with a paediatrician or paediatric neurologist. There are not enough paediatric neurologists to see all children with such episodes urgently.	Thank you for your comment. This will depend on the local provision of paediatric services. The Guideline Committee was aware that there is unequal access to paediatric neurology services for children in England and Wales. Therefore, the Guideline Committee refrained from stating who should do a neurological assessment, as this will depend on local pathways. The Guideline Committee felt that it was important not to introduce delay and the GP should refer into services according to local pathways, for example, acute general paediatricians are very capable of doing an urgent neurological assessment, starting investigations and treatment whilst seeking more specialist advice if needed.
British Academy of Childhood Disability	Full 3.	20	Point 103, line 27	It is not clear who is to do this same day assessment of children with headache+ - ?GP ?general emergency department ?Paediatrician. This should be clarified.	Thank you for your comment. This will depend on the local provision of paediatric services. The Guideline Committee was aware that there is unequal access to paediatric neurology services for children in England and Wales. Therefore, the Guideline Committee refrained from stating who should do a neurological assessment, as this will depend on local pathways. The Guideline Committee felt that it was important not to introduce delay and the GP should refer into services according

					to local pathways, for example, acute general paediatricians are very capable of doing an urgent neurological assessment, starting investigations and treatment whilst seeking more specialist advice if needed.
British Academy of Childhood Disability	Full	20	Point 104, line 41	It is not clear who is to undertake this neurological assessment - if this is intended to be a paediatric neurologist, is there the capacity everywhere in the UK for this on an urgent basis?	Thank you for your comment. This will depend on the local provision of paediatric services. The Guideline Committee was aware that there is unequal access to paediatric neurology services for children in England and Wales. Therefore, the Guideline Committee refrained from stating who should do a neurological assessment, as this will depend on local pathways. The Guideline Committee felt that it was important not to introduce delay and the GP should refer into services according to local pathways, for example, acute general paediatricians are very capable of doing an urgent neurological assessment, starting investigations and treatment whilst seeking more specialist advice if needed.
British Academy of Childhood Disability	Full	20	Point 105, line 43	It is not clear who is to undertake this neurological assessment - if this is intended to be a paediatric neurologist, is there the capacity everywhere in the UK for this on an urgent basis?	Thank you for your comment. This will depend on the local provision of paediatric services. The Guideline Committee was aware that there is unequal access to paediatric neurology services for children in England and Wales. Therefore, the Guideline Committee refrained from stating who should do a neurological assessment, as this will depend on local pathways. The Guideline Committee felt that it was important not to introduce delay and the GP should refer into services according to local pathways, for example, acute general paediatricians are very capable of doing an urgent neurological assessment, starting investigations and treatment whilst seeking more specialist advice if needed.
British Acade	Full	22	Line 1	Should say ‘familial’ rather than ‘familiar’	Thank you for your comment. We have amended this typographical error.

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British Academy of Childhood Disability	Full	22	Point 117 and 118 line 34 and 36	Please clarify who is meant to undertake the 'neurological assessment' - is this the paediatric neurologist?	Thank you for your comment. This will depend on the local provision of paediatric services.
British Academy of Childhood Disability	Full	23	Point 126 and 130, 131line 23, 35, 38	Please clarify who is meant to undertake the 'neurological assessment' - is this the paediatric neurologist?	Thank you for your comment,. This will depend on the local provision of paediatric services.
British Academy of Childhood Disability	Full	24	Point 137 line 14	Please clarify who is meant to undertake the 'neurological assessment' - is this the paediatric neurologist and is there capacity across the UK to do this urgently?	Thank you for your comment. The Guideline Committee was aware that there is unequal access to paediatric neurology services for children in England and Wales. Therefore, the Guideline Committee refrained from stating who should do a neurological assessment, as this will depend on local pathways. The Guideline Committee felt that it was important not to introduce delay and the GP should refer into services according to local pathways, for example, acute general paediatricians are very capable of doing an urgent neurological assessment, starting investigations and treatment whilst seeking more specialist advice if needed.
British Academy of Childhood Disability	Full	24	Point 138 line 16	Please clarify who is meant to undertake the 'neurological assessment' - is this the paediatric neurologist?	Thank you for your comment. The Guideline Committee was aware that there is unequal access to paediatric neurology services for children in England and Wales. Therefore, the Guideline Committee refrained from stating who should do a neurological assessment, as this will depend on local pathways. The Guideline Committee felt that it was important not

					to introduce delay and the GP should refer into services according to local pathways, for example, acute general paediatricians are very capable of doing an urgent neurological assessment, starting investigations and treatment whilst seeking more specialist advice if needed.
British Academy of Childhood Disability	Full	24	Point 144 line 34	Please clarify who is meant to undertake the 'neurological assessment' - is this the paediatric neurologist?	Thank you for your comment,. The Guideline Committee was aware that there is unequal access to paediatric neurology services for children in England and Wales. Therefore, the Guideline Committee refrained from stating who should do a neurological assessment, as this will depend on local pathways. The Guideline Committee felt that it was important not to introduce delay and the GP should refer into services according to local pathways, for example, acute general paediatricians are very capable of doing an urgent neurological assessment, starting investigations and treatment whilst seeking more specialist advice if needed.
British Academy of Childhood Disability	Full	25	Point 152, line 12	Please clarify who is meant to undertake the 'neurological assessment' - is this the paediatric neurologist?	Thank you for your comment. The Guideline Committee was aware that there is unequal access to paediatric neurology services for children in England and Wales. Therefore, the Guideline Committee refrained from stating who should do a neurological assessment, as this will depend on local pathways. The Guideline Committee felt that it was important not to introduce delay and the GP should refer into services according to local pathways, for example acute general paediatricians are very capable of doing an urgent neurological assessment, starting investigations and treatment whilst seeking more specialist advice if needed.
British Academy of Childhood	Full	25	Point 153 line 20	Please clarify who is meant to undertake the 'neurological assessment' - is this the paediatric neurologist?	Thank you for your comment. The Guideline Committee was aware that there is unequal access to paediatric neurology services for children in England and Wales. Therefore, the

Disability					Guideline Committee refrained from stating who should do a neurological assessment, as this will depend on local pathways. The Guideline Committee felt that it was important not to introduce delay and the GP should refer into services according to local pathways, for example, acute general paediatricians are very capable of doing an urgent neurological assessment, starting investigations and treatment whilst seeking more specialist advice if needed.
British Academy of Childhood Disability	Full	25	Point 154 line 22	Sounds like refer to paediatric neurology - please clarify	Thank you for your comment. This would depend on local pathways and the Guideline Committee refrained from specifically stating who should do the neurological assessment.
British and Irish Orthoptic Society	Full	General	General	Eye signs and symptoms in adults appears to have been omitted from the document. We would suggest addition of a section based on adult patients presenting with visual disturbance to include: sudden onset incomitant squint/ diplopia, nystagmus/ oscillopsia, acute loss of vision/ visual field loss. Should be referred to ophthalmology for further investigations.	Thank you for your comment. The guideline was necessarily limited in scope and had to concentrate on areas where practice was variable or unsatisfactory. The Guideline Committee recognised that eye signs and symptoms are often significant and require onward referral, but decided that for the most part current practice is satisfactory.
British and Irish Orthoptic Society	Full	General	General	Acute onset ocular and visual disturbance in adults could be highly suggestive of neurological disturbance and may be difficult to differentiate from other causes without specialist assessment by ophthalmologist/ orthoptist. We would therefore suggest that all patients with new onset visual disturbance are referred on but that a range of 'red flags' could be included in the guidance as well as some standard GP assessments for such presentations in order to determine urgency of referral.	Thank you for your comment. The guideline was necessarily limited in scope and had to concentrate on areas where practice was variable or unsatisfactory. The Guideline Committee recognised that eye signs and symptoms are often significant and require onward referral, but decided that for the most part, current practice is satisfactory.
British Association for the Study of Headache	Full	General	General	The aim of the new NICE guideline on suspected neurological conditions must to be to clearly signpost the correct information to ensure that improvements of care happen for ALL neurological patients, including those with headache which is the commonest neurological symptom with which patients present to their GPs. Better management in primary care is essential and for this reason we urge NICE to include headache as a symptom within this new guideline.	Thank you for your comment. The Guideline Committee has added a cross-reference to the Headaches guideline to the recommendations in the Adults chapter of the guideline.

Suspected neurological conditions

Consultation on draft guideline - Stakeholder comments table
07 August 2017 – 19 September 2017

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

British Association for the Study of Headache	Full	General	General	**Headache omission from the NICE guideline on suspected neurological conditions** A glaring omission in the draft guidance for adults over 16 is headache as a symptom. For this guideline to be practically useful, we strongly urge NICE to include headache as a separate recommendation for adults over 16. As an absolute minimum the new guideline must include the following section: *Headaches in Adults* *For recommendations in headache for those over the age of 12 see the NICE guideline on headaches in over 12s.* Evidence base 1. Headache affects around one in seven adults. 2. Headache is a special case given it is an area in which the neurology pathway could become more efficient with appropriate detection and referral. 3. Headache accounts for a significant workload burden in neurology outpatient; around one third of adult neurology appointments are for headache; many of these cases can and should be managed in primary care. 4. In Oxford, the following research has shown: • At the Oxford CCG-commissioned Oxford University Hospitals NHS Foundation Trust (OUHFT), general neurology outpatient department activity was 10,218 appointments contacts in the financial year 2015/16. 4,086 (40%) of these were new referrals[1]. This includes referrals from non-GP sources (such as consultant-to-consultant, and A&E outpatient referrals). • Headache is a significant burden on outpatient neurology service s. It is difficult to definitively state the true burden of headache in secondary care because outpatient activity is not coded for disease. However, the Oxford research has shown: ○ Choose & Book GP referrals to general neurology outpatient: the reason for referral is coded in 48% of referrals, and headache accounts for 48% of these coded referrals (Figure 2). ○ An internal audit of rapid access clinic referrals at OUHFT showed that 48% of all referrals were for headache (Figure 2). ○ Nationally, we know that headache referrals to neurology outpatient account for more than 25% of all referrals[2]. ○ Internal audit within the OUHFT general neurology outpatient has shown that they receive approximately 90 GP and other clinician referrals alone for headache per month (1,104 per annum) ○ The follow-up rate within the OUHFT general neurology outpatient clinic is 98%[3]. In summary, neurology clinics are over-burdened with headache presentations, many of which would be more appropriately managed elsewhere. It is estimated that general neurology only needs to see 18% of the headache referrals being sent to it. 50% could be managed in the community), 6% could be managed with MRI without appointment, and 10% could be managed with advice directly back to the referrer. Improving triage of headache referrals centrally and making community headache clinics and MRI-without-appointment available has the potential to improve neurology outpatient capacity for other neurological conditions and reduce waiting times. [1] OUHFT Neurosciences Data Extrapolated from 10 months of 2015-16 SLAM Data for all of Neurology. 10m data is: 8,515 total contacts, of which 3,369 first attends (which includes 356 non-consultant FAs). [2] Patterson & Esmonde (1993); Sender J (2004) [3] OUHFT Neurology Outpatient Activities in 2015-16 for OCCG Outpatient (SUS Data)	Thank you for your comments. The Guideline Committee has added a cross-reference to the Headaches guideline to the recommendations in the Adults chapter of the guideline.

British Association for the Study of Headache	Full	General	General	The omission of any mention or consideration of co-morbid mental health conditions in this guidance is a missed opportunity for early detection of mental health conditions in neurological patients. 'Depression is three times more common in people with migraine or severe headaches than in healthy individuals. [1] The Neurological Alliance report that around 50% of neurological patients have co-morbid mental health conditions. This is higher than for the general long-term condition patient population. This is due to the complex interplay between neurological conditions and mental health conditions.[2] 1 World Health Organization. Headache disorders. Fact sheet no.277, 2012. 2 Neurological Alliance 'Parity of esteem for people affected by neurological conditions.' 2017	Thank you for your comment. We have added a reference to depression and coincident psychiatric disorder in the introduction of the Full version.
British Association of Prosthetists and Orthotists	Full	General	General	Question 1: Impact on practice and implementation. This guideline will provide very helpful clarity for the appropriateness of onward referrals for neurological assessment, which is a question faced by BAPO members in clinical practice. Implementation will require wide distribution of the guideline; unless staff are familiar with a guideline it is less likely to be used in practice.	Thanks for your comment.
British Association of Prosthetists and Orthotists	Full	General	General	General: BAPO support and endorse the stated aims and recommendations of this guideline and thank the development group for their work.	Thanks for your comment.
British Psychological Society				**References** Carson, A.J., Ringbauer, B., MacKenzie, L., Warlow, C., Sharpe, M. (2000) *Neurological disease, emotional disorder, and disability: they are related: a study of 300 consecutive new referrals to a neurology outpatient department;* BMJ Journals, http://dx.doi.org/10.1136/jnnp.68.2.202 Draper, K., Ponsford, J. (2009) *Long-term outcome following traumatic brain injury: a comparison of subjective reports by those injured and their relatives;* Neuropsychology Rehabilitation; **19(5)**; 645-61. doi: 10.1080/17405620802613935 Fink, P., Steen Hansen, M., Søndergaard, L. (2005) *Somatoform disorders among first-time referrals to a neurology service; Psychosomatics,* **46(6)**, 540-8. DOI:10.1176/appi.psy.46.6.540 Health Improvement Scotland Annual Report (2012-2013) NHS Scotland http://www.healthcareimprovementscotland.org/previous_resources/policy_and_strategy/annual_report_2013.aspx Morris, R., Huntley, A., Lasserson, D., Wye, L., Checkland, K., England, H., Salisbury, C., Purdy, S. (2007) *Which features of primary care affect unscheduled secondary care use? A systematic review;* BMJ Journals; **4(5)**, http://dx.doi.org/10.1136/bmjopen-2013-004746	Thank you for drawing these references to our attention. The Guideline Committee has considered them in responding to your recommendation-specific comments elsewhere in this Stakeholder table.

				The Neurological Alliance (2017) *Falling Short: How has neurology patient experience changed since 2014;* http://neural.org.uk/store/assets/files/668/original/Neurological_Alliance_-_Falling_Short_-_How_has_neurology_patient_experience_changed_since_2014.pdf	
British Psychological Society	Full version	70	5.5	The Society is concerned that the Guideline makes reference to symptoms associated with specific neurological conditions, when those symptoms can be indicative of other neurological conditions (e.g." …if their handwriting is small and slow, consider referral for possible Parkinson's disease" or "refer adults with transient, repetitive taste or smell hallucinations to have a neurological assessment for epilepsy"). We would recommend that the term "refer for neurological assessment" is used in place of a statement outlining a specific underlying neurological condition. We believe that this would help to ensure that patients have as much information as possible about their potential diagnosis and they do not enter an inappropriate pathway.	Thank you for your comment. The Guideline Committee understands your point, but felt that some of the recommendations to refer needed explanation since they might not be apparent to some in primary care. These brief mentions of the reasoning are not essential but the Guideline Committee thinks they will enhance take up of the recommendations. The key is to get people referred with an appropriate degree of urgency; if the suspected diagnosis is incorrect the patient will still be in the neurology system and the correct management of the true condition will follow.
British Psychological Society	Full version	76	5.7	The Society is concerned that reference is only made to the identification of memory problems in the adult population. Many patients with neurological conditions present with poor attention and concentration, not just memory impairment. They might also present with poor initiation, and other behavioural and executive difficulties which can be mistaken for mood disorders in the absence of memory problems.	Thank you for your comment. The recommendation has been amended to include both global cognitive impairment and behavioural disturbance: *Refer adults for specialist (neurological or memory clinic) assessment if they have progressive memory problems, and have:* • *progressive behavioural change or* • *progressive cognitive difficulties that affect several domains, such as language, numerical skills or sequencing of movements.* *If the clinical presentation is unclear, review with a witness before referring.*
British Psychological Society	Full version	80	5.7.2.1	The Society welcomes advice and treatment for patients with functional neurological disorders. Despite the significant waiting list for Neurology, patients with Functional Neurological Symptoms (FNS) are typically repeat attendees and receive numerous investigations. Up to 30% of neurology outpatients have symptoms not fully explained by an organic condition (Carson et al, 2000; Fink et al, 2005) and a study of 3,781 neurology outpatients in Scotland found that 5% had a primary diagnosis of a Medically Unexplained Symptoms (MUS); such as functional weakness, functional paralysis, non-epileptic attack disorder and functional speech problems (Health Improvement Scotland, 2012). The Society welcomes the Guidance that patients presenting with an established diagnosis of FNS and no identified neurological symptoms could be managed in primary health care settings with adequate support, information and access to appropriate specialist services. However, this recommendation would be a challenge. Despite the evidence for effective treatment with approved psychological therapies direct access to specialised psychological support for this patient group is limited across the UK. Many adult and paediatric mental health services will not accept direct referrals, because patients in this cohort do not typically report symptoms of anxiety, depression and distress.	Thank you for your comments. The Guideline Committee agrees with your comments, but unfortunately it is not in our remit to address the resource issues to which you refer. Your comments will be considered by NICE where relevant support activity is being planned.

				Morris et al (2007) demonstrated a reduction in primary care visits and somatisation severity in patients who had access to brief psychological therapy and consultation with GPs and other medical colleagues who were trained to use reattribution training. The Department of Health has estimated that management of medically unexplained symptoms (MUS) in general accounted for 11% (i.e., £3.1 billion) of adult healthcare costs in the UK in 2007/08, suggesting that significant potential savings could be made by developing services for these patients.	
British Psychological Society	Full version	93	5.11	Loss of smell and taste following Traumatic Brain Injury can accompany marked changes in social skills, mood, insight and behaviour, which can have significant implications for engagement in occupational activities and maintenance of relationships. These problems may occur even with normal neurological scan. These changes may not be picked up in primary care consultation and may require referral to Neurology.	Thank you for your comment. Management of people following head injury is covered by NICE CG176, and the Guideline Committee understands that there is a strong possibility that a guideline will be commissioned on Rehabilitation for Chronic Neurological Disorders Including Traumatic Brain Injury
British Psychological Society	Full version	General		The Society believes that on the whole, the delivery plan considers a broad range of issues pertinent to people with neurological conditions accessing primary care. In particular we welcome the drive to ensure patients that need access to Neurology are seen in a timely manner and that there is more equity across geographical regions. Similarly it is important that GPs have clarity about referral criteria and when a specialist neurological assessment is not required. However, we have concerns regarding the lack of detail in relation to delivery expectations and specific priorities.	Thank you for your comment. Your comment will be considered by NICE where relevant support activity is being planned.
British Psychological Society	Full version	General	General	Unidentified cognitive impairments and psychological conditions may be a significant barrier to patient functioning and well-being. The use of brief screening tools can be helpful in quickly identifying those patients requiring specialist neurological assessment. However, most brief screening tools of cognitive functioning used in primary care are not validated for adults under 60 years of age. Used in these patient groups, false conclusions can be drawn by GPs and other primary care practitioners, particularly those who have limited knowledge or access to advice. This can lead to unnecessary referral or delay in diagnosis. Many of these brief tools fail to adequately assess and identify changes in executive functioning and behaviour, which can be indicators of rarer conditions (e.g. Brain tumours, PSP, Dementia with Lewy Body). With the absence of evidence regarding suitable screening tools for these groups, The Society believes that more investment in research is needed. Improving access to services will require training for referrers in routinely screening for cognitive impairment, mental health problems, adjustment disorders and family stress. Specialist liaison might be sort from local specialist hubs, guided by neuropsychology.	Thank you for your comment.
British Psychological Society	Full version	General	General	For most conditions, rapid access to advice and diagnosis is essential in reducing longer term problems. However, diagnosis in some conditions can take longer and can't be prompt. Sub-clinical changes are not always identified via CT/MRI scans and require specialist neuropsychological assessment of cognitive functioning, sometimes over longer periods (e.g. progressive conditions or when the patient has comorbid psychological factors like depression). This can be a particularly distressing time for patients, who can feel unsupported and in some cases feel that their symptoms are not believed (Falling Short, Neurological Alliance, 2017). Primary care services are in a position to offer advice and links to support (e.g. primary mental health, counselling, third sector organisations) during this period.	Thank you for your comment.
British Psychological Society	Full version	General	General	The Society welcomes a more person centred focus to the guidelines, which highlight 'biopsychosocial' practice (e.g. improving environment, systems and relationships, spanning the primary/secondary interface), moving away from a purely medical model of intervention for people with neurological conditions. We believe that local specialist hubs adopting a partnership approach by offering education and advice to GPs and working with other agencies in the community, (e.g. voluntary sector, expert patient programme) should be made more prominent within the guidance. This will help to reduce demands on secondary care (e.g. mental health). In addition, we encourage supporting people back into, or to sustain, education and/or occupation at a primary care level. In some cases, patients with suspected or diagnosed neurological conditions can put their lives on hold and may need occupational guidance. This might include signposting to third sector organisations or local authority schemes and in some cases may require more specialist intervention. For example, a referral for a neuropsychological assessment is indicated when an individual with epilepsy is having educational or occupational difficulties, has identified abnormalities on scanning, and when they are reporting memory or other cognitive deficits and/or cognitive decline.	Thank you for your comment. NICE guidelines cannot signpost to 3rd sector information because this may change after publication of the NICE guideline. If there are specific pieces of information that you would like to be recommended, you could refer these to be considered separately by the NICE endorsement programme : https://www.nice.org.uk/about/what-we-do/into-practice/endorsement

					Local specialist hubs may well be of value as you suggest, but consideration of these was not part of the remit or scope of the guideline.
British Psychological Society	Full version	General	General	The Society believes that mental health problems needs to be made more prominent in the draft guidance. Many people with neurological conditions are at risk of developing comorbid psychological and psychiatric disorders, which can be neurologically derived or a secondary effect associated with the challenges the condition causes (e.g. rates of up to 60% depression, 50% anxiety and a suicide rate 5-10 times higher than in the general population). In many individuals these effects are not mutually exclusive (Draper & Ponsford, 2009) and require specialist assessment and treatment.	Thank you for your comment. The Guideline Committee has amended the introduction to make mental health needs more prominent. However, the remit of the guideline is to address the need for referral of primary presentations, not treatment of that presentation or any psychological sequelae.
Coeliac UK	Full	12	32	We support the need to increase awareness of neurological symptoms in coeliac disease as non-specialists may not consider coeliac disease as a cause of neurological symptoms. The recommendation to “consider serological testing for gluten sensitivity” requires further clarification. There are no biomarkers or serological tests available to test for non-coeliac gluten sensitivity (NCGS) and there are no NICE guidelines for the diagnosis of this condition. In contrast, the process for diagnosis of coeliac disease is well established by NICE within NG20. If NCGS is suspected, coeliac disease should first be ruled out and referral to a gastroenterologist for further investigation should be made.	Thank you for your comment. In this context, testing for gluten sensitivity should be undertaken to identify coeliac disease, which would then require referral to a non-neurological service, rather than to diagnose non-coeliac gluten sensitivity (which would be the responsibility of the neurologist). Standard serological testing for coeliac disease is now widely available.
Coeliac UK	Full	15	33	This recommendation includes reference to checking anti-gliadin antibodies (AGA) to check for the possibility of peripheral neuropathy. The testing for some antibodies such as AGA is not routinely available other than in certain specialist centres, such as the Sheffield Institute of Gluten-Related Disorders. The use of antibodies which are not widely used such as AGA and Tissue Transglutaminase 6 (TG6) has been reported in some studies [1, 2]. However, as testing for these antibodies is not available to all, and as these tests are not routinely carried out and accepted outside of these specialist centres further consideration needs to be given to the practicalities of carrying out this recommendation. 1. Hadjivassiliou, M., et al., *Neurological Dysfunction in Coeliac Disease and Non-Coeliac Gluten Sensitivity.* Am J Gastroenterol, 2016. **111**(4): p. 561-7. 2. Hadjivassiliou, M., et al., *Transglutaminase 6 antibodies in the diagnosis of gluten ataxia.* Neurology, 2013. **80**(19): p. 1740-5.	Thank you for your comment. In this context, testing for gluten sensitivity should be undertaken in line with the NICE guideline on coeliac disease which would then require referral to a non-neurological service rather than to diagnose non-coeliac gluten sensitivity (which would be the responsibility of the neurologist). Standard serological testing for coeliac disease is now widely available.
Compassion in Dying	FULL	104:	Section 6: Information and Support	We understand that the committee agreed that it would be difficult to provide guidance on the specific information and support available to people prior to a definitive diagnosis due to the fear of causing undue distress. However, we feel that discussing care and treatment preferences is of vital importance for ensuring that people with suspected neurological conditions receive the care that is right for them and that initiating such conversations need not cause undue distress and is not dependent on a definitive diagnosis. 68% of Britons would like more control over decisions about their health[1] and when care preferences are recorded people are much more likely to “die well”.[2] Regardless of diagnosis or whether or not somebody is approaching the end of life, if somebody is presenting symptoms of a neurological condition then they should be given the opportunity to think about and document their wishes for future care. Formally documenting wishes for refusal of treatment in an Advance Decision and/or appointing somebody to make decisions on your behalf through a lasting power of Attorney for health and welfare is particularly important for people in these circumstances, given the increased likelihood of a sudden or progressive loss of capacity.	Thank you for your comments. The Guideline Committee agrees with you that these are extremely important issues, but this guideline is concerned with the need for referral to neurology services, and therefore covers the period before a diagnosis has been established**.** It is difficult to offer meaningful information and support on planning for future treatment and care when it is not clear what condition requires treatment/care.

				We commissioned the International Longevity Centre (ILC) to conduct a literature review of existing evidence on the economic and social impact of Advance Care Planning. Evidence indicates that Advance Care Planning can lead to cost savings for care providers, fewer unplanned or inappropriate hospital admissions, more people dying in their preferred place of care and, crucially, greater patient satisfaction with overall care. Despite this, only 4% of people have made an Advance Decision.[3] Much more needs to be done increase their uptake. Not only this, more needs to be done to ensure that people are involved in decisions about their own care, bringing practice into line with guidance from the General Medical Council, which says doctors must "*share with patients the information they want or need in order to make decisions*."[4] Research has highlighted the importance of initiating conversations about end-of-life care and care planning more broadly sooner rather than later and has warned that a failure to instigate conversations can result in a "perpetual cycle of non-discussion".[5] Clinicians may never perceive there to be a "right time" to share information and support on planning for future treatment and care, but fear of causing undue distress should not prevent the instigation of such crucial discussions that result in positive outcomes for individuals and the healthcare system, particularly as this fear does not appear to be based on empirical evidence. Having worked for many years with people who wish to plan ahead as well as with healthcare professionals on supporting advance care planning practices, we would like to see all clinicians routinely instigating conversations about care planning and viewing it as part of their duty of care. Embedding this practice in guidance is one way to facilitate the culture change that is needed. Indeed, this approach reflects the Government's response to a House of Lords Select Committee Report on the Mental Capacity Act in march 2015, which stressed the urgency to: "*...address the low level of awareness among the general public of Advance Decisions to refuse treatment; promote better understanding among health care staff of Advance Decisions...promote early engagement between healthcare staff and patients about Advance Decisions to ensure that such decisions can meet the test of being valid and applicable when the need arises...*" We therefore strongly recommend that Section 6, information and support, includes a recommendation for doctors and other healthcare professionals to discuss care and treatment preferences; to explain people's legal options for planning ahead under the Mental Capacity Act 2006; and to document these decisions and/or refer the person for further support where appropriate. [1] Ipsos Mori, Global Trends – Health, 2017 [2] 'Plan Well, Die Well', Compassion in Dying, 2015 [3] YouGov, 2013 [4] General Medical Council, Consent: patients and doctors making decisions together, 2008 [5] Brighton L, Bristowe K (2016) "Communication in palliative care: talking about the end of life, before the end of life", Postgrad Med J, 2016 92: 466-470	
Compassion in Dying	FULL	General	General	Compassion in Dying is a national charity working to inform and empower people to exercise their rights and choices around their treatment and 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 lives; • supplying a free resource www.mydecisions.org.uk so that people can make an Advance Decision to Refuse Treatment online; • 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 person-centred care. We welcome this draft guidance, yet feel the recommendations do not provide sufficient guidance to clinicians to empower people with suspected neurological conditions to make decisions about their care and thereby receive the care that is right for them.	Thank you for your comment. The guideline deals with neurological presentations, before a clear diagnosis has been made. The Guideline Committee agrees that people should be empowered to make informed choices about their treatment, but we are dealing with time-points before treatment options can be properly evaluated. End of life care was not included in the scope for this guideline. It is a separate guideline currently in development.

					Please see http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
CSF Leak Association	Short	11	13	1.9 – Tingling and numbness (particularly in the arms) is a documented symptom of Spontaneous Intracranial Hypotension, normally (but not always) stemming from a cerebrospinal fluid leak. It is vital that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present. As with many symptoms relating to SIH, improvement may be witnessed while a patient is lying down, worsen again upon sit or standing, and/or as the day progresses. However, the postural characteristic is not always present and may also subside over time, with symptoms becoming more constant.	Thank you for your comment. The guideline is not designed to cover all the causes of tingling and numbness. Its remit is only to recommend appropriate neurological referral.
CSF Leak Association	Short	14	21	1.11 – Altered smell/taste is a documented symptom of both spinal and cranial cerebrospinal fluid leaks. It is vital that reference is made in this section to this possibility, particularly, but not solely, if other CSF leak symptoms are present.	Thank you for your comment. Thank you for your comment. The guideline is not designed to cover all the causes of altered smell/taste. Its remit is only to recommend appropriate neurological referral. Diagnosis of neurological disorders is outside the scope of this guideline.
CSF Leak Association	Short	15	5	1.12 – Speech problems have been documented as less common/rare symptom of spontaneous intracranial hypotension, sometimes, but not always, in tandem with CSF leak-induced dementia or parkinsonism. It is important that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present.	Thank you for your comment. The guideline is not designed to cover all the causes of speech problems. Its remit is only to recommend appropriate neurological referral.
CSF Leak Association	Short	16	18	1.14 – Tremor is documented as a less common/rare symptom of spontaneous intracranial hypotension. It is important that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present.	Thank you for your comment. The guideline is not designed to cover all the causes of tremor. Its remit is only to recommend appropriate neurological referral. Diagnosis of neurological disorders is outside the scope of this guideline.
CSF Leak Association	Short	18	6	1.16 – Attention, concentration and memory problems in children have been documented as symptoms of spontaneous intracranial hypotension. It is important that reference is made in this section to this possibility if other symptoms of SIH are present.	Thank you for your comment. The guideline is not designed to cover all the causes of attention, concentration and memory problems in children. Its remit is only to recommend appropriate neurological referral. In this instance it is likely that the child will present with other symptoms e.g. headache which will prompt referral.
CSF Leak Association	Short	19	25	1.19 – Dizziness and vertigo in children have been documented as symptoms of spontaneous intracranial hypotension. It is important that reference is made in this section to this possibility if other symptoms of SIH are present.	Thank you for your comment. The guideline is not designed to cover all the causes of dizziness and vertigo in children. Its remit is only to recommend appropriate neurological referral. In this instance the child will probably present with other symptoms e.g. headache which will prompt referral.
CSF Leak	Short	20	1.20	1.20 – Headache (often, but not always, with an orthostatic character or worsening as the day progresses) is a classic, and perhaps the most common, symptom of Spontaneous Intracranial Hypotension in children, normally (but not always) stemming from a cerebrospinal fluid leak. It is	Thank you for your comment. This is rare, but the Guideline Committee has

Association				absolutely vital that specific reference is made to SIH/CSF leak in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present.	added a bullet point to the recommendation.
CSF Leak Association	Short	24	1.24	1.24 – Unsteadiness is documented symptom of Spontaneous Intracranial Hypotension, normally (but not always) stemming from a cerebrospinal fluid leak. It is important that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present.	Thank you for your comment. The guideline is not designed to cover all the causes of unsteadiness in children. Its remit is only to recommend appropriate neurological referral.
CSF Leak Association	Short	25	13	1.26 – Tingling or numbness are documented symptoms of Spontaneous Intracranial Hypotension, normally (but not always) stemming from a cerebrospinal fluid leak. It is important that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present.	Thank you for your comment. The guideline is not designed to cover all the causes of tingling or numbness in children. Its remit is only to recommend appropriate neurological referral.
CSF Leak Association	Short	28	15	1.31 – Tremor is documented as a less common/rare symptom of spontaneous intracranial hypotension. It is important that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present.	Thank you for your comment. The guideline is not designed to cover all the causes of tremor in children. Its remit is only to recommend appropriate neurological referral.
CSF Leak Association	Short	4	19	1.2 - Dizziness (with or without imbalance) is documented and not uncommon symptom of Spontaneous Intracranial Hypotension, normally (but not always) stemming from a cerebrospinal fluid leak. It is vital that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present.	Thank you for your comment. Spontaneous intracranial hypotension presents with postural headache (worse on standing). Whilst dizziness is an occasional accompanying symptom, it is not found in isolation nor is it the predominant symptom. The purpose of the guideline is to help clinicians decide whether a referral to neurology is required, not to offer a comprehensive list of all causes of each presentation; these will be explored after referral.
CSF Leak Association	Short	6	10	1.3 – Facial and jaw pain is documented symptom of Spontaneous Intracranial Hypotension, normally (but not always) stemming from a cerebrospinal fluid leak. It is vital that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present. As with many symptoms relating to SIH, improvement may be witnessed while a patient is lying down, worsen again upon sit or standing, and/or as the day progresses. However, the postural characteristic is not always present and may also subside over time, with symptoms becoming more constant.	Thank you for your comment. The guideline is not designed to cover all the causes of facial and jaw pain. Its remit is only to recommend appropriate neurological referral.
CSF Leak Association	Short	6	21	1.4 – Unsteady gait is documented symptom of Spontaneous Intracranial Hypotension, normally (but not always) stemming from a cerebrospinal fluid leak. It is vital that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present.	Thank you for your comment. The guideline is not designed to cover all the causes of unsteady gait. Its remit is only to recommend appropriate neurological referral.
CSF Leak Association	Short	8	1	1.6 – Limb weakness is a less common, but nonetheless documented, symptom of Spontaneous Intracranial Hypotension, normally (but not always) stemming from a cerebrospinal fluid leak. It is vital that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present.	Thank you for your comment. The guideline is not designed to cover all the causes of limb weakness. Its remit is only to recommend appropriate neurological referral.
CSF Leak Association	Short	9	19	1.7 – Memory failure and cognitive impairment is a documented and not uncommon symptom of Spontaneous Intracranial Hypotension, normally (but not always) stemming from a cerebrospinal fluid leak. It is vital that reference is made in this section to this possibility, particularly, but not solely, if other symptoms of SIH are present. As with many symptoms relating to SIH, improvement may be witnessed while a patient is lying down,	Thank you for your comment. The guideline is not designed to cover all the causes of memory failure and cognitive impairment. Its remit is only to

				worsen again upon sit or standing, and/or as the day progresses. However, the postural characteristic is not always present and may also subside over time, with symptoms becoming more constant.	recommend appropriate neurological referral. The guideline does not cover diagnosis of neurological disorders.
CSF Leak Association	Short	General	General	As a member organisation and registered charity focused specifically on cerebrospinal fluid leaks, we have contact with a substantial number of UK patients suffering from this often debilitating condition; many of our trustees, members and volunteers have or have had a CSF leak/intracranial hypotension and have first-hand experience of what can be an extremely painful and debilitating condition. Once considered rare, CSF leaks are now increasingly recognised as a more common cause of headache and other neurological symptoms. It is estimated that 5 in 100,000 people suffer from spontaneous leaks alone annually (which places it as a more common condition than many others that are far better known), with many more experiencing leaks due to trauma or medical procedures. It has been confirmed to us by a number of UK experts that, even to this day, CSF leaks benefit from very little coverage in education and training and thus many medical professionals may have little knowledge or them and even less practical experience; it is therefore vital that this new guidance acknowledges CSF leaks as being a potential cause of many of the symptoms listed, otherwise our concern is that they will continue to be mis- and under-diagnosed. Every one of the symptoms listed in our response above have been experienced by people with whom we've had contact and, in many cases, have been missed early on in the diagnosis and treatment journey, only later to be confirmed as being related to intracranial hypotension. Had they been identified and considered in the context of spontaneous CSF leaks/intracranial hypotension, it is likely to have led to swifter diagnosis and, in many cases, treatment; while timeous treatment is increasingly seen to result in a more favourable prognosis for many CSF leak sufferers. Raising awareness of the symptoms of intracranial hypotension/CSF leaks so that diagnosis can be made as early as possible is a key objective of our organisation. Significant progress on studies and research into spontaneous Intracranial Hypotension/CSF leaks has been made in the last two decades, yet most guidance available in the UK still lags significantly behind, and we very much hope that this draft document can be updated so as not to continue this trend. Misdiagnosis and delayed diagnosis of those ultimately suffering from spontaneous intracranial hypotension unfortunately remains common, with almost all of our members having experienced both on their respective journeys; misdiagnosis of migraine, NPDH or tension headache appear to be some of the most common experiences. The average period between onset of a CSF leak and correct diagnosis is 13 months, however in many cases had better awareness of the full range of symptoms and presentation of CSF leaks/intracranial hypotension been available to treating doctors, diagnosis could have been made far more quickly and treatment begun and at a much earlier stage. Feedback from our membership shows misdiagnosis and delayed diagnosis to be a factor in almost every single case. Published figures suggest that spontaneous intracranial hypotension is at least as common as, but may be up to five times more common than the far more widely recognised idiopathic intracranial hypertension*, yet this does not seem to be reflected in NHS guidance or pathways, with spontaneous intracranial hypotension/CSF leak barely being mentioned anywhere. Where mention is made, it tends rarely to be more than a passing reference to 'headache' amongst literature relating to lumbar punctures or anaesthesia, while the condition – which can occur spontaneously and unlinked to any obvious cause - is so much more than that, often with may more symptoms, and can be extremely painful, distressing, debilitating and life-changing. While we very much appreciate the opportunity to comment on this draft document, we feel that it is only correct to note how disappointed, and indeed concerned, we are that not a single mention has been made to intracranial hypotension/CSF leaks within the draft, despite it covering a great many symptoms thereof. While neurological symptoms, such as headache, are generally secondary to the CSF leak, given the nature of the condition (e.g. more often than not being invisible) patients are likely to be assessed for primary neurological conditions and we believe that it is absolutely justified that CSF leaks/intracranial hypotension is covered and referenced as possible cause in all of the applicable places. If left unchanged, we are concerned that this guidance - which will be with us for many years into the future - will likely lead to a continuation in the mis- and delayed diagnosis trend that is all too often witnessed by our members and sufferers more generally. There is, however, still time to	Thank you for your comment. The guideline is designed to facilitate recognition and referral of neurological conditions, rather than as a diagnostic tool for individual diseases or conditions. Reference to specific conditions is therefore minimised throughout.

				remedy this and we look forward to you doing so. We would be pleased to work with you to this end and assist in any way that we are able and to flesh out some of the points made, if required. We work with a number of NHS doctors in the fields of neurology and neurosurgery in the preparation of our resources and publications. *SIH incidence rate published in a number of articles is estimated to be 5 in 100,000, while IIH UK has suggested that the incidence rate for IIH is estimated to be around 1 in 100,000. **Selection of some key articles upon which the above is based:** Diagnostic criteria for headache due to spontaneous intracranial hypotension: a perspective. (2011) Schievink WI1, Dodick DW, Mokri B, Silberstein S, Bousser MG, Goadsby PJ. A classification system of spontaneous spinal CSF leaks (2016) Wouter I. Schievink, MD, M. Marcel Maya, MD, Stacey Jean-Pierre, PA-C, Miriam Nuño, PhD, Ravi S. Prasad, MD and Franklin G. Moser, MD, MMM Factors affecting cerebrospinal fluid opening pressure in patients with spontaneous intracranial hypotension. (2017) Yao Ling-Ling, Hu Xing-Yue Update on the Diagnosis and Treatment of Spontaneous Intracranial Hypotension. (2017) Kranz Peter G, Malinzak Michael D, Amrhein Timothy J, Gray Linda The status of diagnosis and treatment to intracranial hypotension, including SIH (2017) Jin-ping Lin, Shu-dong Zhang, Fei-fang He --- NB. Our own library of CSF leak/Intracranial Hypotension articles can be found here: www.csfleak.info/journal-articles	
Department of Health				Thank you for the opportunity to comment on the draft for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for taking the time to review the guideline.
Epilepsy Action	Full	104	6.2.85	Getting timely information and support is very important to people affected by neurological conditions yet a recent patient experience survey found 45% of patients were dissatisfied with information they had received about their condition, 63% were dissatisfied with information they had received about sources of emotional support, and 53% dissatisfied with information they had received about third sector support available. (See Falling Short, Neurological Alliance, 2017) The only advice the Guideline recommends is to check the DVLA notification guidelines and to consider telling their employer, school or college. We are concerned with both of these pieces of advice being given in isolation to additional information and support. Telling an employer, school or college about a suspected neurological condition can have huge implications for individual patients and it may not always be appropriate to do so before a diagnosis has been confirmed. Indeed, until diagnosis is confirmed, patients/employees do not have legal protection under the Equalities Act. Patients will often benefit from additional support in informing an employer or education institution, and patient organisations – such as Neurological Alliance member charities – provide a wealth of support and information in areas such as this. Patients must be made aware of this broader support in parallel to being advised to consider telling an employer or education institution about a suspected neurological condition. Similarly, while safety concerns are paramount in relation to DVLA notification, surrendering a driving license can have a huge impact on an individual's life, for which they may benefit from additional support – and indeed signposting to financial support that may be available to help with	Thank you for your comments. Unfortunately NICE guidelines cannot refer to information from third party organisations because the content of these may change after publication of the NICE guidance. The information to which you refer could be considered separately by the NICE endorsement programme if you wish: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement

				alternative transport. Again, third sector organisations are ideally placed to provide such support. See for example Epilepsy Action's advice and information about driving and epilepsy. We welcome the inclusion here of the principles in the NICE Guideline on Patient Experience in Adult NHS Services. Yet, without specific reference to the importance of information and an individualised approach to services in the neurological conditions guideline, we feel GPs may miss the opportunity to sign post patients to information, helplines and support groups available. The committee notes that it was concerned about unduly worrying patients before diagnosis was confirmed. Our experience is patients are more likely to worry without appropriate information and support, particularly while waiting for a neurologist appointment. Third sector organisations are highly skilled in supporting patients at every stage on the care pathway – even before diagnosis. Indeed, many provide support in understanding the next steps such as what will happen at a neurologist appointment, what tests may be carried out and why. Many third sector organisations work closely together in relation to patients who have similar symptoms or may be incorrectly diagnosed. Much of the information developed by third sector organisations is peer reviewed and developed with reference to academic research, medical expertise and has the NHS England Information Standard.	
Epilepsy Action	Full	11	5	The draft guidance suggests urgent referral for adults whose blackout is accompanied by features that are strongly suggestive of epilepsy seizures, but does not indicate what these features might be. There are many different types of seizure and the manifestation in any individual can be different, and an individual can have one or more than one type of seizure. As such we believe it is critical that a check list indicating the type of symptoms that might be displayed before, during or after a seizure are quickly and clearly available to the GP. While some of these are available in the TLOC guideline in the short period for a GP consultation we would suggest they should be repeated here (and expanded as other features of possible epileptic seizures are not included within the TLOC guidance). We suggest that either the following should be added after line 8 or alternatively a separate section be developed describing suspected epileptic seizures (containing as a minimum the information below) and cross referred to whenever suspected epileptic seizures are mentioned. Suggestive features of epileptic seizures include (from CG109): • A bitten tongue. • Head-turning to one side during TLoC. • No memory of abnormal behaviour that was witnessed before, during or after TLoC by someone else. • Unusual posturing. • Prolonged limb-jerking (note that brief seizure-like activity can often occur during uncomplicated faints). • Confusion following the event. • Prodromal déjà vu, or jamais vu The following (not in the TLoC guideline) are additional indicative features of epileptic seizures and should also be included: • Contraction of muscles and stiffening of the body (tonic phase) • A tonic phase may or may not be followed by uncontrolled jerking of the body (clonic phase) • May have passed urine • May have let out a cry as air is forced out of the lungs • Lips may have gone blue • May have required minutes to many hours to recover post loss of consciousness • May have had to sleep or have severe headaches after • A sudden collapse by loss of muscle tone (maybe accompanied by head, facial or other injury) (atonic seizure) • Brief forceful jerks affecting arms, legs and sometimes the whole body (myoclonic seizures) We are not sure if this section or another is the best to describe focal seizures as these may or may not include a loss of consciousness.	Thank you for your comments. . The Guideline Committee cannot incorporate the level of detail that you suggest within the guideline, certainly not in a recommendation. The guideline covers too many potential diagnoses for that to be feasible. However, we have widened the description of epilepsy in the recommendations and link to evidence table to help non-specialists. The same issue affects our ability to give advice to patients with suspected neurological diagnoses whilst they are awaiting confirmation. There are too many potential diagnoses for us to give condition-specific advice for all.

				The features of suspected focal seizures would be: • The patient may remain alert or may not be aware of what is happening • Symptoms are varied and may include one or more of the following: twitching, numbness, sweating, dizziness, nausea, disturbances to hearing, vision, smell or taste, strong sense of deja vu • The patient may display involuntary movements, including o Part of the body, for example one arm, going stiff o Part of the body going limp or 'floppy' o Rhythmic jerking in part of the body o Brief, irregular jerks in part of the body o Head and eyes turning to one side o Lip smacking, repeated swallowing or chewing o A jerking movement that starts in one part of the body – usually the hand or face – and then spreads bit by bit to other parts of the body o Having repeated movements such as rocking, pedalling or pelvic thrusting o Undressing o Running or walking o Plucking at clothes • These seizures can often progress to other types of seizure • Note: focal seizures vary widely and may include other symptoms not included in the examples above. • What happens after a focal seizure varies from person to person. They might feel fine after a focal seizure and be able to get back to what they were doing straight away. Or they might feel confused or tired for some time afterwards. They might need to sleep. • Some people find they have temporary weakness or can't move part of their body after they've had a seizure. This is called Todd's paresis or Todd's paralysis. It can last from a few minutes up to 36 hours, before going away. Important note. Suspected epileptic seizures as indicated above can occur while the person is awake or asleep. The individual who has had the suspected seizure if not going to be able to describe the symptoms so a first-hand eyewitness account is crucial to identify a suspected seizure. Similarly, the guidance does not include 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 GP should also be advising the patient/their family/carer that a video of any future loss of consciousness will be an invaluable aid to a specialist to support diagnosis. 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. 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	Full	19	15	Inference is made to the features of absence seizures in children, but these are not referenced for adults aged over 16. Typical absence seizures usually start in childhood **or** early adulthood and so should be referenced in both sections.	Thank you for your comment. The Guideline Committee has added a reference to typical absences in adults to the recommendations and link to evidence table on blackouts in adults.

Epilepsy Action	Full	24	137	Reference is made to symptoms suggestive of new-onset epileptic seizures in sleep, but what these symptoms are is not identified. As previously mentioned, existing NICE guidelines focus on ongoing treatment and management and so do not reference in details the features associated with new-onset epilepsy.	Thank you for your comment. The Guideline Committee has now clarified the symptoms of epileptic seizures in the recommendations and link to evidence table.
Epilepsy Action	Full	98	5.13.79	Myoclonic seizures should be referenced by name in this section	Thank you for your comment, but the Guideline Committee believes this is not necessary. Myoclonic jerks are not easily confused with tics.
Epilepsy Action	Full	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.	Thanks for your comment.
Epilepsy Action	Full	General	General	There is little focus in the guidance on suspected epilepsy, other than presentations involving a blackout, for example focal seizures, absence seizures (other than in children) and atonic seizures. There are around 60 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 or empower them to offer a confident diagnosis. 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, the guideline should include 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. These are not included in any detail in NICE clinical guideline for epilepsy (CG137) or NICE clinical guideline for transient loss of consciousness (CG109). Epilepsy Action's primary care resource, The Role of Primary Care in Epilepsy Management, provides information for GPs on 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 should be included in this guideline.	Thank you for your comments. This guideline is based on presenting symptoms rather than dealing with potential diagnoses in any detail, and therefore does not include a unifying section on epilepsy or any other condition. However, in several sections of the guideline there are recommendations which indicate that a referral should be made for a possible diagnosis of epilepsy. The Guideline Committee has also widened the description of epilepsy in the recommendations and 'linking evidence to recommendations' table to help non-specialists.
Epilepsy Action	Full	General	General	The range and complexity of neurological symptoms and conditions make it challenging for GPs and other primary care professionals to recognise and refer patients with suspected neurological conditions. GP typically have a short time with patients and little non-contact time for additional or in-depth reading. Guidance therefore needs to be easily and rapidly accessible and guidelines for referral clear and easy to find. Even with this guidance, we believe that GPs may still in some case need additional support, or a second opinion, when managing a suspected neurological condition. Where suspected epilepsy is concerned, the guidance is not detailed enough to allow a GP to make a confident referral or diagnosis, which could suggest the scope of the guideline is too wide in general. There is also no mention of GP 'hubs' or network models of care, which could help to facilitate this guidance in order to expedite referrals and diagnoses.	Thank you for your comments. The Guideline Committee agrees that the guideline covers a wide range of presentations. It is designed to help GPs make appropriate referrals, and was not intended to go into the details of diagnosis. The Guideline Committee has widened the description of epilepsy in

					the recommendations and link to evidence table to help non specialists. We have referred your comment about GP hubs to the implementation team.
Epilepsy Action	Full	General	General	Given the complexity of this area of health care, and length of even the short version of the Guidance, we are concerned that it will not be widely taken up by primary care professionals; especially given there are few contractual incentives in primary care relating to neurology. Neurology is not a priority for many Clinical Commissioning Groups and Sustainability and Transformation Partnerships. Professional education, an awareness campaign, ongoing audit as part of accountability frameworks, and a simple algorithm are all tools that would support the intentions behind this Guideline to be realised. We would welcome more information about the role of the NICE implementation team in relation to ensuring this Guidance is used.	Thank you for your comment. Your comments will be considered by NICE where relevant support activity is being planned.
FND Action	Full	11	37-38	We feel that this point is unhelpful and suggest that it is removed. Dizziness can be a symptom of a variety of conditions and singling out anxiety disorder and 'suspected' FND as conditions where dizziness may fluctuate and increase during times of stress is misleading.	Thank you for your comment. The Guideline Committee considered that the recommendation is appropriate, but have clarified the term in the glossary.
FND Action	Full	13	39-45	Recent research shows that specialist physiotherapy may help people with functional weakness. We suggest that a referral to specialist physiotherapy is included in this section.	Thank you for your comment. The Guideline Committee agrees and has added this to the 'linking evidence to recommendations' table.
FND Action	Full	15	1-11	We suggest including functional dystonia in this section.	Thank you for your comment. The purpose of the guideline is not to deal with all the possible causes of a presentation, but to aid appropriate referrals. The diagnosis of functional dystonia is specialist and not one that would influence referral.
FND Action	Full	26	15-16	Recent research shows that not all functional symptoms are 'emotionally generated' and the requirement for psychological factors to meet criteria has been removed from DSM-5. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4277679/)	Thank you for your comment.
FND Action	Full 4.	General 5.	General	It is now accepted among neurological specialists that Functional Neurological Disorder (FND) is a diagnosis of positive signs rather than a catch all phrase covering medically unexplained symptoms or a diagnosis of exclusion. We feel the use of 'functional illness' throughout this document is unhelpful and misleading. There is also a difference between FND and Anxiety Disorder. (e.g. Page 11 line 32) 6.	Thank you for your comment. The Guideline Committee has made the wording consistent and provided definitions in the glossary. We have amended the sentence you are referring to as follows: "might be part of a functional neurological disorder or anxiety disorder and might not need referral. Features suggestive of functional neurological disorder include multifocal symptoms, fleeting sensations (such as twitches, buzzing sensations or electric shocks) which evolve with time, a previous diagnosis of functional symptoms which may be in other organ systems, no neurological signs and normal neuroimaging".

Suspected neurological conditions

Consultation on draft guideline - Stakeholder comments table
07 August 2017 – 19 September 2017

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

FND Action	Full	General	General	We note that there is no mention of FND in the sections regarding children. We know that children are affected and would like to see FND included.	Thank you for your comment. The Guideline Committee agrees, but FND is less common in children than adults, and the risk of missing an unusual disease presentation is probably greater in children. The Guideline Committee therefore included some guidance for primary care practitioners to help them recognise FND in adults, but did not feel that this is appropriate in children in whom the diagnosis of FND is best left to specialists.
FND Action	Full	General	General	We note that Non Epileptic Attack Disorder (functional seizures) is not mentioned anywhere in this document. We also note that the NICE guidelines for Epilepsy which does include Non Epileptic Attack Disorder (functional seizures) is out of date and needs updating.	Thank you for your comment. There is no section specifically for seizures. There are sections on blackouts and on dizziness which are perhaps the closest, and the possibility of a functional disorder as a cause is included under dizziness. The Guideline Committee has passed your comments about the Epilepsy guideline to NICE's surveillance team.
FND Action	Full	General	General	We are very pleased to see these NICE guidelines taking shape. We know it is important to have a clear pathway for people with functional neurological disorders to ensure they get the correct diagnosis and treatment. Guidelines such as this will help people get a quicker diagnosis and will improve outcomes which will no doubt lead to cost savings overall.	Thank you for your comment.
FND Hope UK	appendices	60	G.2.218 Table 2	We call for the removal of hypochondrialcal Not supported by Scientific Research, creates bias and impedes patient access to medical care	Thank you for your comment. As this term had been used historically in the literature, it was included in the search strategy to broaden the search and maximise the number of studies retrieved. This does not otherwise influence the evidence review and the word would not have been (and has not been) included in the recommendations.
FND Hope UK	appendices	60	G.2.218 Table 3	We call for the removal of hypochondrialcal Not supported by Scientific Research, creates bias and impedes patient access to medical care	Thank you for your comment. As this term had been used historically in the literature, it was included in the search strategy, to broaden the search and maximise the number of studies retrieved. This does not otherwise influence the evidence review and the word would not have been (and has not been) included in the recommendations.

FND Hope UK	appendices	60	G.2.218 Table 4	We call for the removal of hypochondrialcal Not supported by Scientific Research, creates bias and impedes patient access to medical care	Thank you for your comment. As this term had been used historically in the literature, it was included in the search strategy to broaden the search and maximise the number of studies retrieved. This does not otherwise influence the evidence review and the word would not have been (and has not been) included in the recommendations.
FND Hope UK	Full	101	Table 13	Functional symptoms are not necessarily related to anxiety or mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016). Further, functional changes in brain imaging studies are observed in people with Functional Neurological Disorder, independent of depression, anxiety and childhood trauma (Maurer, LaFaver, Ameli *et al.,* 2016), and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:** **American Psychiatric Association. (2013)**. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Maurer C.W, LaFaver K., Ameli R., et al., (2016)** .Neurology. 2016 Aug 9;87(6):564-70. doi: 10.1212/WNL.0000000000002940. Epub 2016 Jul 6 **Nicholson T.R. Aybek S, Craig T *et al*. (2016).** Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	Thank you for your comments. The diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, the Guideline Committee has clarified the wording and included a definition of functional neurological disorder in the glossary.

FND Hope UK	Full	102	5.14.53	We are concerned that the Recommendations and Links for Tremors/Tics do not make reference to or discuss or make any recommendations for Functional Neurological Disorder (Functional Neurological Disorder) as a condition in its own right. Functional disorders are genuine conditions (Cite Stone and Carson Functional Neurologic Disorders CONTINUUM: Lifelong Learning in Neurology: June 2015 - Volume 21 - Issue 3, Behavioral Neurology and Neuropsychiatry - p 818–837	Thank you for your comment. The diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, the Guideline Committee has clarified the wording and included a definition of functional neurological disorder in the glossary.
FND Hope UK	Full	11	4-12	We argue that we also need to see a requirement for Dissociative Seizures (Non-Epileptic Attack Disorder) within the Black Out Section. 1 in 8 patients are seen during the first fit clinic. (Angus-Leppan H. 2008). We suggest that this should be 'an aware' point as Dissociative Seizures can look like both Epilepsy and Syncope. **References:** **Angus-Leppan H., 2008**. Diagnosing epilepsy in neurology clinics: a prospective study. *Seizure* 2008;**17**:431–6. DOI:10.1016/j.seizure.2007.12.010	Thank you for your comment. The guideline seeks to address issues around neurological referral where there is a need to improve current practice. A presentation with blackout(s) will prompt further investigation, and the Guideline Committee did not feel it was necessary to refer to all the potential causes of blackouts within their recommendations.
FND Hope UK	Full	11	32-36	Implies that clinicians should dismiss recurrent dizziness in individuals with a previous functional illness or anxiety disorder. We argue that this indicates that clinicians should dismiss other causes for the appearance of symptoms and not complete a full examination. To our knowledge, the incidence of other neurological disease or complaints in patients with Functional Neurological Disorder is unknown. Therefore, this statement may compromise the accessibility of further astute neurological diagnoses for a patient with Functional Neurological Disorder who may well have developed an organic neurological pathology, just like any other member of the population, independently of their functional symptoms. Timely and appropriate access to specific and appropriate treatments for their symptoms is imperative for patients with Functional Neurological Disorder, and therefore clear clinical guidelines are essential (Edwards MJ., 2016). **References**: **Edwards M.J. (2016)**. Functional neurological symptoms: welcome to the new normal. Pract Neurol,16(1):2-3. DOI: 10.1136/practneurol-2015-001310	Thank you for your comments. The Guideline Committee has rationalised references to functional neurological disorders. The Guideline Committee did not believe that the recommendations would deter clinicians from referring patients with new symptoms suggestive of underlying physical diseases.
FND Hope UK	Full	11	37-39	Functional symptoms are not necessarily related to anxiety or mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016). Further, functional changes in brain imaging studies are observed in people with Functional Neurological Disorder, independent of depression, anxiety and childhood trauma (Maurer, LaFaver, Ameli *et al.,* 2016), and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017).	Thank you for your comments. The diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, The Guideline Committee has clarified the wording, deleted the sentence 'They are likely to have an emotional basis' and included a definition of functional neurological disorder in the glossary The expression 'functional illness' has been removed from the guideline and substituted with 'functional neurological disorder'.

				References: **American Psychiatric Association. (2013)**. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Maurer C.W, LaFaver K., Ameli R., et al., (2016)** .Neurology. 2016 Aug 9;87(6):564-70. doi: 10.1212/WNL.0000000000002940. Epub 2016 Jul 6 **Nicholson T.R. Aybek S, Craig T *et al*. (2016).** Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	
FND Hope UK	Full	13	39-42	We argue that all patients with new onset limb weakness needs a neurological assessments. The GP should only try to manage recurrent limb weakness if the patient is known to have recurrent functional limb weakness confirmed by a Neurologist and the recurrence is conforming to its usual pattern. Any advice other than this risks patients with Functional Neurological Disorder not being properly assessed for new symptoms. Indeed, whilst, a previous diagnosis of functional disorder may lend clarity to medical uncertainty, this alone should not lead to a diagnosis of Functional Neurological Disorder (Stone and Carson., 2015). Functional Neurological Disorder is a discrete disorder, which can be reliably diagnosed with positive diagnostic criteria such as a Hoover sign or tremor entrainment test (Stone, 2016). Indeed, the use of positive diagnostic criteria are a critical part of a reliable diagnosis (Espay and Lang, 2015; LaFrance, Baker, Duncan *et al.,* 2013; Stone, 2016), in contrast to the overall stance of the NICE guidelines which suggest there is no need for onward referral for patients with functional symptoms. Further, NHS Scotland recognise that effective treatments for Functional Neurological Disorder can be offered in its stepped care pathway recommendations for patients with functional symptoms (Healthcare Improvement Scotland. 2012). Indeed, clinical research indicates that referrals to the correct multidisciplinary teams can facilitate improvements and recovery, which include physiotherapy for motor symptoms and weakness (Demartini, Batla, Petrochilos *et al.,* 2014; Nielsen, Stone, Matthews, *et al*., 2015; Nielsen, Buszewicz, Stevenson, *et al*., 2017)**.** The suggestion in these lines of the NICE guidance implies that functional symptoms are not worthy of referral, in complete contrast to research about the distress and disability caused by functional symptoms, the recommendations of NHS Scotland (Healthcare Improvement Scotland. 2012), and in contradiction of the fact that timely intervention and care could significantly improve the outcome for patients (e.g. Edwards., 2016; Nielsen, Buszewicz, Stevenson *et al*., 2017) and reduce distress (Lehn, Gelauff, Hoeritzauer *et al.* 2016) . Thus, we argue that the inclusion of Functional Neurological Disorder in the NICE guidelines would significantly benefit patients to this end. Further, there is clear recommendation that a neurologist appropriately diagnoses and explains functional neurological symptoms as a first step to good management of the condition (Healthcare Improvement Scotland, 2012; Stone J., 2016). We pose that inclusion of Functional Neurological Disorder in the NICE guidelines would greatly assist a diagnosis and appropriate referral being made and on this basis contest the current guidelines which do not support an onward referral for new onset limb weakness.	Thank you for your comments and references. The recommendation on limb weakness which refer to functional causation specify recurrent limb weakness, not new-onset weakness. There are several preceding recommendations which advise on referral of first-onset weakness, depending on the pattern of presentation. The Guideline Committee believes that the recommendation as stated is appropriate and would not delay the diagnosis of a physical disease. Please note that the recommendation does not say that there is no need for onward referral. It says that a patient might not need neurological referral, which leaves room for discretion in each individual case.

				References: **Demartini, B., Batla, A., Petrochilos, P., et al., (2014).** Multidisciplinary treatment for functional neurological symptoms: a prospective study. *Journal of Neurology*, *261*(12), 2370–2377. http://doi.org/10.1007/s00415-014-7495-4 **Espay AJ., Lang AE., (2015)**. Phenotype-specific diagnosis of functional (psychogenic) movement disorders. Curr Neurol Neurosci Rep, 15:1–9. DOI:10.1007/s11910-015-0556-y. **Healthcare Improvement Scotland. (2012)**., Stepped care for functional neurological symptoms. [pdf] Edinburgh: Healthcare Improvement Scotland. Available at http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_symptoms_report.aspx. [accessed 18 Sept. 2017]. **LaFrance, Baker and Duncan *et al.,* (2013).** Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: a staged approach. Epilepsia, 54:2005–2018. DOI:10.1111/ epi.12356 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Nielsen G., Buszewicz M., Stevenson F., et al., (2017).** Randomised feasibility study of physiotherapy for patients with functional motor symptoms. *J Neurol Neurosurg Psychiatry* 2017;**88**:484–90 **Nielsen G., Stone J., Matthews M., *et al*., (2015).** J Neurol Neurosurg Psychiatry.86(10):1113-9. doi: 10.1136/jnnp-2014-309255. Epub 2014 Nov 28 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17 **Stone J., Carson A., (2015**). Functional neurologic disorders. Continuum 21(3 Behavioral Neurology and Neuropsychiatry): 818-37. doi: 10.1212/01.CON.0000466669.02477.45	
FND Hope UK	Full	13	43-45	Functional symptoms are not necessarily related to anxiety or a mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016). Further, functional changes in brain imaging studies are observed in people with Functional Neurological Disorder, independent of depression, anxiety and childhood trauma (Maurer, LaFaver, Ameli *et al.,* 2016) and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their	Thank you for your comment. The guideline does not state that functional symptoms are necessarily related to anxiety or mental health conditions, and neither states nor is intended to imply that symptoms are "all in the head". The intention behind the recommendations which mention FND is to improve management by helping practitioners to recognise the condition. As part of this the possibility that symptoms might recur at times of stress or strong emotion is referred to, and the Committee believes it is appropriate to do so. There is no attempt to address the mechanism of FND in any greater detail, and to do so would be to go well beyond the scope of this guideline.

				physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:** **American Psychiatric Association. (2013)**. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Maurer C.W, LaFaver K., Ameli R., et al., (2016)** .Neurology. 2016 Aug 9;87(6):564-70. doi: 10.1212/WNL.0000000000002940. Epub 2016 Jul 6. **Nicholson T.R. Aybek S, Craig T *et al*. (2016).** Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	
FND Hope UK	Full	14	18-21	The suggestion in these lines of the NICE guidance implies that memory and concentration difficulties which may be functional symptoms are not worthy of referral, in complete contrast to research about the distress and disability caused by functional symptoms, in contrast to the recommendations of NHS Scotland. (Healthcare Improvement Scotland. 2012), and in contradiction of the fact that timely intervention and care could significantly improve the outcome for patients (e.g. Edwards., 2016; Nielsen, Buszewicz, Stevenson *et al*., 2017) and reduce distress (Lehn, Gelauff, Hoeritzauer *et al.* 2016) . Thus, we argue that the inclusion of Functional Neurological Disorder in the NICE guidelines would significantly benefit patients to this end. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:** **Healthcare Improvement Scotland. (2012)**., Stepped care for functional neurological symptoms. [pdf] Edinburgh: Healthcare Improvement Scotland. Available at http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_symptoms_report.aspx. [accessed 18 Sept. 2017].	Thank you for your comments. The guideline does not intend to imply that functional symptoms are not worthy of referral, but emphasises that once the diagnosis is established that pathways of care other than neurological referral may be appropriate. The Guideline Committee agrees that the initial diagnosis of Functional Neurological Disorder should be made by a specialist.
FND Hope UK	Full	154	9 1	We argue that Functional Neurological Disorder should be included as part of the Acronyms as a disorder in its own right	Thank you for your comment. The details of diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, the Guideline Committee has clarified the wording and included a definition of functional neurological disorder in the glossary.

FND Hope UK	Full	156	10.1 3	We argue that Functional Neurological Disorder should be included as part of the guideline specific term Term: Functional Neurological Disorder Definition: It is due to the problem with how the nervous system sends and / or receives signals from the body. It describes a heterogeneous range of neurological symptoms, such as limb weakness or seizures.	Thank you for your comment. The aetiology of functional neurological disorders is outside the scope of this guideline. However, the Guideline Committee has clarified the wording and included a definition of functional neurological disorder in the glossary.
FND Hope UK	Full	16	4-8	We argue that all patients with new onset of limb weakness need to be referred for a neurological assessment, regardless of previous diagnoses. The GP should only try to manage recurrent limb weakness if the patient is known to have recurrent functional limb weakness confirmed by a Neurologist and the recurrence is conforming to its usual pattern. Any advice other than this risks patients with Functional Neurological Disorder not being properly assessed for new symptoms. Indeed, whilst, a previous diagnosis of functional disorder may lend clarity to medical uncertainty, this alone should not lead to a diagnosis of Functional Neurological Disorder (Stone and Carson., 2015). Functional Neurological Disorder is a discrete disorder, which can be reliably diagnosed with positive diagnostic criteria such as a Hoover sign or tremor entrainment test (Stone, 2016). Indeed, the use of positive diagnostic criteria are a critical part of a reliable diagnosis (Espay and Lang, 2015; LaFrance, Baker, Duncan *et al.,* 2013; Stone, 2016), in contrast to the overall stance of the NICE guidelines which suggest there is no need for onward referral for patients with functional symptoms. Further, NHS Scotland recognise that effective treatments for Functional Neurological Disorder can be offered in its stepped care pathway recommendations for patients with functional symptoms (Healthcare Improvement Scotland. 2012). Indeed, clinical research indicates that referrals to the correct multidisciplinary teams can facilitate improvements and recovery, which include physiotherapy for motor symptoms and weakness (Demartini, Batla, Petrochilos *et al.,* 2014; Nielsen, Stone, Matthews, *et al*., 2015; Nielsen, Buszewicz, Stevenson, *et al*., 2017)**.** The suggestion in these lines of the NICE guidance implies that functional symptoms are not worthy of referral, in complete contrast to research about the distress and disability caused by functional symptoms, the recommendations of NHS Scotland (Healthcare Improvement Scotland. 2012), and in contradiction of the fact that timely intervention and care could significantly improve the outcome for patients (e.g. Edwards., 2016; Nielsen, Buszewicz, Stevenson *et al*., 2017) and reduce distress (Lehn, Gelauff, Hoeritzauer *et al.* 2016) . Thus, we argue that the inclusion of Functional Neurological Disorder in the NICE guidelines would significantly benefit patients to this end. Further, there is clear recommendation that a neurologist appropriately diagnoses and explains functional neurological symptoms as a first step to good management of the condition (Healthcare Improvement Scotland, 2012; Stone J., 2016). We pose that inclusion of Functional Neurological Disorder in the NICE guidelines would greatly assist a diagnosis and appropriate referral being made and on this basis contest the current guidelines which do not support an onward referral for new onset neurological symptoms. **References:** **Demartini, B., Batla, A., Petrochilos, P., et al., (2014).** Multidisciplinary treatment for functional neurological symptoms: a prospective study. *Journal of Neurology*, *261*(12), 2370–2377. http://doi.org/10.1007/s00415-014-7495-4 **Espay AJ., Lang AE., (2015)**. Phenotype-specific diagnosis of functional (psychogenic) movement disorders. Curr Neurol Neurosci Rep, 15:1–9. DOI:10.1007/s11910-015-0556-y. **Healthcare Improvement Scotland. (2012).**, Stepped care for functional neurological symptoms. [pdf] Edinburgh: Healthcare Improvement Scotland. Available at	Thank you for your comment. The guideline does not state that functional symptoms are necessarily related to anxiety or mental health conditions, and neither states nor implies that symptoms are “all in the head”. The intention behind the recommendations which mention FND is to improve management by helping practitioners to recognise the condition. As part of this, the possibility that symptoms might recur at times of stress or strong emotion is referred to, and the Guideline Committee believes it is appropriate to do so. There is no attempt to address the mechanism of FND in any greater detail, and to do so would be to go well beyond the scope of this guideline. The recommendation on limb weakness which refers to functional causation specify recurrent limb weakness, not new-onset weakness. There are several preceding recommendations which advise on referral of first-onset weakness, depending on the pattern of presentation.

				http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_symptoms_report.aspx. [accessed 18 Sept. 2017]. **LaFrance, Baker and Duncan *et al.,* (2013).** Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: a staged approach. Epilepsia, 54:2005–2018. DOI:10.1111/ epi.12356 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Nielsen G., Buszewicz M., Stevenson F., et al., (2017).** Randomised feasibility study of physiotherapy for patients with functional motor symptoms. *J Neurol Neurosurg Psychiatry* 2017;**88**:484–90 **Nielsen G., Stone J., Matthews M., *et al*., (2015).** J Neurol Neurosurg Psychiatry.86(10):1113-9. doi: 10.1136/jnnp-2014-309255. Epub 2014 Nov 28 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17 **Stone J., Carson A., (2015**). Functional neurologic disorders. Continuum 21(3 Behavioral Neurology and Neuropsychiatry): 818-37. doi: 10.1212/01.CON.0000466669.02477.45	
FND Hope UK	Full	16	9-11	Functional symptoms are not necessarily related to anxiety or mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016). Further, functional changes in brain imaging studies are observed in people with Functional Neurological Disorder, independent of depression, anxiety and childhood trauma (Maurer, LaFaver, Ameli *et al.,* 2016) and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:** **American Psychiatric Association. (2013)**. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2	Thank you for your comment. The guideline does not state that functional symptoms are necessarily related to anxiety or mental health conditions, and neither states nor is intended to imply that symptoms are "all in the head". The intention behind the recommendations which mention FND is to improve management by helping practitioners to recognise the condition. As part of this the possibility that symptoms might recur at times of stress or strong emotion is referred to, and the Guideline Committee believes it is appropriate to do so. There is no attempt to address the mechanism of FND in any greater detail, and to do so would be to go well beyond the scope of this guideline.

				Maurer C.W, LaFaver K., Ameli R., et al., (2016) .Neurology. 2016 Aug 9;87(6):564-70. doi: 10.1212/WNL.0000000000002940. Epub 2016 Jul 6. **Nicholson T.R. Aybek S, Craig T *et al*. (2016).** Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	
FND Hope UK	Full	17	38-39	We argue that Functional Neurological Disorder patients may also experience additional neurological symptoms and not just difficulties with word finding with research indicating that the distress and disability that Functional Neurological Disorder patients experience may exceed that of neurology outpatients with organic neurological disease (Stone, Hallett, Carson *et al.*, 2014). By advising that word finding is common in Functional Neurological Disorder patients does not negate the need for a referral to a neurologist for a positive diagnosis (Stone, 2016). **References**: **Stone J., Hallett M., Carson A. *et al*., (2014).** Functional disorders in the Neurology section of ICD-11: A landmark opportunity. Neurology, 83(24):2299-2301. DOI: 10.1212/WNL.0000000000001063. **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	Thank you for your comment. The guideline addresses the issue of when speech difficulty should trigger a referral for a neurological opinion. The recommendation simply reminds practitioners that FND is a common cause of word finding difficulty and **might not** need referral. This would be contextual, for example if the person had presented previously with the same symptom. The Guideline Committee accepted that functional neurological disorder is a diagnosis that should be made by a specialist but detailed recommendations on diagnosis of FND are beyond the remit of the guideline.
FND Hope UK	Full	26	15-16	Functional symptoms are not necessarily related to anxiety or mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016). Further, functional changes in brain imaging studies are observed in people with Functional Neurological Disorder, independent of depression, anxiety and childhood trauma (Maurer, LaFaver, Ameli *et al.,* 2016) and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:**	Thank you for your comment. The diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, The Guideline Committee has clarified the wording and included a definition of functional neurological disorder in the glossary.

				American Psychiatric Association. (2013). American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Maurer C.W, LaFaver K., Ameli R., et al., (2016)** .Neurology. 2016 Aug 9;87(6):564-70. doi: 10.1212/WNL.0000000000002940. Epub 2016 Jul 6. **Nicholson T.R. Aybek S, Craig T *et al*. (2016).** Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	
FND Hope UK	Full	35	4.3 Table 1 Section 5.2.1	Other Outcomes: functional disorders Functional Neurological Disorder is a disorder in its own right and should be named appropriately.	Thank you for your comment. The terminology has been rationalised throughout and the definitions have been included in the glossary.
FND Hope UK	Full	36	4.3 Table 1 Section 5.9	Other Outcomes: functional disorders Functional Neurological Disorder is a disorder in its own right and should be named appropriately.	Thank you for your comment. The terminology has been rationalised throughout and the definitions have been included in the glossary.
FND Hope UK	Full	56	Point 7 & 8	Implies that clinicians should dismiss recurrent dizziness in individuals with a previous functional illness or anxiety disorder. We argue that this indicates that clinicians should dismiss other causes for the appearance of symptoms and not complete a full examination. To our knowledge, the incidence of other neurological disease or complaints in patients with Functional Neurological Disorder is unknown. Therefore, this statement may compromise the accessibility of further astute neurological diagnoses for a patient with Functional Neurological Disorder who may well have developed an organic neurological pathology, just like any other member of the population, independently of their functional symptoms. Timely and appropriate access to specific and appropriate treatments for their symptoms is imperative for patients with Functional Neurological Disorder, and therefore clear clinical guidelines are essential (Edwards MJ., 2016). **References**: **Edwards M.J. (2016)**. Functional neurological symptoms: welcome to the new normal. Pract Neurol,16(1):2-3. DOI: 10.1136/practneurol-2015-001310	Thank you for your comments. We have rationalised references to functional neurological disorders. The Guideline Committee did not believe that the recommendation would deter clinicians from referring patients with new symptoms suggestive of underlying physical diseases. The recommendation specifies recurrent symptoms, not new appearance of symptoms.
FND Hope UK	Full	58	Recommendation 7	Unlike the impression given by the proposed NICE guidelines, experts state that Functional Neurological Disorder is a discrete disorder, which can be reliably diagnosed with positive diagnostic criteria such as a Hoover sign or tremor entrainment test (Espay and Lang, 2015; LaFrance, Baker and Duncan *et al.,* 2013; Stone, 2015). These positive diagnostic criteria are a critical part of a reliable diagnosis, in contrast to the overall stance of the NICE guidelines which suggest there is no need for onward referral for patients with dizziness and imbalance. Further, NHS Scotland have long published a stepped care pathway for Functional Neurological Disorder (Healthcare Improvement Scotland. 2012), advocating a timely referral and the provision of appropriate treatment. We are asking for the NICE guidelines to follow the indisputable clinical evidence for recommendations of positive diagnostic criteria, and bring their guidelines in line with the latest clinical research and pioneering Scottish NHS recommendations. Critically, it is also argued that timely intervention and care could significantly improve the outcome for patients (Healthcare Improvement Scotland. 2012.). This is supported by studies which show that interventions such as physiotherapy can significantly improve symptoms in nearly three	Thank you for your comments. The Guideline Committee does not agree that the guideline regards FND as “not worthy of referral”. At first presentation referral may well be appropriate. However, the guideline does try to steer practitioners away from repeated referral when this is unlikely to benefit the person with symptoms.

				quarters of patients (e.g. Nielsen, Buszewicz, Stevenson *et al*., 2017) . Thus, we argue that the inclusion of Functional Neurological Disorder in the NICE guidelines would significantly benefit patients to this end. Clinical research indicates that referrals to the correct multidisciplinary teams can facilitate improvements and recovery, which include physiotherapy for motor symptoms and weakness (Demartini, Batla, Petrochilos, 2014; Nielsen G., Stone J., Matthews., *et al*., 2015), and that suitable and timely referrals are recommended as being helpful by specialists and can reduce distress for patients (Edwards, 2016; Healthcare Improvement Scotland. 2012; Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, there is clear recommendation that a neurologist appropriately diagnoses and explains functional neurological symptoms as a first step to good management of the condition (Healthcare Improvement Scotland, 2012; Stone J., 2016). We pose that inclusion of Functional Neurological Disorder in the NICE guidelines would greatly assist a diagnosis and appropriate referral being made. The current NICE guidelines do not give any indication of how Functional Neurological Disorder can be diagnosed despite these medical advances. We argue that the current NICE suspected neurological condition guidelines need to not only include Functional Neurological Disorder as a condition in its own right, but include information about the referral and treatment pathways that have been, and are increasingly being developed for Functional Neurological Disorder, in contrast to many comments throughout the document. We argue that the overall implication of the NICE guidelines that functional symptoms are not worthy of referral, are in complete contradiction of the fact that rehabilitative programmes for functional symptoms can be effective and pose the notion that the absence of Functional Neurological Disorder in the NICE guidelines is a limiting factor to the implementation of these specialist recommendations and advice. Therefore, we argue that the suggestion in these lines of the NICE guidance implies that functional symptoms are not worthy of referral, in complete contrast to research about the distress and disability caused by functional symptoms, in contrast to the recommendations of NHS Scotland, and in contradiction of the fact that rehabilitative programmes for functional symptoms can be effective.	The details of diagnosis and management of functional neurological disorder is beyond the scope of this guideline. We have now added physiotherapy to the recommendations and link to evidence table in Concentration difficulties.
FND Hope UK	Full	58	Recommendation 8	Functional symptoms are not necessarily related to anxiety or mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016). Further, functional changes in brain imaging studies are observed in people with Functional Neurological Disorder, independent of depression, anxiety and childhood trauma (Maurer,LaFaver, Ameli *et al.,* 2016) and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:** **American Psychiatric Association. (2013)**. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013	Thank you for your comments. The diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, the Guideline Committee has clarified the wording and include a definition of functional neurological disorder in the glossary.

				Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016). Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Maurer C.W, LaFaver K., Ameli R., et al., (2016)** .Neurology. 2016 Aug 9;87(6):564-70. doi: 10.1212/WNL.0000000000002940. Epub 2016 Jul 6. **Nicholson T.R. Aybek S, Craig T *et al*. (2016).** Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	
FND Hope UK	Full	64	Table 11	Other Outcomes: functional disorders Functional Neurological Disorder is a disorder in its own right and should be named appropriately.	Thank you for your comment. The Guideline Committee has rationalised references to functional neurological disorders and added a definition in the glossary.
FND Hope UK	Full	75	Recommendation 31	Functional symptoms are not necessarily related to anxiety or mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016). Further, functional changes in brain imaging studies are observed in people with Functional Neurological Disorder, independent of depression, anxiety and childhood trauma (Maurer, LaFaver, Ameli *et al.,* 2016) and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:** **American Psychiatric Association. (2013)**. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Maurer C.W, LaFaver K., Ameli R., et al., (2016)** .Neurology. 2016 Aug 9;87(6):564-70. doi: 10.1212/WNL.0000000000002940. Epub 2016 Jul 6.	Thank you for your comments. The diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, The Guideline Committee has clarified the wording and include a definition of functional neurological disorder in the glossary.

				Nicholson T.R. Aybek S, Craig T *et al*. (2016). Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	
FND Hope UK	Full	75	Recommendation 32	We argue the recommendation should be for Functional Neurological Disorder Patients to be a referred to a Neurologist/Specialist - this is not primary care territory. Functional Neurological Patients do not need to have just their concerns allayed, the patients need to know what they have and then access to appropriate multidisciplinary treatment (Edwards., 2016; Stone 2016). NHS Scotland have also created a stepped-care model for treating patients with functional neurological disorders and we argue that stating that functional neurological disorder patients do not require onward referral for specialist opinion denies the Functional Neurological Disorder patient with access to treatment/care. This statement sends out a message that treatment is not required for patients with Functional Neurological Disorder, they just need reassurance. **References:** **Edwards M.J. (2016)**. Functional neurological symptoms: welcome to the new normal. Pract Neurol,16(1):2-3. DOI: 10.1136/practneurol-2015-001310 **Healthcare Improvement Scotland. (2012)**., Stepped care for functional neurological symptoms. [pdf] Edinburgh: Healthcare Improvement Scotland. Available at http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_symptoms_report.aspx. [accessed 18 Sept. 2017] **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	Thank you for your comments. The guideline does not say that patients with a functional neurological disorder (FND should not be referred to a neurologist. The Guideline Committee agrees that the initial diagnosis of FND should be made by a specialist, and at first presentation referral to a neurologist would be appropriate. However, the guideline does try to steer practitioners away from repeated referral when this is unlikely to benefit the person with symptoms. The guideline does not address treatment of FND or any other condition. It is intended only as a guide to appropriate neurology referral.
FND Hope UK	Full	78	Recommendation 36,37	Functional symptoms are not necessarily related to anxiety or mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016). Further, functional changes in brain imaging studies are observed in people with Functional Neurological Disorder, independent of depression, anxiety and childhood trauma (Maurer, LaFaver, Ameli *et al.,* 2016) and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:**	Thank you for your comments. The diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, The Guideline Committee has clarified the wording and include a definition of functional neurological disorder in the glossary.

				American Psychiatric Association. (2013). American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Maurer C.W, LaFaver K., Ameli R., et al., (2016)** .Neurology. 2016 Aug 9;87(6):564-70. doi: 10.1212/WNL.0000000000002940. Epub 2016 Jul 6. **Nicholson T.R. Aybek S, Craig T *et al*. (2016).** Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	
FND Hope UK	Full	80	Table 12 Population	We argue that Functional Neurological Disorder should also be included	Thank you for your comment. The including of this term in the electronic search strategy would not have affected the analysis.
FND Hope UK	Full	85	Component	We argue that some patients with functional sensory symptoms are hyperventilating which either causes their symptoms or makes them worse. But many are not. The way this has been presented is misleading.	Thank you for your comment. The Guideline Committee is content that the current wording is not misleading. This table of possible outcomes describes how a literature search was undertaken to examine the predictive value of clinical features (including hyperventilation and others which may possibly have diagnostic value) in diagnosis of the cause of sensory symptoms. It does not intend to imply that patients with functional sensory symptoms hyperventilate. The search found no evidence on the possibility of association.
FND Hope UK	Full	85	5 Outcomes	Other Outcomes: functional disorders Functional Neurological Disorder is a disorder in its own right and should be named appropriately.	Thank you for your comment. The Guideline Committee has rationalised references to functional neurological disorders and added a definition to the glossary.
FND Hope UK	Full	86	52	We argue that this is not based on any clinical studies and is not sound advice. Patients with other causes of dizziness such as Benign Paroxysmal Positional Vertigo may also have anxiety get misdiagnosed. We suggest using the diagnostic criteria for Persistent Posturo-perceptual Dizziness which is well defined and studied for dizziness (Dieterich, Staab and Brandt T 2016). **References:** **Dieterich M, Staab J and Brandt (2016**). Functional (psychogenic) dizziness. Handb Clin Neurol. 139:447-468. DOI: 10.1016/B978-0-12-801772-2.00037-0.	Thank you for your comment. The Guideline Committee agrees that the cause of dizziness is sometimes misdiagnosed. However, the diagnostic criteria for Persistent Posturo-perceptual Dizziness which you propose are not sufficiently validated to include in a recommendation at present.

FND Hope UK	Full	86	52	Functional symptoms are not necessarily related to anxiety or mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016). Further, functional changes in brain imaging studies are observed in people with Functional Neurological Disorder, independent of depression, anxiety and childhood trauma (Maurer, LaFaver, Ameli *et al.,* 2016), and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered. We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:** **American Psychiatric Association. (2013)**. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Maurer C.W, LaFaver K., Ameli R., et al., (2016)** .Neurology. 2016 Aug 9;87(6):564-70. doi: 10.1212/WNL.0000000000002940. Epub 2016 Jul 6. **Nicholson T.R. Aybek S, Craig T *et al*. (2016).** Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	Thank you for your comments. The diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, the Guideline Committee has clarified the wording and included a definition of functional neurological disorder in the glossary.
FND Hope UK	Full	88	Recommendation 53	Functional symptoms are not necessarily related to anxiety or mental health comorbidity. The new DSM-5 criteria has excluded the need for a psychological trauma or cause in its guidelines (American Psychiatric Association, 2013), a point which is stressed by Dr Jon Stone in his recommendations for effective neurological assessments of patients with functional symptoms (Stone., 2016). The current statement in the NICE guidelines 'There is usually an emotional underpinning', is in great conflict with the latest research which shows that comorbid psychological disorders are not present in every Functional Neurological Disorder sufferer even when incredibly stringent assessments take place (Nicholson, Aybek, Craig, *et al.,* 2016; Stone 2016), and a diagnosis of Functional Neurological Disorder is not possible on the basis of associated psychosocial factors or the absence of other disease pathology (Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, Professor Mark Edwards a movement specialist at St George's, University of London Atkinson Morley Regional Neuroscience Centre (Edwards., 2016) advises clinicians against using phrases such as '"Your symptoms are psychological" since such statements trivialises the reality of the neurological symptoms and discounts them as an independent entity whilst making the patient feel like they are being told that their problem is self-inflicted and that they need to 'try harder' to overcome the problem (Edwards., 2016). Edwards (2016) also stresses, however, that effective treatment of comorbidities of Functional Neurological Disorder such as anxiety, previous trauma or depression, can be effective as part of the package of treatment offered.	Thank you for your comments. The diagnosis and management of functional neurological disorders is outside the scope of this guideline. However, the Guideline Committee has clarified the wording and included a definition of functional neurological disorder in the glossary.

				We are concerned that the proposed NICE guidelines perpetuate the stereotype that Functional Neurological Disorder is 'all in your head', and as a consequence is degrading, belittling and causes further distress for individuals who are already experiencing considerable difficulties due to their physical condition. This attitude could also be argued to feed the current stigma for those suffering from Functional Neurological Disorder, their families and the clinicians which see them (Rommelfanger, Stewart, LaRoche, *et al.* 2017). **References:** **American Psychiatric Association. (2013)**. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Nicholson T.R. Aybek S, Craig T *et al*. (2016).** Life events and escape in conversion disorder Psychol Med, 46(12):2617-26. doi: 10.1017/S0033291716000714. Epub 2016 Jul 5 **Rommelfanger K.S., Stewart A., LaRoche S., *et al.* (2017).** Disentangling Stigma from Functional Neurological Disorders: Conference Report and Roadmap for the Future. Front. Neurol., https://doi.org/10.3389/fneur.2017.00106 **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17	
FND Hope UK	Full	96	Recommendation 72	Other Outcomes: functional disorders Functional Neurological Disorder is a disorder in its own right and should be named appropriately.	Thank you for your comment. The terminology has been rationalised throughout and the definitions have been included in the glossary.
FND Hope UK	Full	General	General	We are concerned that the proposed NICE guidelines for suspected neurological conditions do not make reference to or discuss Functional Neurological Disorder (FND) as a condition in it's own right. Functional disorders are genuine conditions (Stone and Carson, 2015). which are increasingly recognised as a distinct condition in the field of Neurology (e.g. Lehn, Gelauff, Hoeritzauer *et al.,* 2016*)* which calls for it to be added to standard neurology curriculums (Stone and Carson, 2015). The ICD-11 draft proposals (WHO, (2018- *under review*) and DSM-5 (American Psychiatric Association, 2013) classifications, now incorporate functional symptoms following extensive expert consultation and revision (e.g. Stone, Hallet, Carson *et al.*, 2014). After headache, research shows that functional symptoms are actually the second most common reason for a neurology outpatient visit (Stone J, Carson A, Duncan R *et al.,* 2010*)*. Research indicates that the distress and disability that Functional Neurological Disorder patients experience is at least as great as neurology outpatients with organic neurological disease. (Carson A, Stone J, Hibberd C*, et al.,* 2011). This exemplifies our position that Functional Neurological Disorder is recognised as a serious condition with major implications for the overall health and wellbeing of the individual. Therefore, we ask for inclusion of Functional Neurological Disorder in the NICE guidelines, so that they are consistent with, and in-keeping with the most recent classifications to help clinicians in making appropriate and timely diagnoses of a condition which affects such a significant proportion of people. Other sources indicate that the formalisation of procedures would actually serve to reduce overall costs to the healthcare service whilst benefiting patients (Healthcare Improvement Scotland, 2012). Indeed, it has been suggested that the formal recognition of functional disorders in clinical manuals, namely ICD-11, could have a range of benefits, with the potential to: "1. Encourage neurologists to take clinical responsibility for functional neurological disorders and make positive diagnoses rather than diagnoses of exclusion. 2. Establish functional neurological disorders as a core element of neurologic training and curricula. 3. Encourage neurologists to undertake research in functional neurological disorders (where currently they may believe it is not a legitimate area of neurologic endeavour). 4. Enable patients with functional neurologic disorders to more easily access neurology-based treatments, such as specialist neurological physiotherapy, which may benefit them.	Thank you for your comments. The Guideline Committee appreciates that FND is an important clinical condition and we have defined it in the glossary to emphasise this. The diagnosis and management is important but beyond the remit of this guideline. The guideline does not cover any condition, functional or organic, in the detail that you suggest. It is based on symptomatic presentations and is designed to focus on guidance about the need for referral to neurology services.

				5. Promote better collaborative working between neurology and psychiatry. 6. Provide more accurate data to health care providers regarding the service costs of functional neurologic disorders." (Stone J, Hallett M, Carson A *et al.* 2014). 7. (Not applicable) "8. Enable the more widespread use of a diagnostic label that may be more acceptable" (Stone J, Hallett M, Carson A *et al.* 2014). We argue that these same points are salient for the NICE guidelines on many levels, and that it is imperative that on these bases Functional Neurological Disorder is included within the guidelines as a discrete condition, and that the guidelines acknowledge the disability and serious loss of health experienced by patients with Functional Neurological Disorder. Unlike the impression given by the proposed NICE guidelines, experts state that Functional Neurological Disorder is a discrete disorder, which can be reliably diagnosed with positive diagnostic criteria such as a Hoover sign or tremor entrainment test (Espay and Lang, 2015; LaFrance, Baker and Duncan *et al.,* 2013; Stone, 2015). These positive diagnostic criteria are a critical part of a reliable diagnosis, in contrast to the overall stance of the NICE guidelines which suggest there is no need for onward referral for patients with functional symptoms. Further, NHS Scotland have long published a stepped care pathway for Functional Neurological Disorder (Healthcare Improvement Scotland. 2012), advocating a timely referral and the provision of appropriate treatment. We are asking for the NICE guidelines to follow the indisputable clinical evidence for recommendations of positive diagnostic criteria, and bring their guidelines in line with the latest clinical research and pioneering Scottish NHS recommendations. Critically, it is also argued that timely intervention and care could significantly improve the outcome for patients (Healthcare Improvement Scotland. 2012.). This is supported by studies which show that interventions such as physiotherapy can significantly improve symptoms in nearly three quarters of patients (e.g. Nielsen, Buszewicz, Stevenson *et al*., 2017) . Thus, we argue that the inclusion of Functional Neurological Disorder in the NICE guidelines would significantly benefit patients to this end. Clinical research indicates that referrals to the correct multidisciplinary teams can facilitate improvements and recovery, which include physiotherapy for motor symptoms and weakness (Demartini, Batla, Petrochilos, 2014; Nielsen G., Stone J., Matthews., *et al*., 2015), and that suitable and timely referrals are recommended as being helpful by specialists and can reduce distress for patients (Edwards M.J., 2016; Healthcare Improvement Scotland. 2012; Lehn, Gelauff, Hoeritzauer *et al.* 2016). Further, there is clear recommendation that a neurologist appropriately diagnoses and explains functional neurological symptoms as a first step to good management of the condition (Healthcare Improvement Scotland, 2012; Stone J., 2016). We pose that inclusion of Functional Neurological Disorder in the NICE guidelines would greatly assist a diagnosis and appropriate referral being made. The current NICE guidelines do not give any indication of how Functional Neurological Disorder can be diagnosed despite these medical advances. We argue that the current NICE suspected neurological condition guidelines need to not only include Functional Neurological Disorder as a condition in its own right, but include information about the referral and treatment pathways that have been, and are increasingly being developed for Functional Neurological Disorder, in contrast to many comments throughout the document. We argue that the overall implication of the NICE guidelines that functional symptoms are not worthy of referral, are in complete contradiction of the fact that rehabilitative programmes for functional symptoms can be effective and pose the notion that the absence of Functional Neurological Disorder in the NICE guidelines is a limiting factor to the implementation of these specialist recommendations and advice. **<u>References:</u>** **American Psychiatric Association. (2013)**. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th edn. (DSM-5TM). Arlington, Virginia: American Psychiatric Press, Inc., 2013	

				Carson A., Stone J., Hibberd C., *et al.* (2011). Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease'. *Journal of Neurology, Neurosurgery & Psychiatry.* **82:**810-813. **Demartini, B., Batla, A., Petrochilos, P., et al., (2014).** Multidisciplinary treatment for functional neurological symptoms: a prospective study. *Journal of Neurology*, *261*(12), 2370–2377. http://doi.org/10.1007/s00415-014-7495-4 **Edwards M.J. (2016)**. Functional neurological symptoms: welcome to the new normal. Pract Neurol,16(1):2-3. DOI: 10.1136/practneurol-2015-001310 **Espay AJ., Lang AE., (2015)**. Phenotype-specific diagnosis of functional (psychogenic) movement disorders. Curr Neurol Neurosci Rep, 15:1–9. DOI:10.1007/s11910-015-0556-y. **Healthcare Improvement Scotland. (2012)**., Stepped care for functional neurological symptoms. [pdf] Edinburgh: Healthcare Improvement Scotland. Available at http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_symptoms_report.aspx. [accessed 18 Sept. 2017]. **LaFrance, Baker and Duncan *et al.,* (2013).** Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: a staged approach. Epilepsia, 54:2005–2018. DOI:10.1111/ epi.12356 **Lehn A., Gelauff J., Hoeritzauer I. *et al.,* (2016).** Functional neurological disorders: mechanisms and treatment. *J Neurol,* 263:611–620. DOI 10.1007/s00415-015-7893-2 **Nielsen G., Stone J., Matthews M., *et al*., (2015).** J Neurol Neurosurg Psychiatry.86(10):1113-9. doi: 10.1136/jnnp-2014-309255. Epub 2014 Nov 28. **Nielsen G., Buszewicz M., Stevenson F., et al., (2017).** Randomised feasibility study of physiotherapy for patients with functional motor symptoms. *J Neurol Neurosurg Psychiatry* 2017;**88**:484–90. **Stone J and Carson A (2015)**. Functional Neurologic Disorders CONTINUUM: Lifelong Learning in Neurology. Behavioral Neurology and Neuropsychiatry, 21(3), 818–837 doi: 10.1212/01.CON.0000466669.02477.45 **Stone J., Hallett M., Carson A. *et al*., (2014).** Functional disorders in the Neurology section of ICD-11: A landmark opportunity. Neurology, 83(24):2299-2301. DOI: 10.1212/WNL.0000000000001063. **Stone J., Carson A., Duncan R. *et al.,* (2010).** *Who is referred to neurology clinics?--the diagnoses made in 3781 new patients.* Clin Neurol Neurosurg. 112(9):747-51. Available from DOI:10.1016/j.clineuro.2010.05.011). **Stone J. (2016)**. Functional Neurological Disorders: the neurological assessment as treatment. Pract Neurol,16:7-17. **WHO, (2018- *under review*)**. ICD-11 Beta Draft. [online]. Available at: http://apps.who.int/classifications/icd11/browse/f/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f1069443471 [accessed 18 Sept.17]).	
FND Hope UK	Full	General	General	We recommend patients with functional symptoms be referred to treatment through neurological services as quickly as possible to minimise overall medical and social costs involved. The direct cost to the NHS for Medically Unexplained Symptoms (MUS), which in this study included functional symptoms, are thought to be approximately £3.1b. Another £18b is estimated to be lost due to indirect costs of all MUS, not to mention additional social costs as well.	Thanks for your comment. The Guideline Committee agrees that it is important to recognise functional symptoms as quickly as possible, and have therefore reminded practitioners

				Reference: **Graham A**., Functional Neurological Symptoms in North East Neurology Services: A HealthCare Needs Assessment, Public Health England North East Centre. 2016	to consider this in several chapters of the guideline. For example, please see the recommendations in the dizziness chapter: *1.2.7 Be aware that recurrent dizziness might be part of a functional neurological disorder or anxiety disorder and might not need referral.* *1.2.8 Advise adults with recurrent dizziness and an anxiety disorder or a suspected functional neurological disorder that their dizziness will fluctuate and might increase during times of stress.*
FND Hope UK	Full	General	General	We argue that the terminology throughout the NICE Guidance for Suspected Neurological Conditions should be standardised to say Functional Neurological Disorder, rather than Functional Illness i.e. (Page 11/ Line 32), or Functional Disorder i.e.(Page 13/ Line 43), or Psychogenic Tremors (i.e. Page 36/ Table 5.14)	Thank you for your comment. The Guideline Committee has changed 'functional illness' to 'functional neurological disorders' throughout the guideline and included the definition in the glossary. The term psychogenic tremors was not used in the recommendations but was one of the outcomes of interest in the protocol for the literature search.
FND Hope UK	Full	General	General	We would like to thank NICE for the inclusion of Functional Neurological Disorder especially in the memory section of the Guidance Notes.	Thank you for your comment.
Forward-M.E.	Full	29-30	'Related NICE' g'lines list	Add: Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition NICE clinical guideline 32 (2006) to the list	Thank you for your comment. The Guideline Committee did not consider this relevant to the scope of this guideline which is about recognition and referral of neuro diseases, not about management of these conditions.
Forward-M.E.	Full	30	Following 'Related NICE' g'lines list	If 'CFS/ME' patients are to be covered in the present guideline, add new heading 'Guidelines presently under consideration for review' and list: *Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children* National Collaborating Centre for Primary Care, August 2007; NICE Guideline CG53	Thank you for your comment; we have added it to the list of related guidance.
Forward-M.E.	Full	75	Rec 31	Delete 'other functional disorders for example, chronic fatigue syndrome and fibromyalgia'	Thank you for your comments. The recommendation itself does not contain this sentence. The recommendations and link to evidence table has been amended.
Forward-M.E.	Full	78	Recs 36-38	It is factually inaccurate to refer to 'CFS; ME' in a section on functional disorders. Please refer to general comments.	Thank you for your comment. The Guideline Committee has changed the

					recommendations and link to evidence tables to remove any inference that CFS/ME is a functional neurological disorder. CFS/ME is included in this guideline as it is recognised that some of the symptoms are neurological in nature.
Forward-M.E.	Full	78	Recs 36-38 line 8	re terminology: M.E. means 'myalgic encephalomyelitis'.	Thank you for your comment.
Forward-M.E.	Full and short	General	General	All references to 'ME' and/or 'CFS' as a 'functional' disorder should be removed. Rationale for this : no such 'functional' disorder exists. The UK government and related departments of government have repeatedly confirmed the official position - that these terms relate to a neurological disorder, in keeping with the WHO International Classification of Diseases 'G' code. The UK Government has repeatedly gone on record to the effect that 'CFS' and/or 'ME' are considered to be neurological disorder(s) of unknown origin, most recently in the House of Lords, see Hansard, 4 July 2017 Col 781 [Volume 783]. This is not new, numerous examples could be cited including written response to a Parliamentary Question in March 2013 Hansard: https://www.publications.parliament.uk/pa/cm201213/cmhansrd/chan123.pdf [page 854W; e-page 126] The relevant WHO ICD 10 Code is G93.3: Diseases of the nervous system (G90 – G99) Other disorders of the nervous system (G90 – G99) **G93 Other disorders of the brain** **G93.3 Postviral fatigue syndrome** Benign myalgic encephalomyelitis [Chronic fatigue syndrome is indexed to G93.3] Adoption of this classification is mandatory - there is a legal obligation for the Department of Health to provide ICD data to the WHO and the NHS was mandated to implement ICD-10 on 1st April 1995. For the avoidance of doubt, WHO ICD categories are mutually exclusive: "This is to confirm that according to the taxonomic principles governing the Tenth Revision of the World Health Organisation's International Statistical Classification of Diseases and Related Health Problems (ICD-10) it is not permitted for the same condition to be classified to more than one rubric as this would mean that the individual categories and subcategories were no longer mutually exclusive." (Personal correspondence)	Thank you for your comments. We have changed the wording in the recommendations and link to evidence table on page 75 of the Consultation version of the Full Guideline, and removed the reference to CFS as a functional disorder.
Forward-M.E.	Full and short	General	General	We note that this draft guideline proposes to include disorders that are of an associative/conversion/functional nature as well as *bona fide* neurological conditions. Therefore, to be legitimately mentioned in the guideline, a disorder must fall into one of these two broad categories- and it is important to be accurate as to which. Yet the draft mentions ME and CFS while apparently ruling out either type of neurological presentation in this regard. It is odd that the draft guideline sees fit to mention CFS or M.E. at all, given the perspective taken in respect of these terms in the draft. Which is, as noted above, the unsubstantiated and untenable position that these terms describe a non-neurological 'functional' disorder rather than a *bona fide* neurological condition given the G93.3 classification.	Thank you for your comments. The Guideline Committee has changed the wording in the recommendations and link to evidence table on page 75 of the Consultation version of the Full Guideline, and removed the reference to CFS as a functional disorder. It is appropriate for the guideline to mention CFS because some of the symptoms of the condition can prompt consideration of a referral to neurology.
Forward-M.E.	Full and short	General	General	The above anomaly requires to be resolved. In this regard, we note that G93.3 and several other G90 – 99 'Other Disorders of the Nervous System' codes are not contained in the NHS schema for 'defining neurological disorders' that is reference 17 in the draft guideline [spreadsheet]. It is not clear what the organising principle is for inclusion and exclusion in this schema.	Thank you for your comment. The document from the Neurological Intelligence Network (reference 17) was used as part of the search strategy, to help map symptoms to conditions.

				In the circumstances, we request that NICE make a decision as to whether to omit all references to CFS and ME from the guideline on the basis that – for whatever reason, the NHS has seen fit to exclude G93.3 from the defining neurological conditions schema [Ref 17 in the draft guideline]. If the decision is to retain them, then these disorders must be accurately described/classified, not least because of the adverse consequences of the ensuing NHS approach to patient care that can and will flow from getting this wrong.	Unfortunately these literature searches did not find many relevant papers. The Guideline Committee produced the recommendations based on their own experience and expertise in the (many) instances where there was no research literature to guide them. Reference 17 is therefore not of major importance in deciding the content of the guideline It is appropriate for the guideline to mention CFS because some of the symptoms of the condition can prompt consideration of a referral to neurology.
Forward-M.E.	Full and short	General	General	We note that there has historically been confusion between CFS and 'fatigue syndrome' - Code F48.0 in the mental & behavioural disorders section. However, as the F48 (*'other neurotic disorders')* codes do not appear in the 'defining neurological conditions' work [Ref 17 in the draft guideline] it is particularly perplexing that 'NICE' have still sought to take the line that the term 'functional' can legitimately be applied. It is essential that the proposed guideline should be truthful, rational, and ethical.	Thank you for your comments. The Guideline Committee has changed the wording in the recommendations and link to evidence table on page 75 of the Consultation version of the Full Guideline, and removed the reference to CFS as a functional disorder. It is appropriate for the guideline to mention CFS because some of the symptoms of the condition can prompt consideration of a referral to neurology.
Forward-M.E.	Full and short	General	General	We note the growing international consensus on CFS and ME, and the relatively emergence of key documents in the USA. The 2015 report of the US Chronic Fatigue Syndrome Advisory Committee, following reports from the US Institute of Medicine of the National Academies and the US National Institute for Health in that year, states that: "The disease is not psychiatric in nature and should not be equated with neurasthenia, somatic symptom disorder or functional somatic disorder." [paragraph 15]	. Thank you for your comments. The Guideline Committee has changed the wording in the recommendations and link to evidence table on page 75 of the Consultation version of the Full Guideline, and removed the reference to CFS as a functional disorder. It is appropriate for the guideline to mention CFS because some of the symptoms of the condition can prompt consideration of a referral to neurology.
Forward-M.E.	Full and Short	General	General	There is no mention of autonomic dysfunction which is common in neurological illnesses such as 'CFS/ME' and can be the root cause of many of the symptoms complained of.	Thank you for your comment. A Comprehensive discussion of the symptomatology of CFS/ME is beyond the scope of this guideline which is based on types of presentation, not on specific causes of those presentations. CFS/ME is covered in more detail a separate NICE guideline.
Genetic Alliance UK	Short	5-6 9 10 12	5.28-6.6 5-11 1-4	We are concerned that this guideline encourages non-specialist clinicians to inappropriately diagnose functional neurological disorder in patients with less common neurological conditions, rather than making the necessary referral to specialists, exacerbating the existing problem with delayed diagnoses.	Thank you for your comments. The Guideline Committee agrees that people with rare diseases generally experience a longer time to diagnosis

		15	21-28 15-16	The 'Diagnostic Odyssey' is the term used in the field of rare disease to describe the medical journey travelled by patients with a rare disease (and their families) from initial disease recognition or onset of symptoms to a final diagnosis, which can involve serial referrals to several specialists and a plethora of, often invasive, tests. This odyssey can be prolonged and, as a result, have serious consequences for the health of patients. For example, Our research shows that 71% of patients had to see more than three doctors and 1 in 10 patients stated that they had to see more than 10 doctors before getting a final diagnosis – an average rare disease patient consults with five doctors (Rare Disease UK, *The Rare Reality*, 2016). Additionally over half (52%) of people said they had been given an incorrect diagnosis before receiving their final diagnosis. The average number of misdiagnoses was three. Being misdiagnosed with functional illness is very common for these patients. Misdiagnosis can be extremely stressful for patients and family members; it can prevent access to effective treatments, lead to incorrect, potentially damaging treatments, being prescribed and even cause unnecessary deterioration in the condition. This situation is particularly prevalent in rare diseases, but the problem of delayed diagnosis also affects more common conditions. For example, the Neurological Alliance have written at length about widespread problems with timely and accurate diagnosis generally in neurological conditions. The introduction to the full guideline acknowledges that distinguishing functional from organic symptoms requires a high degree of skill which cannot be expected of generalist clinicians. It also mentions the negative consequences of misdiagnosis and delayed referral, and reference the UK Strategy for Rare Diseases. It is unfortunate that after this sensible introduction the guideline itself is potentially very damaging for rare disease patients. Numerous published papers (e.g.. Reuber *et al* 2005, Stone *et al* 2009) and treatment guidelines (e.g.. by Healthcare Improvement Scotland) have detailed how diagnosis of functional neurological disorder should be diagnosed on the basis of positive signs of inconsistency and incongruity, not simply by exclusion of the most common neurological conditions or based on a judgement of the individual's mental state. Each of the recommendations on this topic uses the same language, and there are many aspects that are deeply problematic. For example, the way the guideline is written as a list of symptoms with recommendations in the form of 'if.. then..' creates the impression that clinicians should work their way down the list until they reach a recommendation that fits, and so reach a diagnosis of functional neurological disorder by default if none of the previous paragraphs applied. The phrasing 'be aware' empowers and encourages generalist clinicians to make a dismissive judgment that they simply do not have the relevant specialist knowledge and experience to make properly. There are a number of rare neurological conditions which present with normal neuroimaging, but normal neuroimaging is presented as if it automatically means non organic. It is also important to remember that an individual may have both a neurological condition and functional symptoms, so the reference to previous diagnosis of functional illness is unhelpful. We understand that the primary purpose of this guideline is as a form of referral management: to minimise inappropriate referrals by detailing the situations where a referral to neurology is appropriate and thus conserve resources. However, the guideline as drafted is not fit for purpose and may have profoundly damaging effects. Lengthening the diagnostic odyssey for patients with rare neurological conditions, in addition to causing significant harm and unnecessary distress, is also a false economy, having the opposite consequence to that intended. For example, a higher number of patient-doctor interactions as currently required to secure a diagnosis puts unnecessary strain on NHS resources, which could be reduced by making a timely referral to a specialist who could appropriately diagnose and initiate treatment. This is also the case even if the patient's symptoms are entirely functional: timely diagnosis by a clinician with the necessary expertise to make the functional neurological disorder diagnosis has been shown to improve both clinical outcomes and patient satisfaction (Stone *et al* 2013).	particularly when the presenting symptoms might be due to other much more common conditions. It is understandable that evidence for the common diagnoses will be sought first, and for most people this will be the correct approach. We also agree that there is a risk of diagnosing functional illness too readily. However, we recognise that symptoms can have a functional basis and that it is important to identify these cases since doing so prevents unnecessary referral/investigation, and because it speeds up the delivery of appropriate management to this group of people. The diagnosis of functional neurological disorder is usually one made by a specialist, and is outside the scope of this guideline; the recommendations around functional illness refer to repeat presentations rather than the initial one.
Headway – the brain injury association	Full	11	39	Adults who are advised that their dizziness will fluctuate and might increase at times at stress should also be provided printed information about dizziness and tips for managing this on a regular basis. Headway's factsheet on balance and dizziness can offer this information and be disseminated where appropriate.	Thank you for your comment. Unfortunately, NICE guidelines cannot refer to sources of information from third parties. Management of dizziness is outside the scope of the guideline, which is on recognition and referral of suspected neurological conditions.

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Headway – the brain injury association	Full	13	45	Adults who are advised that their limb weakness might fluctuate and increase during times of stress should also be provided printed information about limb weakness and tips for managing this on a regular basis. Headway's factsheet on hemiplegia and hemiparesis can offer this information and should be disseminated where appropriate.	Thank you for your comment. Unfortunately, NICE policy is not to refer to sources of information from third parties since these can change after the guideline is published. The factsheet could be considered separately by the NICE endorsement programme if you wish: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
Headway – the brain injury association	Full	14	21	Adults who have memory problems following a functional illness of acquired brain injury can be given Headway's booklet on Memory problems after brain injury for information and coping strategies.	Thank you for your comment. NICE policy is not to refer to sources from third party organisations because these can change after the guideline is published. The factsheet could be considered separately by the NICE endorsement programme if you wish: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
Headway – the brain injury association	Full	17	21	Can clarification be given about how long 'immediately after a head injury' refers to?	Thank you for your comment. The term 'Immediately' is defined on page 1 of the Short guideline.
Headway – the brain injury association	Full	19	43	This section is entitled **Information and support** yet there is not much in the way of providing guidance on offering follow-up support to patients. We suggest including a point in this section for clinicians to provide details of local support services or contact details of supporting organisations. For instance, Headway's helpline can offer information and support to survivors of an acquired brain injury and can send cards to units with their contact details.	Thank you for your comment. NICE policy is not to refer to sources from third party organisations because these can change after the guideline is published.
Headway – the brain injury association	Full	26	30	We are concerned that this guideline states that it is impractical for a generalist to keep abreast of neurological treatments and to recognise neurological symptoms, especially in the context of the paragraph in question. Many people with symptoms of acquired brain injury rely on their GP to refer them to appropriate neurological specialists for further investigation. Delayed access to this specialist support due to a lack of understanding among GPs can cause severe injury or even death in some tragic cases. Even though we recognise that it is not possible for GPs to have in-depth knowledge of conditions such as acquired brain injury, we would recommend removing this sentence that appears to undermine the need for GPs to recognise the symptoms of potential brain injury.	Thank you for your comment. The sentence to which you refer, and the paragraph which contains it, make a broad point about the impossibility of a generalist GP having the same depth of knowledge as a specialist in the field. It does not intend to imply that GPs cannot recognise symptoms or signs of important neurological conditions, and it

					does not say anything specific about brain injury.
Meningitis Research Foundation	Full	113	N/A	'Recommendation 96: Presenting symptom of meningitis, encephalitis and poisoning' states within the recommendation that "However, body temperature should distinguish poisoning from meningitis and encephalitis". We are concerned that this recommendation could be misleading as a fever/high temperature is sometimes absent in individuals with meningitis/encephalitis, and there are also some drugs which can lead to increased body temperature.	Thank you for your comment. You are correct but the Guideline Committee cannot cover all diagnostic uncertainties in the guideline. These circumstances would be covered by the previous recommendation where all children with unexplained confusion would be referred urgently to hospital.
Meningitis Research Foundation	Short	10	1	Raised intracranial pressure (RICP) in adults can result in abnormal posturing (decerebrate or decorticate). RICP can be caused by meningitis/encephalitis. However looking for other signs of meningism/RICP or recommendations for onward referral/management are not included here.	Thank you for your comment. Decorticate or decerebrate posturing is characterised by severe depression of consciousness and is not in the differential diagnosis of adults or children presenting in primary care with a primary problem of abnormal posture.
Meningitis Research Foundation	Short	22	11	For consistency, the list of signs and symptoms of RICP is not as comprehensive as the list in NICE CG102.	Thank you for your comment. The Guideline Committee acknowledges this, but we are looking at a slightly different population. In meningitis, the raised ICP is acute.
Meningitis Research Foundation	Short	25	1	RICP in children can result in abnormal posturing (decerebrate or decorticate). RICP can be caused by meningitis/encephalitis. However looking for other signs of meningism/RICP or recommendations for onward referral/management are not included here.	Thank you for your comment. The guideline cannot cover every neurological presentation and has tried to include those where referral practice is sub-optimal. Decerebrate and decorticate posturing are dramatic and well recognised findings which are currently referred appropriately.
Meningitis Research Foundation	Short	27	14	Squint can be caused by brainstem compression which can be caused by RICP. There are no recommendations listing what should be done in children with squint and other signs of RICP, as this can be caused by meningitis/encephalitis.	Thank you for your comment. This is covered in recommendation 1.30.3: *Refer urgently children with paralytic squint for neurological assessment, even in the absence of other signs and symptoms of raised intracranial pressure.*
Motor Neurone Disease Association	Full	104	14-25	The information and support section suggests that people tell the DVLA and their employer that they may have a suspected neurological condition. Prior to receiving a confirmed diagnosis, however, people have no protection under the Equality Act if they are fired as a result of their condition. We suggest that GPs should ordinarily not recommend notifying employers until a diagnosis is confirmed. Similarly, although safety concerns are of paramount importance in relation to DVLA notification, it should be noted loss of a driving licence can have a major impact on people's independence and their quality of life. People are required to notify the DVLA if diagnosed with MND or if they feel their condition will affect their driving. However they should not be pressured to do so unnecessarily if these conditions are not met. In this situation primary care practitioners should be prepared to discuss with the individual whether they need to take any action relating to driving. They should also be ready to signpost to sources of support for alternative transportation, including third sector organisations.	Thank you for your comments. The recommendation says that informing an employer should be considered if symptoms are affecting the ability to work. Whether this is done or not will, of course, depend on the particular circumstances of each person.

				Rather than focusing on advice which may be perceived as having possible negative consequences, the information and support section should focus on accessing information and advice to help people understand their symptoms, their likely impacts, and their options for care and treatment. This should include signposting to then wide range of support available through the third sector.	The Guideline Committee agrees that DVLA notification is primarily about safety. NICE guidelines cannot signpost to 3rd sector information because this may change after publication of the NICE guideline. If there are specific pieces of information that you would like to be recommended, you could refer these to be considered separately by the NICE endorsement programme : https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
Motor Neurone Disease Association	Full	67	1-30	Section 5.4, 'Gait unsteadiness', refers to a number of specific neurological conditions for investigation in relation to unsteadiness of gait. We are concerned this may lead practitioners to focus too narrowly on the named conditions rather than other possible causes. The NICE MND Guideline (NG42) notes that "MND causes progressive muscular weakness that can present as isolated and unexplained symptoms", including "loss of dexterity, falls or trips" (p.5). Consequently we suggest that the guideline should include a recommendation for people presenting with unexplained falls, trips and/or loss of dexterity to be referred for a neurological assessment in accordance with the NICE Guideline on MND.	Thank you for your comment. The recommendations and link to evidence tables in the full guideline explain why the Guideline Committee arrived at its recommendations. They mention some specific conditions as examples, but this should not impact on the diagnostic process which follows referral.
Motor Neurone Disease Association	Full	73	6-9	We support the recommendation for adults with progressive limb weakness to be referred for a neurological assessment in line with the NICE Guideline on MND (NG42). However, we note that the NICE MND Guideline states that "if you suspect MND, refer the person without delay". The need for urgency is not currently reflected in the language of the draft guideline, which calls for "a prompt rather than urgent review" (p.74). We suggest that this recommendation should be altered to recommend an 'urgent referral' to reflect the intention of the NICE Guideline on MND.	Thank you for your comment. The Guideline Committee has amended the recommendation: *For adults with slowly (within weeks to months) progressive limb or neck weakness:* • *refer for assessment of neuromuscular disorders in line with the recommendations on recognition and referral in the NICE guideline on motor neurone disease or* • *refer urgently if there is any evidence of swallowing impairment* • *refer immediately if there is breathlessness at rest or when lying flat or respiratory compromise (breathlessness, breathlessness lying flat, morning headache or recurrent chest infections).*
Motor Neurone Disease	Full	95	32-38	We support the recommendation to refer adults with progressive slurred or disrupted speech to have an assessment for motor neurone disease, in line with the recommendations on recognition and referral in the NICE Guideline on MND. However, we suggest this should be altered to recommend an "urgent referral", in line with the NICE Guideline on MND which states that people with suspected symptoms of MND should be referred without delay.	Thank you for your comment. The recommendation has been amended as follows. Please note that the NICE MND guideline says that referral should

e Association				MND's impact on bulbar functions can also cause symptoms such as dysphagia, excessive saliva, a choking sensation when lying flat, or a weak cough (as per the MND Association's Red Flags diagnosis tool, developed in partnership with the Royal College of General Practitioners.	be made without delay, but does not say that this should necessarily be an urgent referral *For adults with progressive slurred or disrupted speech:* • *refer for an assessment for neuromuscular disorders , in line with the recommendations on recognition and referral in the NICE guideline on motor neurone disease* • *refer urgently if there is any evidence of swallowing impairment* • *refer immediately if there is breathlessness at rest or when lying flat* *or respiratory compromise (breathlessness, breathlessness lying flat, morning headache or recurrent chest infections).*
Motor Neurone Disease Association	Full	96	25	The draft guideline states that "MND prognosis is not affected by early diagnosis" and implies that early diagnosis of MND is consequently not important. Although life expectancy may not be significantly affected by early diagnosis, early diagnosis enables people with MND to access vital support services to maintain their independence and quality of life for as long as possible, including services such as physiotherapy and occupational therapy. It also enables people to make provision to prepare for the rapid progression of the disease, such as accessing home or vehicular adaptations, communication aids, or services such as voice banking which enables people to record their own voice for when they lose the ability to speak. It is also important to note that the drug Riluzole has been shown to extend life by 3-6 months in some MND patients when taken for 18 months. The guideline should therefore not imply that early diagnosis of MND is not valuable or important, and so we believe this line should be removed. We note that the NICE Guideline on MND calls for people to be referred "without delay" when MND is suspected.	Thank you for your comment. The Guideline Committee has amended the recommendations and link to evidence table to highlight that people with MND should be promptly referred to enabled them to access support services to maintain their independence and quality of life for as long as possible, including services such as physiotherapy, occupational therapy and respiratory support. In addition, there are safety considerations because people with bulbar difficulties may also run into problems with chewing and swallowing. The committee noted the recommendations on recognition and referral in the NICE guideline on MND (NG42) and agreed to cross-refer.
Motor Neurone Disease Association	Full	General		We welcome NICE's decision to develop a guideline covering suspected neurological conditions presenting in primary care. For a rapidly progressive and terminal condition such as motor neurone disease (MND), rapid referral and diagnosis is key to accessing the treatment and support that enables people to maintain their wellbeing and independence for as long as possible. The comparative rarity of MND means that many primary care practitioners have little experience of working with people living with the condition, and the same is true for a number of other neurological conditions. Survey data produced by the Neurological Alliance for its 2016 report 'Neurology and Primary care' found that 84% feel that they could benefit from further training on identifying and managing people presenting with neurological conditions. Consequently we believe that the development this guideline is an important and welcome initiative. We recognise that this is a very wide-ranging guideline that provides information relating to a large number of diverse symptoms and conditions, and the length of the draft guideline reflects that broad scope. However, it is important to consider that GPs are working within the constraints of extremely busy workloads and 10-	Thank you for your comments. NICE will consider what else might be done to implement the guideline. However, the Guideline Committee has given clear section headings in the guideline, and feel that GPs should be able to navigate to the section of interest fairly easily. Also please note that

				minute appointments on average. At 31 pages of text, even the shorter version of the guideline may be difficult to use regularly in practice in primary care settings. NICE should consider developing a diagnostic pathway algorithm or decision tool to improve implementation and usage of the guideline.	recommendations have generally been ordered in terms of urgency to help.
Motor Neurone Disease Association	Full	General	General	The draft guideline does not include any recommendations for people presenting with respiratory symptoms that may be indicative of a neurological disorder. The NICE Guideline Motor Neurone Disease: Assessment and Management (NG42) notes that "breathing problems, such as shortness of breath on exertion or respiratory symptoms that are hard to explain" may be a symptom of MND. The guideline should include consideration of unexplained respiratory symptoms and should recommend a neurological assessment for people presenting with these symptoms, in line with the recommendations of the NICE MND guideline.	Thank you for your comment. There is a recommendation for immediate referral if respiratory problems present together with limb weakness. The Guideline Committee feels that unexplained respiratory symptoms are better assessed by respiratory physicians; standard respiratory function tests should identify those in whom breathlessness is due to muscle weakness.
Multiple Sclerosis Trust	Appendix	General	General	Appendix A cites the Neurological Alliance publication, The Invisible Patients published in January 2015. The Neurological Alliance subsequently updated this survey and published Falling Short: How has neurology patient experience changed since 2014. They surveyed thousands of people with neurological conditions and found that 42% of people saw their GP five or more times before seeing a neurological specialist – an increase from 31.5% in 2014; clearly the situation has worsened in the two years between the surveys.	Thank you for your comment. Although the Guideline Committee can't update the guideline scope we have updated the introduction to reflect your comment.
Multiple Sclerosis Trust	Full	29	27	Multiple Sclerosis in adults: management CG186 is not included in the list of related NICE guidelines. Is this an omission?	Thank you for your comment. The Guideline Committee has added it to the list of related guidance.
Multiple Sclerosis Trust	Full	General	General	We are concerned that despite the wide range of symptoms indicative of multiple sclerosis, there is so little reference to MS - in the full 168 page guideline we counted just four mentions of multiple sclerosis/MS.	Thank you for your comment. The guideline is based on symptomatic presentations and the need to refer these to neurology, and the recommendations could be written with little or no mention of the possible diagnoses. The Committee thought it would be helpful to mention some conditions as examples to explain their reasoning, but did not intend this to be a comprehensive list of possible diagnoses.
Multiple Sclerosis Trust	Full, short	General	General	The MS Trust welcomes the development of a guideline on recognition and referral of suspected neurological conditions. Questions about diagnosis of multiple sclerosis make up about 1 in 10 of the enquiries handled by the MS Trust helpline. We are very much aware of the problems of getting timely referral from GPs for people with symptoms indicative of MS, particularly as people often visit their GP over a period of time with a series of apparently unconnected symptoms. The proposed guideline should emphasise the importance of recognising a history of previous neurological symptoms.	Thank you for your comment. The guideline concentrates on recognition and referral, but is not intended as a detailed guide to the assessment of patients.
Multiple Sclerosis Trust	Full, short	General	General	The updated NICE MS Clinical Guideline CG 186 was published in 2014. Despite the availability of this guideline, a recent survey of GPs published by the Neurological Alliance (Neurology and primary care, August 2016) reported that less than half (47%, 392 of 830 respondents) felt confident in their ability to make an initial assessment and referral for people presenting with signs and symptoms of multiple sclerosis. This would suggest that the MS guideline is not supporting GPs and raises concern that NICE guidelines are not resources routinely accessed by GPs. Without seeing other tools and resources that are planned to support the proposed guideline, it's difficult to see how this draft guideline will improve matters.	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned.

Suspected neurological conditions

Consultation on draft guideline - Stakeholder comments table
07 August 2017 – 19 September 2017

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Multiple Sclerosis Trust	Full, short	General	General	Both versions of the guideline should include a clear statement that they do not cover neurological conditions for which recognition and referral by non-specialists is already covered by NICE guidance and should include a list of these guidelines. Without this there is a danger that the proposed guideline could be viewed as a comprehensive list. However, we also wish to point out that existing guidelines, such as CG 186, focus more strongly on the ongoing management of neurological conditions rather than on initial assessment and referral.	Thank you for your comment. This guideline is based on symptomatic presentations, not on specific conditions. The guideline refers to related NICE guidance where appropriate.
Multiple Sclerosis Trust	Full, short	General	General	There are frequent references to functional neurological disorders in both versions of the draft guideline but no guidance is offered to help a GP support someone with functional neurological symptoms. We would welcome input to the draft guideline from neurologists specialising in this area. A diagnosis of functional neurological disorder can be particularly difficult for patients to understand so this may be one area where signposting to information would be most welcome such as http://www.neurosymptoms.org/ or https://fndhope.org/).	Thank you for your comments. The guideline is intended to deal only with referral issues, not with management. The Guideline Committee received input from clinicians skilled in the area of functional neurological disorder.
Multiple System Atrophy Trust		72-73	4	We are concerned that in many places the Guideline refers to one or two conditions in relation to specific symptoms. This may delay detection of other, rarer, neurological conditions.	Thank you for your comment. The Guideline Committee has amended the recommendations and link to evidence, to the table on ataxia and where relevant, to reflect commoner causes. However, this is not a diagnostic guideline and the aim is to facilitate appropriate referral for expert diagnosis, where necessary.
Multiple System Atrophy Trust	Appendices	General	General	We note that many appendices are empty and assume this is due to inadequate evidence. This is indicative of a broader issue in neurosciences in that investment in research is inadequate meaning evidence of 'what works' is sparse, particularly for rarer conditions, and particularly in primary care settings. In some cases, this is also due to lack of service infrastructure to support research. An example of this issue is the scarcity of research around MSA. This is clearly an issue for NIHR and other bodies than NICE. However, NICE's focus on what is deemed 'high quality evidence' hampers development of neurological guidance. For many rarer conditions, double blind randomised controlled trials are not only unethical, but also impracticable, given the small pool of patients that are potential participants for such research. We would urge NICE to adopt a consensus based approach to what is deemed adequate evidence.	Thank you for your comment and for highlighting the issues around research in neuroscience. However, the reason there wasn't much evidence included in this guideline was not due to the fact that the Guideline Committee had restricted their searches to high quality randomised trials, but to the fact that there was no evidence that specifically answered our clinical questions. The type of study design we look for depends on the type of question being asked. In this guideline we were mainly looking for clinical prediction studies with multivariate analyses that accounted for at least some of the key confounders identified by the committee. This would provide evidence that the association of specific signs and symptoms for example headaches with dizziness is indicative of a specific neurological condition. Unfortunately, there was a lack of such evidence and therefore not many studies were included in the guideline.

Suspected neurological conditions

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Multiple System Atrophy Trust	Full version	104	16	Getting timely information and support is very important to people affected by neurological conditions yet the recent Neurological Alliance patient experience survey found 44% of people with MSA were dissatisfied with information they had received about their condition, and the same percentage were dissatisfied with information they had received about third sector support available. (See *Falling Short, Neurological Alliance, 2017)* When people do finally make it through to sources of support, such as the MSA Trust, they are grateful for the opportunity to get more individual advice and to meet others experiencing the same issues. We are accredited to the NHS England Information Standard so we cannot understand why organisations such as ours are not recommended by Neurologists and Consultants as a matter of process rather than luck. 77% of people with MSA subsequently have regular contact with us and other third sector groups, even when their condition advances so there is clearly a need for such support. The only advice the Guideline recommends is to check the DVLA notification guidelines and to consider telling their employer, school or college. We are concerned with both of these pieces of advice being given in isolation to additional information and support. • Telling an employer, school or college about a suspected neurological condition can have huge implications for individual patients and it may not always be appropriate to do so before a diagnosis has been confirmed. Indeed, until diagnosis is confirmed, patients/employees do not have legal protection under the Equalities Act. Patients will often benefit from additional support in informing an employer or education institution, and patient organisations – such as Neurological Alliance member charities – provide a wealth of support and information in areas such as this. Patients must be made aware of this broader support in parallel to being advised to consider telling an employer or education institution about a suspected neurological condition. • Similarly, while safety concerns are paramount in relation to DVLA notification, surrendering a driving license can have a huge impact on an individual's life, for which they may benefit from additional support – and indeed signposting to financial support that may be available to help with alternative transport. Again, third sector organisations are ideally placed to provide such support. See for example, our own information leaflet on Driving and MSA. We welcome the inclusion here of the principles in the NICE Guideline on Patient Experience in Adult NHS Services. Yet, without specific reference to the importance of information and an individualised approach to services in the neurological conditions guideline, we feel GPs may miss the opportunity to sign post patients to information, helplines and support groups available. The committee notes that it was concerned about unduly worrying patients before diagnosis was confirmed. Our experience is patients are more likely to worry without appropriate information and support, particularly while waiting for a neurologist appointment. Third sector organisations are highly skilled in supporting patients at every stage on the care pathway – even before diagnosis. Indeed, many of us provide support in understanding the next steps such as what will happen at a neurologist appointment, what tests may be carried out and why. Many third sector organisations work closely together in relation to patients who have similar symptoms or may be incorrectly diagnosed. Much of the information developed by third sector organisations is peer reviewed and developed with reference to academic research, medical expertise and has the NHS England information standard.	Thank you for your comments. The Guideline Committee appreciates that there are many excellent examples of supportive information for people with specific diagnoses. Unfortunately NICE guidelines cannot refer to information from third party organisations because these can change after publication of the NICE guidance. If there are specific pieces of information which you would like to be highlighted, these could be considered separately by referring them to the NICE endorsement programme: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement The advice on employment and driving is made with care. The recommendation on informing employers only suggests considering this, and refers to the situation where the person may have difficulty in carrying out their job. The other part of this recommendation only suggests that the person should look at the DVLA website to decide whether it is necessary to inform the DVLA. We agree in both instances that it would also be useful to point the person towards other lines of support, although for reasons given in the preceding paragraph we cannot specify this support within the guideline.
Multiple System Atrophy Trust	Full version	26	1-43	The MSA Trust welcomes the development of a Guideline on suspected neurological conditions in primary care. In the most recent Neurological Alliance Patient Survey, the results for people with Multiple System Atrophy (MSA) indicated that around half had seen a GP more than five times before being referred to a Neurologist and over half had waited over six months for a diagnosis. Given that MSA is such a complex condition it may be reasonable for consultants to spend time getting to the right diagnosis (and our" Red Flag" guidance in identifying MSA can help here), but as it is a progressive condition delay in referral often impacts adversely on people with MSA. The MSA Trust would be happy to work with NICE to ensure this Guideline addresses delays in detection and referral of neurological conditions, as well as inefficiencies in the pathway. To this end, we want to ensure the final Guideline is comprehensive in its content, easy to use for primary care professionals, and widely taken up by the health system. Although we are happy the issue of diagnosis of suspected Neurological conditions is being addressed, a key issue for us is identifying how, in practical terms, these guidelines will **actually** be used, and not end up as a laudable but academic exercise.	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned.
Multiple System Atrophy Trust	Full version	27	10-15	The range and complexity of neurological symptoms and conditions make it challenging for GPs and other primary care professionals to recognise and refer patients with suspected neurological conditions. We feel that even with this additional guidance, non-specialists working in primary care may still, in some cases, require additional support and a second opinion.	Thank you for your comments The Guideline Committee agrees that there may well be value in some of the implementation methods you suggest

				The new models of care set out in NHS England's GP Forward View – primary care networks or hubs – will mean access to greater expertise across a 'hub' area, which may include GPs with a special interest in neurological conditions and specialist nurses. Primary care networks or hubs could also facilitate the development of areas of expertise amongst primary care professionals. These new models of care will increase the pool of knowledge across GP surgery hubs, as the number of neurological cases seen across a hub area will be greater than for an individual GP surgery. The Guidance does not currently make any reference to hubs or network models of care and how this could facilitate implementation of this new Guidance. Furthermore, pilot schemes to enable GPs to speak to neurologists on the phone or via video conference have been successful in improving appropriate referral rates – see for example the Walton Centre Vanguard, or the work by the neurology strategic clinical network. Such schemes might be included in the shared learning database to support implementation. We would also urge the Guidance development group to speak to these pilot projects about findings from their work to understand more about the sorts of questions GPs are asking in relation to neurological conditions, to inform the development of this Guidance. Would it possible to consider adding another category to the 'refer urgently', 'refer immediately', 'refer' criteria which stipulates seeking a second opinion? – a phone call to a neurologist is far more efficient than a wasted neurology outpatient appointment – and more likely to lead to the better pathway for the patient.	such as Primary Care hubs. However, consideration of these was not part of the remit or the scope of the Guideline. We also agree that phone calls can be useful, but we cannot recommend this within the guideline since access to neurologists is beyond our control and will require local negotiation.
Multiple System Atrophy Trust	Full version	31	30-33	The draft Guidance notes that the wide range of neurological conditions has meant the scope concentrated on 'more common presentations of neurological symptoms'. We believe that several common presentations of neurological symptoms are missing from this guidance – or not given the emphasis required to effectively detect conditions - which may lead to (even relatively common) neurological conditions being missed or misdiagnosed. Similarly, if one of the intentions of this guideline is to increase referrals of rarer conditions, rarer symptoms must be included to ensure timely diagnosis. We suggest the following signs and symptoms of neurological conditions are added to the Guidance and would be happy to supply further evidence and information in these areas. While some of these symptoms are mentioned in passing in the Guidance, they are not always experienced in tandem with the symptoms listed in the draft Guidance which may lead to them being missed. We believe each of these areas should be covered as separate recommendations given they are common symptoms of several neurological conditions. • Disturbance of bladder and bowel function, sexual dysfunction These are also symptoms that patients may be embarrassed or reluctant to mention to their GP. This makes it even more paramount that primary care professionals are aware of their link to neurological conditions so they can ask appropriate questions during consultations. The Guidance should encourage GP's to ask about such symptoms. We regularly hear of people eventually diagnosed with MSA whose first major symptoms may be bladder dysfunction with perhaps some movement disorder. In these situations, it is common for the first "specialist" consultation to be with an Urologist. If the movement disorder is not asked about the person may end up being "trapped" in one pathway without appropriate referral across to Neurology. This could also lead to inappropriate surgery. There are a range of conditions, including MSA, that cause **autonomic failure and postural hypotension** so this should be noted as a potential flag for referral?	Thank you for your comments. The guideline was necessarily limited in scope and had to concentrate on areas where practice was variable or unsatisfactory. The Guideline Committee recognised that autonomic signs and symptoms are often significant and require onward referral, but decided that for the most part current practice is satisfactory.
Multiple System Atrophy Trust	Full version	General	General	The draft Guidance is attempting to make the demand side of neurology outpatient appointments more effective and efficient. One of the major problems in this approach is that without any action to also address the supply side of neurology services, it is likely to fail. It is well documented that there is huge geographical variation in neurology services: • Not all GPs can refer directly for MRI scans meaning an outpatient neurology appointment is required to get referral for imaging. • There is a national shortage of neurologists, with some areas carrying long standing vacancies. • In other specialisms, such as neuropsychiatry and neuropsychology, access is even more patchy across the country. It is paramount that work is undertaken by Health Education England, NHS England, the Association of British Neurologists and others to address the supply side in relation to access to neurology services across the country. We would welcome conversations with other agencies about how we and other organisations could support initiatives to address these issues.	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned.
Multiple System Atrophy Trust	Full version	General	General	Given the complexity of this area of health care, and length of even the short version of the Guidance, we are concerned that it will not be widely taken up by primary care professionals; especially given there are few contractual incentives in primary care relating to neurology. This Guidance cannot be launched in a vacuum. Neurology is not a priority for many Clinical Commissioning Groups and Sustainability and Transformation Partnerships. Professional education, an awareness campaign, ongoing audit as part of accountability frameworks, and a simple algorithm are all	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned.

				tools that would support the intentions behind this Guideline to be realised. We would welcome a further conversation with NICE (the Royal College of General Practitioners, Primary Care Neurology Society, and others) about how we and others can support this Guidance to be used. We would also like to understand more about the role of the NICE implementation team in relation to ensuring this Guidance is used.	
Multiple System Atrophy Trust	Full version	General	General	We would be interested to explore the extent to which other (non-neurological) NICE Guidance refers to potential neurological conditions (and in time should cross refer to this new guidance). Neurological patients often find themselves 'stuck' in the wrong part of the health service, for example in ear nose and throat clinics or continence services – without appropriate referral to neurology. This new guidance is an opportunity to review the representation of neurology in other guidance beyond neurology, where symptoms may be indicative of neurological condition.	Thank you for your comments. The Guideline Committee appreciates the problem to which you refer. The guidance is directed mainly at presentations in primary care, but we would anticipate that it might be consulted by non-neurologists working in secondary care.
Multiple System Atrophy Trust	Full version	General	General	We note that mental health is mentioned only twice in the whole Guideline – in relation to tic disorder. The Neurological Alliance's recent report *Parity of Esteem for people affect by Neurological Conditions* (2017) found that around 50% of neurological patients have co-morbid mental health conditions (this rises to around 80% of people with multiple system atrophy) . This is higher than for the general long-term condition patient population, where 30% of patients have a mental health condition. This is due to the complex interplay between a neurological conditions and mental health condition (see our report for further detail). The omission of any mention or consideration of co-morbid mental health conditions in this Guidance is a missed opportunity for early detection of mental health conditions in neurological patients.	Thank you for your comment. The Guideline Committee has added a reference to depression and coincident psychiatric disorder in the introduction to the Full version of the guideline. However, the remit of the guideline is to address the need for referral of primary presentations, not treatment of that presentation or any psychological sequelae.
Multiple System Atrophy Trust	Short version	6-7	21-26	Regarding gait unsteadiness and handwriting difficulties it should be noted that people may describe these in a more oblique manner. So, people may describe limb heaviness or nagging unresponsiveness of a limb or limbs rather than gait or handwriting problems.	Thank you for your comment. The Guideline Committee appreciates that patients may not use the exact same words as we use in our headings, but health care professionals will be able to map these alternative descriptions to the appropriate section.
Multiple System Atrophy Trust	Short version	9	12-15	This recommendation refers only to cauda equine syndrome. These symptoms could reflect other conditions, for example Multiple System Atrophy. Overall, we recommend NICE reviews the parts of the Guidance that refer only to one or two specific conditions and where there is evidence that symptoms may be indicative of other conditions, adding these conditions to the list. Alternatively, there should be a note in the Guidance explaining that other rarer neurological conditions should also be considered in relation to recommendations which stipulate one or two conditions. This is important not only so that patients are not stuck on the incorrect pathway, but also to ensure patients have as much information as possible about their potential diagnosis when leaving the GP surgery. Patients can and do research possible diagnoses online and should be given the broadest possible amount of information at this stage. A more general, but related point, is that in many places the Guidance is written around a handful of more common conditions and it is hard to see how rarer conditions would fit in.	Thank you for your comment. It is not the purpose of the guideline to mention every possible cause of each presentation. It is aimed at ensuring that referral is appropriate, so that the detailed diagnostic work can then take place.
Muscular Dystrophy UK	Full	general	general	We support the recommendations which have been put forward in the guideline. We welcome the references to muscular dystrophy and neuromuscular conditions throughout the guideline and the focus on Duchenne muscular dystrophy from pages 132-136.	Thank you for your comment.
Muscular Dystrophy UK	Full	general	general	Question 3: Muscular Dystrophy UK and the Royal College of General Practitioners (RCGP) have produced the first ever online course for GPs on the presentation and management of neuromuscular conditions in primary care. Nearly 1,000 GPs have taken the training module, which helps 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. We encourage promotion of this module and other helpful resources alongside the guideline to ensure the required support is available for patients with the different types of muscular dystrophy and neuromuscular conditions along the diagnosis and care pathway.	Thanks for your comment. NICE cannot promote particular training modules within a guideline because the modules may change after publication of the guideline.

					The module could be considered separately by the NICE endorsement programme if you wish: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
myaware	Full	104 – 105	General	The recent Neurological Alliance Patient Experience Survey identified that 45% of patients were unhappy with the information they had received about their condition, 63% were dissatisfied with the information they had received about sources of emotional support and 53% were dissatisfied with signposting to third party organisations who could help them. We would like the guideline to specifically include the work that third party organisations such as myaware can provide – this is of benefit both to the patient and to overstretched NHS services. Myaware (and many other third sector organisations) is equipped to provide accurate and clear patient information written by medical specialists; to answer questions and queries that are not patient specific; to re-direct patient specific questions and queries back to appropriate medical services; to provide Counselling services; to provide welfare and benefits advice; to support lifestyle changes appropriate to the medical condition; to advise on work, study and driving related issues and to arrange carefully moderated peer support to reduce the feelings of isolation which can lead to mental health issues.	Thank you for your comment. Unfortunately, NICE cannot refer to information from 3rd sector sources because the information may change after publication of the NICE guideline.
myaware	Full	31	30 – 33	The draft Guidance considers 'more common presentations of neurological symptoms'. We are concerned that 'typical' signs and symptoms of myasthenia are not included. These could include be double vision; ptosis; speech and swallowing difficulties; drooping mouth; neck and / or limb weaknesses and would be happy to supply further evidence and information about the symptoms. People with myasthenia are frequently tested for stroke, Bell's Palsy or MND before myasthenia is considered. We appreciate that the wide range of neurological conditions make the development of these guidelines difficult, but believe that provision of more detailed diagnostic tools with a broader range of symptoms for the use of primary care practitioners would reduce the delay, high cost and emotional stress associated with misdiagnosis or delayed diagnosis. Our experience of working with GPs to increase their awareness of the myasthenias is that they would be keen to use suitable tools and information sources to assist them with identification of the rarer neurological conditions more effectively (we believe there are around 12,000 people with myasthenia in the UK).	Thank you for your comment. Advice on recognition and management of specific conditions is beyond the scope of this guideline, although the Guideline Committee considered these conditions when drafting the recommendations. The guidance does not set out to mention every possible condition which might cause a particular symptom; its aim is to advise on referral, after which an accurate diagnosis should be made. Some of the symptoms that you mention as possible presentations of myasthenia are included in the gGuideline (limb weakness, speech problems). Others were excluded. The Guideline Committee made these decisions based on whether a presentation is currently dealt with appropriately or not (in general) and on the frequency of the presentation.
myaware	Full	72 – 75	General	Although myasthenia gravis (but not Ocular MG, Congenital Myasthenic Syndromes or Lambert Eaton Myasthenic Syndrome) is mentioned in section 5.6 there appears to be no reference to eye symptoms which are common in this condition, or to a-symmetrical symptoms. We agree that the initial presenting features of the myasthenias are often not recognised by non-specialists and agree that GP's should feel confident to re-refer, however, as mentioned in comment 2 above even when a referral is made there are usually significant delays before an appointment is obtained. And during this waiting period the patient is forced back into the care of a GP who is ill-equipped to deal with a patient with rapidly worsening myasthenic symptoms. As a charity we regularly assist those with suspected myasthenia in these circumstances who are waiting for a neurology appointment, are suddenly very unwell and who are unable to obtain a timely GP appointment (sometimes being advised that the wait will be several weeks. These patients are frequently admitted to hospital through A&E and often experience an extended inpatient stay following a spell in ICU. We believe that in many cases earlier diagnosis and appropriate drug therapy would significantly reduce these hospital admissions.	Thank you for your comment. The Guideline Committee acknowledges your concerns about delays in GP and neurology appointments, but these resource issues are not governed by NICE and are beyond the remit of this guideline. It is hoped that the guideline will reduce inappropriate referrals and should therefore improve access to Neurology services when needed.
myaware	Full	General	General	Myaware welcomes this Guideline on suspected neurological conditions in primary care. The average time from first symptoms to diagnosis of myasthenia amongst myaware members is 26 months during which time patients have typically experienced multiple appointments in primary care,	Thanks for your comment. The Guideline Committee acknowledges

				frequently been sent to non-neurological consultants such as Ophthalmologists, and often end up with suspected myasthenic crisis in A&E before they are eventually diagnosed. These delays impact adversely on the patient's life, ability to work or study and on their mental health. Multiple NHS appointments which don't lead to myasthenia being identified are clearly costly as well as tying up services that could be more appropriately used by other patients.	that diagnosis of myasthenia is frequently slow. You do not specify any particular recommendations, but overall we believe that this guideline will improve the appropriateness of referral to neurology services. We have reworded recommendation 1.7.5 to clarify that the recommendation does not only cover Motor Neurone Disease.
myaware	Full	General	General	We have concerns about the impact on primary care of the lack of specialist neurology services in some parts of the UK. Even when a GP suspects myasthenia, extended delays in accessing neurology clinics have an adverse impact because the patient frequently needs specialist medical care during the waiting period, and is forced back into primary care which is ill equipped to deliver the medical support needed during this time. As many patients with myasthenia are older people, they frequently have co-morbidities and myaware has sympathy for the Primary Care professionals coping with patients in this category who also have suspected or undiagnosed myasthenia. Some patients end up in ICU via A&E when their undiagnosed myasthenia deteriorates suddenly bypassing a long waiting list for a neurology appointment, but with a serious risk to their health and high cost to the individual and the NHS. 113 patients died of myasthenia in England and Wales in 2013. Myaware is keen to work with NICE to reduce inefficiencies in the care pathway and to seek effective ways of speeding up referrals for suspected myasthenia to an appropriate consultant.	Thank you for your comment. This guideline focuses on referral of symptomatic presentations rather than specific conditions such as myasthenia. The Guideline Committee is sorry that access to specialist neurology is difficult, but one of the purposes of this guideline is to reduce the number of inappropriate referrals and we hope this will improve access for those who need it.
myaware	Full	General	General	For patients with suspected myasthenia referral to a neurologist with a special interest in neuromuscular conditions or myasthenia is the ideal in achieving a quicker diagnosis and more rapidly achieving management of the condition. The shortage of neurological services and patchy distribution of such specialists is a concern to myaware, not only because it can result in poor patient experience, but because we also recognise the cost to the NHS in multiple primary and secondary care appointments while the myasthenia remains unstable. Where there is a specialist myasthenia service, myaware members are frequently willing to undertake long journeys to access it because they see that it is likely to give them a better outcome.	Thank you for your comment. The Guideline Committee is sorry that access to specialist neurology is difficult, but one of the purposes of this guideline is to reduce the number of inappropriate referrals and we hope this will improve access for those who need it.
myaware	Full	General	General	We feel that this Guideline currently misses an opportunity to address the frequent co-morbidity of mental health conditions with neurology and point to the 2017 Neurological Alliance report 'Parity of Esteem for people affected by Neurological Conditions' which identifies the fact that people with a neurological condition are far more likely to have mental health needs than the general population.	Thank you for your comment. The Guideline Committee agrees that mental illness is a common concomitant of neurological conditions. This has now been described in the introduction.
myaware	Full	General	General	It would be helpful if the Guideline could include the contribution that third sector organisations already play in raising awareness of neurological conditions with primary care professionals. Myaware, along with many other charities, invests heavily in provision of high quality information and relevant training for GPs which is well received by them. But many GPs are unaware of the information and support that is available to them from the third sector, and we would like the Guideline to address this and signpost the primary care to relevant organisations that can assist them in their care of neurology patients.	Thank you for your comment. Unfortunately The Guideline Committee cannot refer to sources from third party organisations within a guideline.
National Neuro Advisory Group	Full version	General	General	The National Neuro Advisory Group (NNAG) welcomes the development of a Guideline on suspected neurological conditions in primary care, which seeks to address significant issues in the current care pathway. The NNAG brings together professional bodies, patient organisations, commissioners, data analysts, researchers and providers; working together to improve services and outcomes for neurological patients. Each of our individual organisations has submitted our own response and we do not repeat the detail here. Instead we share our broader, collective concerns with the draft Guidance. • The Guidance is attempting to cover a very broad scope. It is currently too long to be usable by primary care professionals during a short consultation with a patient. We recommend creating two separate Guidelines – one for children and one for adults.	Thank you for your comments. The processes adopted by NICE in drawing up a guideline can be viewed on the NICE website, and include a consultation process to determine the scope. Time constraints meant that not every neurological presentation could be included, and the GC based its

				• We do not understand the rationale for why some symptoms and conditions are included and not others. We believe that several common presentations of neurological symptoms are missing from this guidance – or not given the emphasis required to effectively detect the underlying condition. In other parts of the guidance, very rare conditions are named in relation to symptoms, but other conditions are not included, including conditions that are treatable with early identification. Notably headache is inadequately covered in the adult section of the guidance. Several symptoms of potential neurological conditions are missing – for example, disturbance of bladder and bowel function, sexual dysfunction and disorders of vision. Mental health is almost entirely absent from this Guideline, despite being a common co-morbidity of neurological conditions. • The level of expertise assumed by this Guidance is inconsistent and generally pitched at a level higher than a primary care generalist. An example of this is the way in which functional symptoms are described. Indeed, leading neurologists often struggle to correctly identify functional symptoms as distinct from an organic neurological condition. We do not believe non-neurological specialists working in primary care – not just GPs but also health visitors, pharmacists and others - will be able to effectively use this Guidance to identify and appropriately refer patients with suspected neurological conditions without significant amendments. Furthermore, the Guidance is not suitable for use by patients and carers. • The section on information and advice is not fit for purpose to ensure patients receive the support required at the point of visiting a GP with first symptoms ahead of diagnosis. Signposting to third sector and other sources of support is essential to ensure patients have the information they need when they leave the GP surgery. As the new national leadership group for neurology, we are disappointed that we have not been invited to input into the development of this guidance ahead of the formal stakeholder consultation period. We would like to invite the NICE team to run a consultation session specifically with the NNAG members (and also suggest involving the NHS England Clinical Reference Group for Neurosciences) ahead of the next draft being produced so we can address the points made above in detail. We bring together all the different part of the health system to better align activity and improve outcomes for patients. Collectively we have a huge amount of expertise to contribute to the success of this Guidance. Ensuring timely and appropriate referrals from primary care is one of the key priorities for neurology service improvement and we are keen to work with NICE to ensure this Guidance works towards addressing this. We do however have serious concerns with the current draft which we would like to see addressed before we, as the national leadership group for neurology, can support this Guidance:	decision primarily on whether or not current referral practice could be improved, and secondly on how common the presentation is. The recommendations will be separate for adults and children when the final version is published on the NICE website. The guideline is not intended primarily as a guide to diagnosis, and a high level of diagnostic acumen is not expected of a general physician. It is designed to guide the need for referral to neurology. The Guideline Committee agrees that diagnosis of functional symptoms can be difficult, but the relevant recommendations in the guidance refer to recurrent, rather than first, presentation. Unfortunately NICE is unable to signpost to third party sources of information. If there are specific pieces of information that you would like to be recommended, you could refer these to be considered separately by the NICE endorsement programme : https://www.nice.org.uk/about/what-we-do/into-practice/endorsement.
NICE GP Reference Panel	Short	13	23	Should this be qualified in the same way as cervical radiculopathy (and/or linked to NICE back pain guidance)?	Thank you for your comment. The Guideline Committee has amended the recommendation by adding a cross-reference to NG59.
NICE GP Reference Panel	Short	17	6	I don't think most GPs will be aware of a list of drugs which would be considered first-line therapy for essential tremor. Could you clarify or provide a link?	Thank you for your comment. The Guideline Committee has amended the recommendation to include a link to first-line treatment as specified in the BNF.
NICE GP Refere	Short	5	6	'HINTS' test does not appear to be a test that could be adopted widely in General Practice (training requirements aren't listed in the guideline or appendices). Given the very common presentation of vertigo, and comparative rarity of cerbro-vascular causes (literature from secondary care sources will inevitably overstate the ratio), several respondents expressed concern that this would increase unnecessary referrals.	Thank you for your comment. Although the guideline is mainly aimed at primary care it also includes presentation to A&E departments, hence the inclusion

nce Panel					of the HINTS test. The Guideline Committee has added the following recommendation for doctors who are not familiar with the HINTS test: *Refer immediately adults with sudden-onset acute vestibular syndrome in whom benign paroxysmal positional vertigo or postural hypotension do not account for the presentation, in line with local stroke pathways, if a healthcare professional with training and experience in the use of the HINTS test is not available*.
NICE GP Reference Panel	Short	5	7	The term 'gait unsteadiness' is open to interpretation, and we would be grateful if this could be further qualified	Thank you for your comment. The Guideline Committee does not think that "gait unsteadiness" will be misunderstood. We agree that there are many different types of unsteadiness, but this guideline is not the appropriate place for a detailed analysis of the differences. The referral recommendations in this section take the common types into account, and allow for different presentations. Detailed diagnosis will occur once the person is referred.
NICE GP Reference Panel	Short	9	1	Our respondents interpreted this as review six weeks after orthotic intervention. As direct and/or soon referral to this service is not widely available, we felt that the timescales for neurological referral should be clarified.	Thank you for your comment. Timescales for referral are defined at the beginning of the document.
NICE GP Reference Panel	Short	General	General	Thank you. There were several comments that this was useful, relevant and clear advice. At the same time it was noted that there was a lot of detail to digest and the document might better serve as a reference rather than as a working guide for the busy clinician.	Thank you for your response. The Guideline Committee accepts that there are a lot of recommendations, although we do not think that these are individually too detailed. The final guideline is available online, with links that take the user directly to each sub-heading. We hope this will help busy clinicians access the relevant recommendations when required.
NICE GP Reference Panel	Short	General	General	'Do not refer' One comment asked that this could be framed 'more positively' as referrals will take into account non-clinical factors, a failure of reassurance or pressure for a second opinion. Despite the guidance few GPs will attain the status of neurology triage expert.	Thank you for your comment. The Guideline Committee agrees that the referral decision has to take into account many factors, and as with any guideline the recommendations have to be applied to the individual

					circumstances of each patient. The 'do not refer' recommendations have been changed to 'do not routinely refer' to allow flexibility.
NICE GP Virtual forum	Short	General	General	It would be helpful if statements on referral pathways were reworded to take into account local variations e.g. cauda equina pathways may be orthopaedic rather than neurological; carpal tunnel pathways often involve local primary care consultation ('referral' is generally interpreted as 'secondary care referral')	Thank you for your comment. Referral in this guideline is assumed to be to neurology unless stated otherwise. The recommendations which mention local pathways do so specifically because the Guideline Committee recognised that there are existing local arrangements for some conditions that work well and may not necessarily involve neurology. The recommendation on referral for assessment for cauda equina syndrome has been amended to take account of local pathways: *Refer immediately, in line with local pathways, adults who have severe low back pain radiating into the leg and new-onset disturbance of bladder, bowel or sexual function, or new-onset perineal numbness, to have an assessment for cauda equina syndrome.*
Novartis Pharmaceuticals UK Ltd	Short	11	22	We suggest making the following amendment to the following text for clarity and to ensure appropriate diagnosis or different types of migraine: *For recommendations on diagnosing and managing migraine with **or without** aura see the NICE guideline on headaches in over 12s.*	Thank you for your comment. A recommendation on headache has now been added to the guideline. This guideline is about the need for referral; differentiation between different types of migraine is beyond the scope.
Novartis Pharmaceuticals UK Ltd	Short	20	16	We suggest making the following amendments to the following text for clarity: *For recommendations on headache **or migraine** in children aged over 12 years see the NICE guideline on headaches in over 12s*	Thank you for your comment. The Guideline Committee has made this amendment.
Novartis Pharmaceuticals UK Ltd	Short	General	General	We suggest providing further detail in this guideline regarding the diagnosis of headache and migraine in adults. In the recommendations for adults aged over 16 years section headache and migraine are only referred to in relation to other symptoms. We encourage NICE to include headache and migraine as a separate recommendation for adults over 16 to ensure appropriate diagnosis and management.	Thank you for your comment. A new recommendation on headache has been added which refers to the existing NICE guideline on headache.

Suspected neurological conditions

Consultation on draft guideline - Stakeholder comments table
07 August 2017 – 19 September 2017

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Optical Confederation	Full	118		Again, we note a request to perform or request fundoscopy, we again seek to remind you that there is currently no provision for this as part of GOS. If this is to be delivered via optical practices then an extended primary care service would need to be put in place. The Optical Confederation and LOCSU would be very happy to assist with this as we have for other conditions.	Thank you for your comment. The Guideline Committee does not have any role in deciding what is included in GOS.
Optical Confederation	Full	120		Recommendation 105 - Fundoscopy. We are pleased to see the acknowledgement that examination of the retinal fundus should be considered an essential part of the neurological examination. However, we are disappointed that reference is only made to the examination of children and not adults. Further, the recommendation advises that this should be requested from an ophthalmologist or optician. While optometrists can undertake this examination, there is currently no mechanism to provide for this under the NHS. NHS regulations and NHS England are very clear the general ophthalmic services (GOS) are for sight testing and case finding only and that this sort of service, although not at all difficult to implement through the existing infrastructure, would require an extended primary care service to be put in place by commissioners. It would be helpful to the NHS if this were made clear in the final guideline.	Thank you for your comment. The Guideline Committee does not have any role in deciding what is included in GOS. The recommendation which mentions fundoscopy only appears in the children's section because it refers to headaches as a presenting symptoms and headaches are not included for adults (because there is an existing NICE guideline which covers this).
Optical Confederation	Full	26	13	Reference is made to primary care and in this context this is explained to include opticians. We presume by this you mean optometrists and dispensing opticians. The guidance fails to offer any help to this section of primary care, either by defining our role in the referral process or by providing any practical help for differentiating between those patients who warrant urgent referral compared to those that do not. In response to a previous version of this consultation we made the following comments. • *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.* • *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* • *Specific referral criteria for the referral of patients with vision related signs and symptoms would be welcomed by optometrists.* • *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 neurological disease either causing symptoms or evidenced by functional deficits such as clumsiness.*	Thank you for your comments. The Guideline Committee agrees that optometrists pick up and refer problems appropriately. This guideline is directed at improving current practice where this is required. There already exists a NICE guideline on diagnosis and management of headache which includes 'red flag' features, and re-iteration would be inappropriate here. Current practice by optometrists to refer directly to specialist care in case of clinical urgency is entirely appropriate, and the criteria are contained within this guideline which will be of relevance to optometrists. The role of optometrists in assessing visual symptoms and signs is beyond the scope of this guideline.
Optical Confederation	Full and short	General		We are disappointed to not see any mention of sudden onset adult squint at all and particularly the role that optometrists and dispensing opticians play in the detection and referral of these patients.	Thank you for your comment. The guideline cannot cover every possible neurological presentation and the Guideline Committee prioritised primarily on the basis of current referral practice and whether it is sub-optimal or not. The Committee felt that sudden onset squint is generally referred appropriately.
Optical Confederation	Full and short	General		We would like to highlight the role optometrists and dispensing opticians can play in the quicker diagnosis and treatment of neurological conditions. One example is the South Tees Optical Referral Project (STORP). This is designed to fast-track the referral of specific visual field defects and papilloedema into the appropriate neurosciences department. This scheme differs to previous schemes in that it relies upon hard physical signs rather than clinical suspicion.	Thank you for your comment. The guideline cannot cover every possible neurological presentation and the Guideline Committee prioritised primarily on the basis of current referral practice and whether it is sub-optimal or

					not. The Committee felt that visual field defects and papilloedema are referred appropriately.
Optical Confederation	Short	1	6	Optometrists and dispensing opticians are likely to see many patients who present in non-specialist settings with symptoms suggestive of a neurological condition. However, they do not appear to feature in the short guidance at all and receive only a passing mention in the full guidance. This is despite the fact that in an earlier version of the consultation we advised the following. *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* • *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.*	Thank you for your comments. The Guideline Committee agrees that optometrists pick up and refer problems appropriately. This guideline is directed at improving current practice where this is required.
Optical Confederation	Short	31	6	We are pleased to see an acknowledgement of the lack of support to help non-specialists deal with neurological symptoms. However, we are disappointed to see that help has not been extended to optometrists and dispensing opticians.	Thank you for your comment. The guideline is not about treating symptoms, but about the need for referral to neurology.
Optical Confederation	Short	4	21	Optometrists and dispensing opticians routinely encounter patients presenting for examination, either via self-referral or at the request of their GP, who are experiencing dizziness. Some of these patients will have nystagmus, while we accept there is a clinical distinction between horizontal and both vertical and rotatory nystagmus, optical practices will be sent many of these patients from GPs. Unfortunately, there is no acknowledgment of the role of optometrists and dispensing opticians in the management or referral process.	Thank you for your comment. The Guideline Committee agrees that optometrists pick up and refer problems appropriately. This guideline is directed at improving current practice where this is required.
Parkinson's UK	Full	12	22	Diagnosis of the progressive ataxias has generally been a long process partly due to poor understanding demonstrated by health professionals. (Ataxia UK, Management of the ataxias: towards best clinical practice: third edition, 2016, p.4) We recommend that reference is made here to the importance professionals must place on recognition of the wide variation in presentation of unsteady gait. This is important in order to identify rare neurological conditions through symptoms such as sitting imbalance, jerky pursuit and intention tremor (Ibid, p.8). However it is also important that professionals recognise variations such as bradykinesia, lack of coordination and stooping as important indications of common neurological conditions such as Parkinson's (P Mazzoni, B Shabbott, J Camilo Cortés, Motor Control Abnormalities in Parkinson's Disease, Cold Spring Harbour Perspectives in Medicine, 2012, table 1)	Thank you for your comment. As stated in the introduction, expertise in the finer points of neurological examination is not expected of a primary care physician. The guideline seeks to help primary care practitioner decide who needs onward referral for the detailed examination to take place.
Parkinson's UK	Full	12	25	We welcome the guidance to refer adults urgently for diagnosis/treatment; however we recommend that this go further to specify a timeframe in which patients must be seen. It is important that people with suspected neurological conditions get access to treatment as soon as possible. Initial treatment with levodopa shows improvement for people with Parkinson's who experience unsteady gait (Long-term effectiveness of dopamine agonists and monoamine oxidase B inhibitors compared with levodopa as initial treatment for Parkinson's disease (PD MED), The Lancet; Volume 384, No. 9949, p1196–1205, 27 September 2014).	Thank you for your comment. The timeframes of immediate, urgent and routine referral are defined in the introduction to the Short version: • 'Refer urgently' means the person should be seen by the specialist service within 2 weeks. • 'Refer immediately' means the person should be seen by the specialist service within a few hours, or even more quickly if necessary. • 'Refer' means a routine referral.

Parkinson's UK	Short	10	15	We recommend that this section highlight that health professionals should be aware of memory problems as a symptom of Parkinson's. They may present as a variety of cognitive symptoms, ranging from mild forgetfulness to diagnosed dementia. Often these symptoms are missed in people with Parkinson's, despite them being very disabling and for many, the most troubling symptoms. In the early stages people may experience difficulties with attention and completing tasks, for example by losing their train of thought or becoming easily distracted. Later on in the condition more serious cognitive disturbances can occur. These changes can significantly impact daily functioning as well as quality of life. Where cognitive problems are more than what is expected with normal aging, but not enough to significantly interfere with daily activities, they may be due to mild cognitive impairment. This non-motor symptom occurs in about 30 per cent of people with Parkinson's (JG. Goldman and I. Litvak, Mild Cognitive Impairment in Parkinson's Disease, Minerva Med. 2011 Dec; 102(6): 441–459).	Thank you for your comment. The guideline is not designed to cover all the causes of memory problems. Its remit is only to recommend appropriate neurological referral.
Parkinson's UK	Short	11	9	We recommend that guidance is included here to highlight that dystonia can by a symptom of other neurological conditions like Parkinson's. Health professionals should be aware of this in order to facilitate a timely and accurate diagnosis.	Thank you for your comment. The guideline is not designed to cover all the causes of dystonia. Its remit is only to recommend appropriate neurological referral.
Parkinson's UK	Short	14	13	We recommend that further clarification is included here to include various sleep disturbances. Up to 96% of patients with Parkinson's suffer from various sleep-related problems (Annals of Indian Academy of Neurology, Sleep disorders in Parkinson's disease: Diagnosis and management, 2011 Jul; 14(Suppl1): S18–S20). Healthcare professionals should be aware of symptoms like violent or injurious behaviour during sleep and dreams that appear to be 'acted out' which can indicate REM sleep behaviour disorder (RBD). Up to half of all patients with RBD can progress to develop Parkinson's and other neurodegenerative conditions (multiple system atrophy, diffuse lewy body dementia) nearly 10-50 years after onset of RBD symptoms (Ibid).	Thank you for your comment. The guideline is not designed to cover all the causes of sleep disturbance. Its remit is only to recommend appropriate neurological referral and the type of sleep behaviour to which you allude is covered by rec 1.11.6.
Parkinson's UK	Short	14	22	We recommend that guidance is included here to highlight that unexplained loss of sense of smell can be an early indicator of Parkinson's. Not all people with a reduced sense of smell develop Parkinson's, but many people with Parkinson's do have a reduced sense of smell. According to Braak's hypothesis, the earliest signs of Parkinson's are found in various parts of the nervous system, including the olfactory bulb in particular, which controls sense of smell. (Carmen D. Rietdijk et al, Exploring Braak's Hypothesis of Parkinson's Disease, Frontiers in Neurology, 2017; 8: 37.) It is therefore important that Healthcare Professionals consider this symptom as a potential indication of early stage Parkinson's.	Thank you for your comment. The guideline is not designed to cover all the causes of altered smell/taste. Its remit is only to recommend appropriate neurological referral.
Parkinson's UK	Short	17	10	Alongside reference to the pathway on patient experience in adult NHS services we recommend that specific emphasis is noted within the guideline noting that high quality information and support is available to people with neurological conditions. For instance Parkinson's UK supports people living with the condition and their carers, families and friends. Third sector organisations are highly skilled in supporting people living with health conditions at every stage on the care pathway – even before diagnosis. Indeed, many provide support in understanding the next steps such as what will happen at a neurologist appointment, what tests may be carried out and why. Many third sector organisations work closely together in relation to patients who have similar symptoms or may be incorrectly diagnosed. Much of the information developed by third sector organisations is peer reviewed and developed with reference to academic research, medical expertise and has the NHS England information standard. We are particularly concerned that patients are experiencing a lack of information, particularly at the time of diagnosis (Neurological Alliance, Falling Short, 2017 p.12). This study found that 53% (n=2,830) of patients were dissatisfied with the signposting they had received from healthcare professionals to sources of voluntary sector support (ibid). Combined with extensive waiting times for neurological referrals, a lack of information and signposting from the NHS can mean that people with suspected neurological conditions may wait for months without reassurance. This causes distress which can trigger poor health outcomes. One person with Parkinson's told us: *"Out of the blue I had a suspected stroke and was rushed to hospital. After testing, the doctors said it wasn't a stroke, but told me I needed to see a neurologist. From that moment I started worrying...My stress levels went through the roof…I literally barely slept from July to September…I went to the doctor to ask about when I'd get a diagnosis, he told me he couldn't do anything to speed up the process. I was put on pills for my anxiety – my wife said it was like living with a different person. By September 2016 I'd waited 3 months for news. I was so ill with anxiety that one night I thought I was having a heart attack and was rushed to hospital. It was horrendous. At this point we decided we couldn't wait any longer and paid to get diagnosed privately…Since my private diagnosis, I've had absolutely no information or advice about my condition from the NHS, and I've not been given any medication. If we hadn't gone private, I think I'd still be waiting for my diagnosis ten months later. My GP hasn't been able to give any*	Thank you for your comments. The Guideline Committee agrees that 3rd sector organisations are of great benefit to the people with the conditions on which they concentrate. However, NICE policy is not to recommend information from specific 3rd sector sources because this can change after the publication of a NICE guideline. If there are specific pieces of information which you would like to be highlighted, these could be considered separately by referring them to the NICE endorsement programme: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement

				support as they don't seem to know much about Parkinson's, plus I see a different person each time. The only support I've received is from my local Parkinson's UK group who gave me resources, and contact details for the local Parkinson's nurse." (ibid)	
Parkinson's UK	Short	7	7	We are concerned that various common presentations of neurological symptoms are missing from this section such as gait dysfunction. This could lead to a condition like Parkinson's being missed or misdiagnosed. Similarly, no mention is made within this section about the various combinations which can indicate gait disturbance. We recommend that these symptoms are included in order to help health professionals diagnose Parkinson's.	Thank you for your comment. The guideline cannot deal with every neurological presentation, and the Guideline Committee had to prioritise which to include. It did this based on whether current referral practice is sub-optimal, and the frequency of the presentation. Gait apraxia is usually a late feature of idiopathic Parkinson's disease.
Pernicious Anaemia Society	Short	12	6	Be aware that the latest guidelines from the British Committee for Standards in Haematology acknowledge the current failings of the Serum B12 Test. Peripheral Neuropathy is a common consequence of untreated B12 Deficiency and whilst some patients feel relief after replacement therapy B12 others are left with permanent numbness and tingling. Consider using MMA and Homocysteine along with the 'Active B12 Test' (Holotranscobalamin). Assessing the patient's B12 status using the serum B12 test may very well not prove that the symptoms are caused by low B12.	Thank you for your comment. The Guideline Committee has amended the recommendation to allow different methods of checking for B12 deficiency dependent on local availability.
Pernicious Anaemia Society	Short	12	21	Lhermitte's Sign is another indicator of B12 Deficiency – and again a serum B12 test may not prove to be accurate	Thank you for your comment. The guideline does not cover the details of diagnosis of neurological disorders.
Pernicious Anaemia Society	Short	14	21	A 'metallic taste' is another symptom experienced by patients with low B12. This can and does occur leading up to the patient's next replacement therapy injection.	Thank you for your comment. The guideline is not designed to cover all the causes of altered smell/taste. Its remit is only to recommend appropriate neurological referral.
Pernicious Anaemia Society	Short	24	1-27	Development delay may be associated with B12 Deficiency. Although it is now difficult to get an accurate diagnosis of Pernicious Anaemia it may be worthwhile physicians investigating whether any parent, or grandparent or other blood relative has been diagnosed with Pernicious Anaemia in the past. It is now proven that there is a familial link in Pernicious Anaemia though there is a paucity of research on infantile and juvenile Pernicious Anaemia (the youngest member of the PA Society is 18 months and her brother is the second youngest at 4 years).	Thank you for your comment. This is best left to those in secondary care and The Guideline Committee does not think it is appropriate to include it in this guideline on referral to neurology.
Pernicious Anaemia Society	Short	6	11 & 12 (1.3.1)	Many members of the PA Society reported that they had numbness in their face and a feeling of 'spiders crawling' prior to diagnosis so it could be a symptom of low B12	Thank you for your comment. The guideline is not designed to cover all the causes of numbness or tingling. Its remit is only to recommend appropriate neurological referral.
Pernicious Anaemia Society	Short	6	27 (2.4.3)	Unusual Gait (gradual) is a prime symptom of Sub-Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia (SACD). A blood test should be conducted to determine the patient's Vitamin B12 Status although the current Serum B12 test is now largely discredited. Homocysteine and MMA would be better indicators of any deficiency. Note the symptoms of PA and SACD are insidious and wide ranging and the patient might have other symptoms of B12 Deficiency which have been overlooked. Many members of the PA society were finally diagnosed as having PA and SACD only after developing neurological problems (perhaps due to the failings of the serum B12 assay.	Thank you for your comment. The guideline is not designed to cover all the causes of gait difficulty. Its remit is only to recommend appropriate neurological referral. Details of the diagnosis of B12 deficiency is not within the scope of this guideline.
Pernicious Anaemi	Short	9/10	23	Memory loss (short term) is a common symptom of Pernicious Anaemia (B12 Deficiency). This can be worrying for patients especially when they remain undiagnosed (33% of members of the PA Society waited over 5 years for a correct diagnosis). A Serum B12 test should be used to determine the B12 status of the patient but be aware that there is no consensus on what constitutes a deficiency or sub-clinical deficiency and that there are local variations on thresholds. Be aware also that serum B12 test is not an accurate assay in determining the status in patients.	Thank you for your comment. The guideline is not designed to cover all the causes of memory loss. Its remit is

a Society					only to recommend appropriate neurological referral.
Pernicious Anaemia Society	Short	General	General	Vitamin B12 Deficiency affects around 6 million people in the UK. Because of problems with the current Assays to determine the B12 Status of Patients and whether the patient has Pernicious Anaemia as the cause of any deficiency diagnosis is problematic and often late which leads to many patients developing irreversible nerve damage. Any patient presenting with neurological issues, especially peripheral neuropathy or memory loss should have their B12 level evaluated using MMA/Homocysteine and HoloTC.	Thank you for your comment. The Guideline Committee decided that recommending use of assays of MMA/homocysteine and HoloTC was not appropriate for primary care.
Primary Care Neurology Society	7. Full	8. General	9. General	We are concerned that this draft guideline makes no mention of headache in the 'Adults' section of the guidelines. While we accept that there a NICE guideline for headaches already exists, we believe that this new comprehensive guideline on suspected neurological problems needs, at the very least, to mention headache and then refer the reader/user to the headache specific guideline; especially as headache can be a presenting symptom of a neurological problem as well as standalone condition.	Thank you for your comment. The Guideline Committee has added a cross-reference to the NICE Headache guideline into the Adults section of this guideline.
Primary Care Neurology Society	Short	13	1 - 3	We feel some clarification is required about the 'referral in line with local pathways' as we believe that not all patients with mild need referring. One suggestion is splint as a first option if mild and no weakness.	Thank you for your comment. Local pathways usually describe the pathway of care for such patients including the possibility of management without referral.
Primary Care Neurology Society	Short	15	22 - 25	We recommend that these patients would be better seen first by ENT first neurology to visualise vocal cords.	Thank you for your comment. A reference to ENT examination has been added to the recommendation (1.13.3).
Primary Care Neurology Society	Short	15	27 - 29	Consider adding to end of this section that don't refer unless severe and disabling or new onset.	Thank you for your comment. The Guideline Committee does not think that new onset tics need necessarily be referred.
Primary Care Neurology Society	Short	17	7-8	Consider adding new onset or disabling head tremor, rather than just anyone with head tremor.	Thank you for your comment. The wording has been modified so that referral is recommended only for those with troublesome symptoms
Primary Care Neurology Society	Short	5	6-16	There is concern about the relevance of the HINTs to general practice. When discussed at a practice meeting, it was discovered that the most academic and respected GP in a leading practice with GPs with a special interest in neurology were not familiar with the test, nor were the GP trainees who had just completed their hospital medicine attachments.	Thank you for your comment. The guideline is mainly for primary care but the scope also covers those who present to A&E departments, hence the recommendation to consider a HINTS test. The recommendation emphasises that is should only be done by someone trained in its use.
Primary Care Neurology Society	Short	6	13-15	We would like consideration to be given to whether GPs should advised to refer those with Trigeminal neuralgia aged <40 as it is considered slightly atypical in that age group	Thank you for your comment. The guideline was necessarily limited in scope and cannot cover everything. It is expected that where patients have unusual features referral would be appropriate.

Suspected neurological conditions

Consultation on draft guideline - Stakeholder comments table
07 August 2017 – 19 September 2017

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Primary Care Neurology Society	Short	6	17	We don't believe temporal arteritis has presented/been described in anyone under 50yrs, so we would suggest changing adult to aged 50 or over.	Thank you for your comment. The Guideline Committee agrees that temporal arteritis is rare before the age of 50 years, and therefore symptoms in much younger adults are unlikely to be taken as suggestive of this disease, which is how the recommendation is worded.
Primary Care Neurology Society	Short	7	7-9	Consider adding "or Parkinson's Disease" after normal pressure hydrocephalus, as difficulty initiating walking can also occur in Parkinson's.	Thank you for your comment. Gait apraxia is usually a late feature of idiopathic Parkinson's disease.
Primary Care Neurology Society	Short	8	19-25	These statements appear to be confusing; they both suggest referral for assessment of MND in progressive limb weakness but in different time frames. It needs to be clarified, because if the GP strongly suspects MND a rapid referral for an early diagnosis should be made.	Thank you for your comment. The Guideline Committee considered that urgent referral for suspected MND should be mandated only if there is evidence of respiratory compromise.
Primary Care Neurology Society	Short	8	19-21	It should explain why those patients with Bell's Palsy should be referred	Thank you for your comments. The explanation for the recommendation is to be found in the recommendations and link to evidence table contained within the full guideline. Detailed explanations are not appropriate in the recommendation itself.
Primary Care Neurology Society	Short	8	27	We don't understand why 'median nerve compression' is not included in this bullet point.	Thank you for your comment. Management of median nerve compression differs from this and is covered in recommendation 1.10.9: *Refer in line with local pathways if symptoms of carpal tunnel syndrome are severe or persistent after initial management*.
Primary Care Neurology Society	Short	9	5-8	There is concern amongst GPs that they will need to have the expertise to make a diagnosis of a functional problem and there will be concern that they are missing something.	Thank you for your comment. Identification of new or persisting symptoms as functional in nature is usually made by a specialist. . However, the recommendations refer to recurrent presentations, and if this occurs in someone with a previous diagnosis of functional neurological disorder it is appropriate to ask GPs to consider whether a further referral is necessary.
Primary Care Neurolo	Short	9-10		Very good, clear guidance	Thank you for your comment.

gy Society					
Primary Care Neurology Society	Short	General	General	The length of the short version of the draft guideline is a little concerning. While we realise the need for the guideline to be comprehensive, to ensure that the we help General Practitioner to engage more in neurology, we would like to suggest a further document is produced in addition to the Short Guideline, which offers 'Key messages'	Thank you for your comment. The Guideline Committee acknowledges the issue you identify, but other stakeholders have criticised us for leaving out some of the potential presentations which would make the guideline longer still. Your comments will be considered by NICE where relevant support activity is being planned.
Royal College of General Practitioners				This guideline risks further disenfranchising patients with Ehlers-Danlos Syndrome and the linked conditions, Mast Cell Activation Syndrome and Autonomic Dysfunction (ref 6) in two key ways. Firstly, there is no mention of these conditions in the guideline, despite evidence that they may well present with neurological features (refs 1-3, 6, 9). Secondly, the guideline places emphasis on recognising what it terms 'functional illness' in order to avoid 'unnecessary' referrals. Patients with the above conditions commonly face an epic diagnostic odyssey. As with many rare diseases, misdiagnosis along the way is frequent, and is associated with a longer time from first symptoms to diagnosis (ref 14). This gap is significantly longer if the misdiagnosis is psychiatric/psychological in nature (ref 4-5). The toxic combination of a lack of awareness of these conditions and a push to designate 'unexplained' symptoms as psychogenic will cause more patients to face an unacceptable delay in receiving the appropriate diagnosis and therefore treatment. This in fact risks wasting more NHS resources than if timely referral and diagnosis were made (unpublished data). The statement repeated several times in the guideline that 'Features suggestive of functional illness include multifocal symptoms, fleeting sensations… a previous diagnosis of functional illness, no neurological signs and normal neuroimaging.' puts patients at risk. There are conditions which have multifocal symptoms, no consistent neurological signs and can have imaging reported as being normal which are not at all psychogenic. By following this instruction, we risk prolonging the time taken for patients to receive a correct diagnosis, since psychological misattribution is associated with a significant increase in the time to correct diagnosis. [Ref 4, 5]. Research published last year revealed one subgroup of such patients who now have a genetic explanation, linked with a complex and apparently non-specific presentation and consistently abnormal blood results (ref 8). It is time we started to acknowledge these conditions as real physiological entities rather than inferring that multifocal and evolving symptoms (found more commonly in female patients) are 'emotional' (Recommendation 31 page 75 of full guideline). For example, Afrin et al. (ref 9) describes the frequency of various symptoms amongst a cohort of patients with MCAS. This shows the following rates with respect to neurological symptoms mentioned in this guideline: presyncope/syncope (71%), headaches (63%), paraesthesia's (58%), cognitive dysfunction (49%) and tremor (13%). Since MCAS is relatively newly discovered and therefore physician awareness is low, patients with MCAS risk being labelled as having functional disorders when in fact they may have a complex immunological/inflammatory condition. Of course, I am not arguing that these patients are best served by referral to a neurologist, simply that in failing to mention MCAS, this guideline misses a prime opportunity to improve awareness and thereby diagnosis of this surprisingly common condition. Hypermobile EDS/Hypermobility Spectrum Disorder is now considered to be a highly prevalent condition, with perhaps as many as 95% of patients remaining undiagnosed. Tinkle et al. note that 'Based on data obtained from a large epidemiological study undertaken on a population of 12,853, 3.4% had joint hypermobility and widespread pain which was been used as a proxy for hEDS' (ref 6). There are a number of neurological manifestations of Ehlers-Danlos Syndrome, some of which may initially seem 'odd' and risk being labelled as 'functional' (ref 1). This would include patients with Chiari Malformation and Spontaneous CSF Leaks, which are commonly missed and about which there is a low level of awareness amongst generalists (ref 6). CSF leaks are particularly debilitating and can feature all manner of symptoms which might easily be thought of as not	Thank you for your comments. The purpose of the guideline was not to identify the causes of each presentation, but to guide practitioners in identifying which patients require referral, and to indicate the appropriate urgency of referral. There are therefore numerous conditions, including those you mention as well as some commoner disorders, which are not mentioned by name. The Guideline Committee agrees that people with rare diseases generally experience a longer time to diagnosis, particularly when the presenting symptoms might be due to other much commoner conditions. It is understandable that evidence for the common diagnoses will be sought first, and for most people this will be the correct approach. The Guideline Committee also agrees that there is a risk of diagnosing functional illness too readily. However, the Guideline Committee recognises that symptoms can have a functional basis and that it is important to identify these cases, since doing so prevents unnecessary referral/investigation, and because it speeds up the delivery of appropriate management to this group of people. There is clearly a tension here between recognition of rare diseases on one hand and functional illness on the other. The guideline tries to balance these, but in order to do so it is necessary to

				representing a standard medical diagnosis. Features change with posture and can vary from day to day (ref 10). However, this condition, if recognised, is amenable to a relatively simple treatment which can be transformative (ref 10). Recommendation 37 refers to CFS and fibromyalgia. We know that these diagnoses are often given to patients who have (undiagnosed) EDS (ref 13). Persistent fatigue is a key feature of hEDS, with 90% of over 40s with the condition describing it (ref 13). The minimisation of the attendant memory and concentration issues and the recommendation not to refer means that patients will miss a further opportunity to reach a correct diagnosis. In particular, these symptoms may represent autonomic dysfunction, which again is easily missed and amenable to successful treatment (ref 4). I personally feel uncomfortable using the label of 'functional illness' too widely, especially where it is specifically described as being 'emotional' in origin. There are too many examples in our collective past, and present, of doctors attributing illnesses to a psychogenic cause simply because we had not yet understood their physical basis. To summarise, at the very least, the guideline should include specific reference to the conditions EDS, Spontaneous CSF Leak, MCAS and Autonomic Dysfunction in order to ensure that patients with these complex and frequently missed conditions are not further disenfranchised by this guideline's references to 'functional illnesses'. 1) Castori M, Voermans NC. Neurological manifestations of Ehlers-Danlos syndrome(s): A review. Iran J Neurol. 2014 Oct 6;13(4):190-208. https://www.ncbi.nlm.nih.gov/pubmed/25632331 2) Castori M, Morlino S, Ghibellini G, Celletti C, Camerota F, Grammatico P. Connective tissue, Ehlers-Danlos syndrome(s), and head and cervical pain. Am J Med Genet C Semin Med Genet. 2015 Mar;169C(1):84-96. doi: 10.1002/ajmg.c.31426. Epub 2015 Feb 5. https://www.ncbi.nlm.nih.gov/pubmed/25655119 3) Henderson FC Sr, Austin C, Benzel E, Bolognese P, Ellenbogen R, Francomano CA, Ireton C, Klinge P, Koby M, Long D, Patel S, Singman EL, Voermans NC. Neurological and spinal manifestations of the Ehlers-Danlos syndromes. Am J Med Genet C Semin Med Genet. 2017 Mar;175(1):195-211. doi: 10.1002/ajmg.c.31549. Epub 2017 Feb 21. https://www.ncbi.nlm.nih.gov/pubmed/28220607 4) http://www.eurordis.org/IMG/pdf/voice_12000_patients/EURORDISCARE_FULLBOOKr.pdf 5) Wilshire, Carolyn & Ward, Tony. (2015). Psychogenic explanations of physical illness: Time to examine the evidence. . 10.13140/RG.2.1.1344.7125. https://www.researchgate.net/publication/283476227_Psychogenic_explanations_of__illness_Time_to_examine_the_evidence 6) Tinkle B, Castori M, Berglund B, Cohen H, Grahame R, Kazkaz H, Levy H. 2017. Hypermobile Ehlers–Danlos syndrome (a.k.a. Ehlers–Danlos syndrome Type III and Ehlers–Danlos syndrome http://onlinelibrary.wiley.com/doi/10.1002/ajmg.c.31538/full 7) Seneviratne SL, Maitland A, Afrin L. 2017. Mast cell disorders in Ehlers–Danlos syndrome. Am J Med Genet Part C Semin Med Genet 175C:226–236. http://onlinelibrary.wiley.com/doi/10.1002/ajmg.c.31555/full 8) Lyons JJ et al. Elevated basal serum tryptase identifies a multisystem disorder associated with increased TPSAB1 copy number http://www.nature.com/ng/journal/v48/n12/full/ng.3696.html	point out the possibility that symptoms may be due to a functional illness.

				9) Characterization of Mast Cell Activation Syndrome Lawrence B Afrin, Sally Self, Jeremiah Menk, John Lazarchick Blood Dec 2016, 128 (22) 3683; http://www.bloodjournal.org/content/128/22/3683 10) Kranz PG1, Malinzak MD2, Amrhein TJ2, Gray L2. Update on the Diagnosis and Treatment of Spontaneous Intracranial Hypotension. Curr Pain Headache Rep. 2017 Aug;21(8):37. doi: 10.1007/s11916-017-0639-3. https://www.ncbi.nlm.nih.gov/pubmed/28755201 11) Ling, H., Braschinsky, M., Taba, P., Lüüs, S.-M., Doherty, K., Hotter, A., Poewe, W. and Lees, A. J. (2011), Decades of delayed diagnosis in 4 levodopa-responsive young-onset monogenetic parkinsonism patients. Mov. Disord., 26: 1337–1340. doi:10.1002/mds.23563 http://onlinelibrary.wiley.com/doi/10.1002/mds.23563/abstract 12) Stone J, Reuber M, Carson A Functional symptoms in neurology: mimics and chameleons Practical Neurology 2013;13:104-113. file:///C:/Users/Emma%20Reinhold/Downloads/Stone%20-%20Functional%20Symptoms%20Mimics%20and%20Chameleons.pdf 13) Hakim A, De Wandele I, O'Callaghan C, Pocinki A, Rowe P. 2017. Chronic fatigue in Ehlers–Danlos syndrome—Hypermobile type. Am J Med Genet Part C Semin Med Genet 175C:175–180. http://onlinelibrary.wiley.com/doi/10.1002/ajmg.c.31542/full 14) Rebecca Nunn “It’s not all in my head!” - The complex relationship between rare diseases and mental health problems Orphanet Journal of Rare Diseases201712:29 https://doi.org/10.1186/s13023-017-0591-7	
Royal College of General Practitioners	Short	11	2	Abnormalities of head and neck posture in primary care will most often be the result of minor injury, or waking with the head in an odd position, and may be linked to moderate anxiety or stress. Is that what the authors mean by the rather label of ‘cervical dystonia? Also what is the predictive value of the odd feature of the symptom improving when the patient touches the chin with their hand?	Thank you for your comments. Dystonia is a condition characterised by more or less fixed abnormalities of posture, commonly of the neck. It is not related to psychological morbidity or stress. The Guideline Committee considered that delay in recognition and referral of cervical dystonia was a significant problem in England and Wales. The guideline is designed to aid GPs in recognising this condition. Please see rationale of the recommendation on cervical dystonia in the full version of the guideline (Rationale 41).
Royal College of General Practitioners	Short	13	1	Odd that the authors should open the section on carpal tunnel with the word ‘Refer’. Here the standard procedure is to give steroid injections at least twice before referral. But in any case, this is a prime candidate for shared decision making.	Thank you for your comment. This recommendation states that referral should usually follow initial management, and is therefore compatible with your comment
Royal College of Genera	Short	17	5	This illustrates particularly well what is wrong with the whole guideline. We all know that essential tremor is benign, and does not need any treatment. We could all, probably, distinguish between essential tremor and Parkinson’s disease. But some GPs may not feel very confident about it, and some patients may want more reassurance than they get from a GP whom they might regard as insufficiently skilled in neurology (‘a high level of competence in neurological examination would not be expected of a generalist’). It is not helpful to say such patients should not be referred.	Thank you for your comments. This is a guideline not a rulebook, and has to be applied to each individual situation, including one where a GP lacks

l Practitioners				Also: why do those with essential tremor of the head need referral? What if the tremor is de Musset's sign?	confidence and may decide to refer anyway. However, in other situations the recommendation may empower a GP who is confident but under pressure from a patient to refer. Please also note that all 'do not refer' recommendations were changed to 'do not routinely refer'. The rationale for the recommendations is provided in the recommendations and link to evidence table within the full guideline. Head tremor can often be readily treated using botulinum toxin, unlike postural tremor of the hands. De Musset's sign would normally trigger a cardiological, rather than a neurological, assessment.
Royal College of General Practitioners	Short	4	19	Dizziness & vertigo This whole section has an air of unreality about it. In primary care the likely causes are acute labyrinthitis, benign paroxysmal positional vertigo, hypoglycaemic episodes (which present usually with other obvious features) and postural hypotension. I would only begin to consider neurological causes if none of these (and some other rarer conditions) were obviously absent. In other words this has been written the wrong way round.	Thank you for your comment. Thank you for your comment. We agree that the commonest causes of vertigo do not require referral to neurology, and the recommendations have been amended to make that clear.' The Guideline Committee agrees that the commonest causes of vertigo do not require referral to neurology. However, the remit of the guideline is to cover referral to neurology, and that is what has been covered..
Royal College of General Practitioners	Short	7	4	GP's may be unaware that abnormalities of gait are a direct consequence of coeliac disease. GPs will check for nutrient deficiency but our understanding is that the mechanisms of neurological disorders associated with coeliac are yet to be elucidated. (	Thank you for your comment. This guideline is a pragmatic one dealing with referral, and does not address the aetiology of neurological conditions.
Royal College of General Practitioners	Short	7	14	Do any patients present with handwriting difficulties as the primary symptom? Come to think of it, does anybody do any handwriting these days?	Thank you for your comment. Yes to both although the Guideline Committee agrees that future versions of the guideline may have to deal with difficulties in texting.

Royal College of General Practitioners	Short & full	General		• What is it for? It says to help primary care physicians and non-neurologists avoid unnecessary referrals and be quicker with those that indicate urgency. But it is unclear that this kind of instruction ('accepted that a high level of competence in neurological examination would not be expected of a generalist') will achieve that. The text says 'It is not intended as a substitute for a textbook…' but that it is exactly how it reads. The committee seems to be unaware of the real position in primary care, when presentations are often much vaguer than presented here and referrals are made by GPs concerned not to miss serious disease. My own experience is that if the features are as clear as they are set out here then the decision whether to refer is very straightforward. If only life were that simple! • I have not looked through every section, but the literature searches have often failed to come up with any evidence, so that a lot of recommendations derive from the experience of the committee members. This limitation is not included in the shortened version, so that anyone who only consults that will be unaware how much rests on the distilled expertise of so-called experts • This in turn gives the guideline an unmistakable feel that it is specialists speaking from their perspective, and there are some examples where the advice betrays this (see below). In addition, there ae several instances where the feel is of specialists telling generalists how to handle problems that the generalists will be more familiar with – most obviously functional and anxiety disorders. **(Please also see the Joint Commisssiong guidance on medically unexplained symptoms. http://www.jcpmh.info/good-services/medically-unexplained-symptoms/**	Thank you for your comments. You are questioning the need for the guideline. We accept that there are those in primary care who find these referral decisions easy, but others do not. The aim of the guideline is to provide some help with the more clear-cut presentations which nevertheless are sometimes inappropriately referred or not referred. Please note that the committee included representation from primary care, and was therefore well informed about the nature of presentations there. The uncertainty around the evidence base is reflected in the wording of the recommendations e.g. 'consider'.
Royal College of Nursing	General	General	General	The Royal College of Nursing welcomes proposals to develop this guideline. The RCN invited members who care for people with neurological conditions to review this document on its behalf. The comments below reflect the views of our members.	Thank you for your response.
Royal College of Nursing	General	General	General	The draft guideline seems comprehensive. We are concerned with how the neurology team will cope with the demands that may potentially arise from the recommendations?	Thank you for your comment. It is hoped that the recommendations will reduce inappropriate referrals and allow neurology services to focus on the appropriate ones.
Royal College of Paediatrics and Child Health			9	Refer according to local pathways as these may include Mental health services for Attentional problems in children *as below re Tics*	Thank you for your comment. The Guideline Committee agrees that 'referral according to local pathways' is the appropriate wording. Mental health services may be the appropriate pathway, but mental health services for children in England are stretched and there could a long wait to be seen. Therefore, community child health would be the first point of referral with onward referral to CAMHS if warranted.
Royal College of Paediatrics and Child Health	10.	23/24 (1.22.1)	25	If referring just to a physio therapist because of hypotonia , agree 'community physio..' suggest state do this via the Child Development Team (so that a link to consideration of cause is readily accessed) *ie if bad enough to refer to physio , still need to consider cause*	Thank you for your comment. The Guideline Committee agrees and has changed this to suggest referral to physiotherapy, through the community paediatric team, for consideration of diagnosis and therapeutic interventions.
Royal College of Paediat		27/28	12	Tics with possible ADHD – refer according to local service pathways (ie as directed locally to Camhs OR Child development) *All ADHD does not need to go to a Paediatric Neuro development service as much ADHD requires a family behavioural emotional approach as part of and after diagnosis (+/- medication) .*	Thank you for your comment. The Guideline Committee agrees that referral to Paediatric Neurology is not

rics and Child Health					applicable to all and that the correct wording is to 'consider' referral.
Royal College of Paediatrics and Child Health		General		A helpful summary. Brief and clearer than some. But need be aware of local variations in service provision, as above, or will generate delays and uncertainties for families if referrals' bounce' back	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned.
Royal College of Paediatrics and Child Health	Short	General	General	The recommendations cover a very wide range of presentations over all ages so this one short document encompasses a wide so many common (and rare) symptoms that it reads like a textbook of paediatrics. There are so many cross references to other NICE documents that it may be difficult to understand or implement in acute primary or secondary care. There are guides as to when and when and where to refer for specialist assessments e.g. paediatrician or paediatric neurologist but also advice to refer for "neurological assessment" without explanation of what that means. A qualified doctor ought to be able to undertake a neurological examination of a child before referring to other services in most of the situations described. The crossover between advice for children and for adults is confusing – for those over 12 yrs – as is reference to other NICE guidelines. The evidence base in the Full document is very slim and there were few paediatricians on the committee to provide consensus advice.	Thank you for your comments. The Guideline Committee acknowledges that the guidance covers a lot of ground, but have tried to focus only on the need for referral. Most of the cross references are for further information. We agree that the evidence base is regrettably thin.
Royal College of Paediatrics and Child Health	Short summary	Page 18 (1.16.1)	7	Mild lack of clarity: Refers to a child with both memory loss AND attentional problems? or either ? The text suggests this means either	Thank you for your comment. The Guideline Committee has amended the conjunction to 'or' to clarify the meaning of the recommendation.
Royal College of Pathologists	11.	12.	13.	I do wonder about the order in which these recommendations have been listed - in a document relating to clinical excellence it does seem a little odd, from a patient safety perspective, to start recommendations with guidelines on when not to refer - I would have thought it wiser to start with "refer immediately" etc.	Thank you for your comment. The Guideline Committee has reordered the recommendations to reflect urgency and frequency of presentation.
Royal College of Psychiatrists	Short	12	21	Although a functional disorder may not need referral (to neurology), there should be advice to refer to mental health services if the disorder does not resolve	Thank you for your comment. Referral to services other than Neurology is outside the scope of this guideline.
Royal College of Psychiatrists	Short	6	4	As phrased, this statement risks excluding people with anxiety disorders from physical assessment. We suggest removing 'with dizziness and an anxiety disorder' and just referring to where a functional disorder is likely.	Thank you for your comment. This recommendation does not preclude referral for assessment of those with anxiety disorders.
Royal College of Psychiatrists	Short	9	9	Although a functional disorder may not need referral (to neurology), there should be advice to refer to mental health services if the disorder does not resolve or is recurrent. A functional disorder history itself should not preclude referral – it is the neurology at the time.	Thank you for your comment. Referral to services other than Neurology is outside the scope of this guideline. .

Royal College of Psychiatrists	Short	9	27	We suggest changing 'affective disorders' to 'depression' for clarity	Thank you for your comment. The Guideline Committee considered the term 'Depression' was too specific. The recommendation refers to the broader category of affective disorders.
Royal College of Psychiatrists	Short	General		Several symptoms have advice not to refer if a likely functional disorder. It may be more useful to include one overarching recommendation that for many neurological symptoms, an underlying functional disorder is possible. In such cases, specialist mental health, ideally Liaison Psychiatry, assessment is indicated where symptoms persist, are recurrent or associated with significant mental health history or mental state abnormality. Milder disorders may meet criteria for IAPT.	Thank you for your comment. The Guideline Committee has considered this but it would be difficult to place such a recommendation appropriately within the guideline, unless we repeated it in several places which would defeat the object. Management of functional neurological disorders and other functional symptoms is beyond the scope of this guideline.
Royal College of Speech and Language Therapists	Full	95	Section 5.12	We notice that this section and the accompanying recommendation make no mention of a referral to speech and language Therapy. Unlike section 7.13 'speech problems in children' which does make a specific recommendation for referral to speech and language therapy. Speech problems in adults impact on communication and can lead to social isolation and reduced participation and wellbeing. Speech problems can also impact on a person's employment and leisure activities and lead to job loss. We suggest an additional recommendation of referral to a speech and language therapist specialising in adult neurology, who can assist with the diagnostic process and provide appropriate support, management and information. The evidence to support this can be found in other NICE guidelines such as: 1. Parkinson's disease in adults NICE guideline [NG71] Published: July 2017 Recommendation 1.7.7 'Consider referring people who are in the early stages of Parkinson's disease to a speech and language therapist with experience of Parkinson's disease for assessment, education and advice. [2017]' 2. Motor neurone disease: assessment and management NICE guideline [NG42] Published: February 2016 '1.11.1 When assessing speech and communication needs during multidisciplinary team assessments and other appointments, discuss face to face and remote communication, for example, using the telephone, email, the Internet and social media. Ensure that the assessment and review is carried out by a speech and language therapist without delay. [new 2016]'	Thank you for your comment. The recommendation in children is based on poor speech development. This does not apply in adults where the problem will be loss, or alteration, of speech. The Guideline Committee agrees that speech therapy is important, but the main purpose of this guideline is to help decide whether a neurology referral is required for diagnosis of the cause of the speech problem.
Royal College of Speech and Language Therapists	Full	general	General	We notice there is no mention in the guideline of the symptom of swallowing difficulties / dysphagia which may indicate onset of a neurological problem and therefore requires full investigation including referral to speech and language therapy.	Thank you for your comment. The guideline was necessarily limited in scope and had to concentrate on areas where practice was variable or unsatisfactory. The Guideline Committee recognised that swallowing difficulties are often significant and require onward referral, but decided that for the most part current practice is satisfactory. We have added swallowing difficulties to the recommendations on motor neurone disease :

					1.7.5 Refer adults with slowly (within weeks to months) progressive limb weakness for neurological assessment in line with the recommendations on recognition and referral in the NICE guideline on motor neurone disease. Referral should be urgent if there is any evidence of swallowing impairment or respiratory compromise (breathlessness, breathlessness lying flat, morning headache or recurrent chest infections). 1.11.2 Refer adults with progressive slurred or disrupted speech to have an assessment for motor neurone disease, in line with the recommendations on recognition and referral in the NICE guideline on motor neurone disease. Referral should be urgent if there is any evidence of swallowing impairment or respiratory compromise (breathlessness, breathlessness lying flat, morning headache or recurrent chest infections).
Royal College of Speech and Language Therapists	Short version	15	5- 25	As above. The RCSLT notice that no reference is made to referral to speech and language therapy for adults over 16 years. We feel it would be appropriate to include 'Referral to Speech and language Therapy for assistance with the diagnostic process and support for the person with speech problems including assessment treatment and information to support management'.	Thank you for your comment. The Guideline Committee considered that referral for speech and language therapy would not normally be expected to take place before Neurological referral.
Society and College of Radiographers	Full	105	6.2	Recommendation 85 – DVLA and disclosure to employer: The Society and College of Radiographers recognises and accepts that all HCP's have a duty to inform and signpost people with neurological conditions to seek advice from the DVLA as part of their professional responsibilities.	Thank you for your comment.
Society and College of Radiographers	Full	57,58	5.2.1.5 1	Recommendation 4 - Isolated dizziness: The Society and College of Radiographers welcomes advice leading to the reduction of inappropriate referrals to neurology services and would hope that the same criteria is applied to direct referral to neuroimaging.	Thank you for your comment.
Society and	Full	58	5.2.1.5 1	Recommendation 7 - Recurrent dizziness as a feature of functional disorder: The Society and College of Radiographers welcomes the inclusion of additional features of functional disorders in people who present with recurrent dizziness to further inform healthcare professionals (HCP's) involved	Thank you for your comment.

College of Radiographers				with the referral and justification of neuroimaging requests. The Society and College of Radiographers agree that this may reduce inappropriate imaging involving both ionising and non-ionising radiation.	
Society and College of Radiographers	Full	62	5.2.2.5	Recommendation 10 - For adults with sudden-onset acute vestibular syndrome : The Society and College of Radiographers recognises that the standard of training of HCP's in the use and outcomes of the (head-impulse– nystagmus–test-of-skew) HINTS test is likely to have a direct impact on the referral rate for magnetic resonance imaging (MRI) imaging. In addition to this the number and distribution of suitably trained HCP's is likely to affect regional referral rates to MRI services. The Society and College of Radiographers also recognise a potential knock on effect to Computed Tomography (CT) services in areas where MRI may be unavailable.	Thank you for your comment.
Society and College of Radiographers	Full	68	5.4.14	Recommendation 16 – Rapidly progressive unsteadiness of gait: The Society and College of Radiographers supports the recommendation for referral to specialist services rather than non-specialists undertaking investigative tests. This would help to keep the radiation burden to the population as low as reasonably practicable and may result in speeding up access to more target neuroimaging where appropriate.	Thank you for your comment.
Society and College of Radiographers	Full	78	5.7.1.1 1	Recommendation 35 – Adults under 50: The Society and College of Radiographers accept the evidence that Neurodegenerative disorders affecting memory are rare in those under 50. The Society and College of Radiographers also accept the criteria indicating that neurological referral would not be appropriate for concentration difficulties alone. We would therefore like to highlight the particular significance of incidental abnormal structural appearances on neuroimaging in this age group.	Thank you for your comment. This is outside the scope of the guideline.
Society and College of Radiographers	Full	79	5.7.1.1 1	Recommendation 40– Recurrent episodes of dense amnesia: The Society and College of Radiographers welcomes positive measures to raise awareness of transient global amnesia (TGA) being a clinical diagnosis which does not require investigation or treatment in addition to recommendations against referral.	Thank you for your comment.
Society and College of Radiographers	Full	93	5.11.14	Recommendation 65 – Sudden-onset distortion of sense of smell or taste: The Society and College of Radiographers welcomes measure to address the issue of excessive imaging and referral for this symptom with improved communication and education.	Thank you for your comment.
Society and College of Radiographers	Full	96	5.12.14	Recommendation 70 – Sudden onset of speech disturbance: The Society and College of Radiographers suggests that the reference to The NICE stroke guideline (CG58) Prostate cancer: diagnosis and treatment, should read **(CG68)** Stroke and transient ischaemic attack in over 16s: diagnosis and initial management.	Thank you for your comment. The Guideline Committee has amended the reference to the Stroke guideline.

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Society and College of Radiographers	Full	general	general	Throughout the document, cost effectiveness criteria are assessed in relation to referral to neurologists. It would appear that no account is made of the impact and costs of direct referral to neuroimaging services. Where improved education leads to a reduction in inappropriate referrals, imaging costs may be reduced but more significantly, waiting times for appropriate referrals may also be reduced. This could lead to people receiving earlier treatment and benefitting from improved outcomes.	Thank you for your comment. The Guideline Committee agrees with your point. However, in this instance, it would not have made any difference to the recommendations since consideration of the impact on waiting times would only have enhanced the already satisfactory cost-effectiveness.
SUDEP Action	Short	10	16	The phrase 'do not' is used frequently throughout this document, which may not be the most helpful of phrasing to use in order to help encourage clinicians to value the guideline and use it to help change their practice. Instead could it not become a positive phrasing to give clear steering on when action *should* be taken? E.g.: Refer adults if…	Thank you for your comment. The guideline is intended to include both situations i.e. when referral is appropriate and when it is not. Recommendations to refer already appear much more than not to refer. Also please note that the 'do not refer' recommendations have been changed to 'do not routinely refer'.
SUDEP Action	Short	14	16-18	A concern here is that Clinicians, who are already short on time, are unlikely to refer to 2 sets of guideline documents regarding a neurological condition such as epilepsy; particularly if they have low knowledge of the condition and in particular of the importance of a swift diagnosis/referral to specialists. This could also cause confusion where in some places when discussing epilepsy, they are referred to the TLOC guidelines, and in other places the Epilepsy guidelines (pg4, lines 13-14 for example).	Thank you for your response. The Guideline Committee acknowledges this point, but equally there is the potential for significant confusion if multiple guidelines, which are up-dated at different times, deal separately with the same management issue. Referring across guidelines is much easier with suitable electronic linkage. Your comments will be considered by NICE where relevant support activity is being planned.
SUDEP Action	Short	18	15-16	This statement reads a little ambiguous – does it imply that for children already with an epilepsy diagnosis/on AEDs presenting with a suspected additional neurological condition that Clinicians should take into account concentration and memory issues could be a side effect & not the presences of a co-morbidity? Could it also cause non-specialist clinicians to act with caution in prescribing AEDs due to these noted potential side effects?	Thank you for your comment. It is intended to make them think carefully about drug effects. Before referring, review of potential side effects would be considered good clinical practice.
SUDEP Action	Short	29	3	It would be useful if the resource page contained a list of neurological charities that also provide advice and support both to clinicians and to patients. If such a list already exists, it would be worth checking this is up to date. Organisations such as the Neurological Alliance could possibly help with this. Any information regarding providing information to patients suspected of having a neurological condition should signpost them to relevant Neurology third sector organisations. In the case of the clinician suspecting an epilepsy diagnosis, the patient should be provided with epilepsy risk and safety information *prior to referral* in order to support them and their family in reducing their risks and helping to keep them safe before their specialist appointment, as we know from our bereaved families and via the Epilepsy Deaths Register that in some cases people have died before this appointment arrives or a diagnosis is made, and opportunities are potentially missed to reduce risks before their death which might have changed	Thank you for your comments. NICE guidelines cannot refer to information provided by third party organisations. If there are specific pieces of information which you would like to be highlighted, these could be considered separately by referring them to the NICE endorsement programme:

				their outcome. This need to provide risk information early is supported by research which highlighted that in a retrospective study, 80% of people who had been diagnosed with epilepsy saw a worsening in seizures in the 3-6 months prior to death, with 90% not being engaged with health professionals to support them in their risk management (Shankar, 2014).	https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
SUDEP Action	Short	29-30	24-23	We welcome this section on helping Clinicians to put the guideline into practice as the implementation of guidelines into clinical practice is vital for change to be made in the care of people with neurological conditions.	Thank you for your comment.
SUDEP Action	Short	31	1	This section helps set the scene for the guideline, however could go further in showing the burden of Neurological conditions, and the urgency in quick/accurate diagnosis of suspected neurological conditions. For example*, It is thought there are over 12.5 million people living with a Neurological Condition in the UK, equating for approximately 59,000 per CCG. (*Neurological Alliance*, 2017). This compares to 7 million living with Cardiovascular Disease, or 5 million with Diabetes (British Heart Foundation and Diabetes UK).* Public Health England/The Neurology Intelligence Network are also shortly due to publish a report on Neurology Mortality, showing a significant number of UK deaths each year (compared to other Long-Term Conditions), and highlighting how many deaths are avoidable if steps are put in place to support the patient, particularly in the case of Epilepsy). So, there is likely to be some striking statistics available here to show to clinicians reading the guideline why suspected neurological conditions should be taken seriously, and referred quickly by clinicians who are first presented with a patient with symptoms.	Thank you for your comments. The Guideline Committee agrees about the importance of neurological conditions and this is outlined in the introduction and is part of the rationale for producing this document. NICE guidelines cannot refer to information provided by third party organisations.
SUDEP Action	short	4	4-8	We know that some clinicians who are not specialised in neurological conditions may lack confidence/awareness in when to refer patients with suspected conditions for further assessment – so this specificity outline here is helpful compared to other guidelines where this is lacking or ambiguous. At SUDEP Action we know from our Epilepsy Deaths Register (www.epilepsydeathsregister.org) and from our Support Service, the importance of swift referral with regards to suspected Epilepsy, as delayed diagnosis, in the case of many of the families we support, can lead to the patient dying before an accurate diagnosis is made, or even specialist appointment is received. With over 1200 epilepsy-related deaths each year in the UK, and 50% of these being SUDEP, Sudden Unexpected Death in Epilepsy (Thurman 2015) it is vital the people with suspected epilepsy have access/referral to specialist services for diagnosis, treatment, information and management of the condition as quickly as possible. 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 is clearly the main thrust of this guideline, and it is important that clinicians are given such guidance in a way that does not require them to access multiple additional documents or guidelines.	Thank you for your comments.
Teva UK	Full version	General	General	Suggest Headache (also Episodic & Chronic Migraine) is added to **5 Part 1: Adults aged over 16 – signs, symptoms and investigative tests** We are concerned that this recommendation may imply that Headache in Adults is not a significant symptom.	Thank you for your comment. A recommendation on headache has been added which refers to the NICE headache guideline.
Teva UK	Short version	General	General	We are concerned that this recommendation may imply that Headache in Adults is not a significant symptom.	Thank you for your comment. The Guideline Committee has added a recommendation concerning headache to the guideline.
The Brain Tumour Charity and the Children's Brain Tumour Research	Full	13	22-25	**Recommendation 26: Limb or fatal weakness in adults** *"Refer urgently adults with rapidly (within hours to days) progressive weakness of a single limb or hemiparesis for investigation, including neuroimaging, in line with the recommendation on brain or central nervous system cancers in adults in adults in the NICE Guideline on Suspected Cancer."* We support the inclusion of this recommendation.	Thank you for your response.

Centre, University of Nottingham					
The Brain Tumour Charity and the Children's Brain Tumour Research Centre, University of Nottingham	Full	19	1-8	**Recommendations 84-85: Information and support** *"Advise adults with suspected neurological conditions to:* • *Check the Government's information on driving with medical conditions to find out whether they might have a condition that needs to be notified to the DVLA* • *Consider telling their employer, school or college if their symptoms might affect their ability to work or study."* We think that recommendations 84 and 85 are too stringent, as individuals only have a legal obligation to inform the DVLA when they have received a diagnosis of a neurological condition. Given that many of the symptoms that can suggest a brain tumour are common to other, more mild conditions, the risk is that these recommendations would cause unnecessary anxiety to patients when presenting with symptoms to healthcare professionals. There are some discrepancies on this issue, which these recommendations do not take into account. For example, if you had a brain tumour as a child, but have not had any recurrence of the tumour since and do not have epilepsy as a result of your brain tumour, you should be able to have a driving licence. We recommend that healthcare professionals signpost to The Brain Tumour Charity's information resource on this topic, "Driving and Brain Tumours" , which provides information about when individuals have to inform the DVLA about their brain tumour diagnosis and how to do this.	Thank you for your comments. The Guideline Committee does not agree that the recommendation is stringent. It says that informing an employer should be considered if symptoms are affecting the ability to work. Whether this is done or not will depend on the particular circumstances of each person. In relation to the DVLA the recommendations also suggests checking whether the DVLA should be informed, which is a reasonable suggestion given that safety concerns must be paramount. It does not mandate contacting the DVLA pre-diagnosis.
The Brain Tumour Charity and the Children's Brain Tumour Research Centre, University of Nottingham	Full	20	10-11	**Recommendation 98: Dizziness and vertigo in children** *"Be aware that isolated dizziness in children is unlikely to be a symptom of a brain tumour if there are no accompanying symptoms or signs."* Whilst the rationale for this recommendation cites NICE's Guidance on Referral of Suspected Cancer when it comes to accompanying symptoms, we believe it should reference the symptoms of a brain tumour in children, teenagers and young people that are cited in the HeadSmart Clinical Guideline. This is particularly important given the concerns expressed by the Children's Cancer and Leukaemia Group (CCLG) about the use of primary care evidence in the Guidance on Referral for Suspected Cancer, of which there is little for childhood cancers.	Thank you for your comment. The Guideline Committee agrees that recognition of brain tumours in children is of the utmost importance. Unfortunately we cannot refer directly to guidelines devised by third parties.
The Brain Tumour Charity and the Children's Brain Tumour	Full	20	27-42	**Recommendations 103-104: Headache** Recommendation 103: *"Refer children aged under 12 years with headache immediately for same-day assessment, according to local pathways, if they have any one of the following:* • *Headache that wakes them at night* • *Headache that is present on awakening in the morning* • *Headache that progressively worsens* • *Headache associated with vomiting* • *Headache associated with ataxia* • *Headache associated with squint or failure of upward gaze ("sunsetting")*	Thank you for your comments. The Guideline Committee has expanded this recommendation, although not exactly as you suggest. This is a guideline for referral to neurology, not to other services.

Research Centre, University of Nottingham				Recommendation 104: *"Refer urgently all children aged under 4 years with headache for neurological assessment."* We support the inclusion of "Headache associated with vomiting" within Recommendation 103, as this is one of the accompanying symptoms for headache that is included in the HeadSmart Clinical Guideline, which could suggest a brain tumour. Recommendation 103 could be strengthened by including *"Headache associated with confusion/disorientation/reduced consciousness/pervasive lethargy,"* and other symptoms included in the HeadSmart Clinical Guideline. Recommendation 104 could be strengthened by the inclusion of one of the Delphi process statements in the HeadSmart clinical guideline that: "In a child with a known migraine or tension headache a change in the nature of the headache requires reassessment and review of the diagnosis." We also support the inclusion of the recommendation in the HeadSmart clinical guideline that CNS imaging is required for: • Persistent headaches that wake a child from sleep • Persistent headaches that occur on waking • A persistent headache occurring at any time in a child younger than 4 years	
The Brain Tumour Charity and the Children's Brain Tumour Research Centre, University of Nottingham	Full	21-22	16-44; 1-21	**Recommendations 110-115: Head shape or size abnormalities** *Recommendation 110: For all children under 4 years with suspected abnormal head shape or size:* • *Take 3 consecutive measurements of the child's head circumference at the same appointment, using a disposable paper tape measure* • *Plot the longest of the 3 measurements on a standardised growth chart, corrected for gestational age* • *If the child's head circumference is below the 2nd centile, refer for paediatric assessment* Recommendation 110 could be reinforced by reference to the research behind the HeadSmart clinical guideline found that based on 17 studies, increased head circumference/macrocephaly ranked as the most common symptom (21%) of children with intracranial tumours under 4 years. These recommendations could be strengthened by the inclusion of a number of recommendations in the HeadSmart clinical guideline: • CNS imaging, which is required for: an increasing head circumference (crossing centiles) with 1 or more other symptoms/signs associated with a brain tumour (i.e. headache, nausea/vomiting, visual symptoms, motor symptoms, endocrine or growth symptoms, behavioural change. • Young children under the age of 2 who may not be able to communicate other symptoms of raised intracranial pressure should have their head circumference measured, plotted and compared with previous measurements.	Thank you for your comments**.** The following recommendation covers the child with increasing head size and potential brain tumour who should be referred urgently: *For children with a head circumference measurement that differs by 2 or more centile lines from a previous measurement on a standardised growth chart (for example, an increase from the 25th to the 75th centile, or a decrease from the 50th to the 9th centile):* • *refer to paediatric services for assessment and cranial imaging to exclude progressive hydrocephalus or microcephaly or* • *refer urgently to paediatric services if the child also has any of the following signs or symptoms of raised intracranial pressure:* *-tense fontanelle* *-sixth nerve palsy* *-failure of upward gaze ('sunsetting')* *-vomiting* *-unsteadiness (ataxia)* *-headache.* Please also note NICE guidelines cannot refer to recommendations from non-NICE guidelines.

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The Brain Tumour Charity and the Children's Brain Tumour Research Centre, University of Nottingham	Full	22-23	43-44; 1-14	**Recommendations 121-123: Motor development delay and unsteadiness** *Recommendation 121 – "Refer immediately children with new onset gait abnormality to acute paediatric services."* Recommendation 121 should be strengthened by reference to the recommendation in the HeadSmart Clinical Guideline, which advises that CNS imaging is required when there is: • Regression in motor skills, **abnormal gait/co-ordination with no other cause**, focal motor weakness, swallowing difficulties with no local cause, abnormal head position Abnormal gait and co-ordination occurred in up to 78% of patients and focal motor abnormalities in up to 19%. These recommendations could be strengthened by including a reference to the Brain/CNS tumours in Children and Young People recommendation of the NICE Suspected Cancer Guideline, which recommends very urgent referral for unsteadiness and incoordination of limbs and abnormal gait: *"Consider a very urgent referral (for an appointment within 48 hours) for suspected brain or central nervous system cancer in children and young people with newly abnormal cerebellar or other central neurological function."*	Thank you for your comments. The Guideline Committee has covered this comprehensively in the guideline in separate recommendations in the Motor development delay and unsteadiness section Unfortunately the Committee cannot refer directly to guidelines devised by third parties.
The Brain Tumour Charity and the Children's Brain Tumour Research Centre, University of Nottingham	Full	23	16-17	**Recommendation 124: Posture distortion in children** Recommendation 124 – *"In children with abnormal neck posture, check whether painful cervical lymphadenopathy is the cause."* Recommendation 124 could be strengthened by adding that where children present with abnormal neck posture, a visual assessment is needed to check for symptoms which may suggest a brain tumour.	Thank you for your comment. The possibility of abnormal head posture being due to a brain tumour is covered in a separate recommendation in this section.
The Brain Tumour Charity and the Children's Brain Tumour Research Centre, University of	Full	24	38-44	**Recommendations 145-147: Squint** Recommendation 145 – *"Refer children immediately to acute paediatric services if new-onset squint occurs together with ataxia, vomiting or headache, in line with the recommendation on brain and CNS cancers in children and young people in the NICE guideline on suspected cancer."* Recommendation 145 could be strengthened by the alignment with the HeadSmart clinical guideline, where a Delphi panel concluded that whilst children with a concomitant squint required early assessment, this should be in the first instance by an ophthalmologist who could then determine the need for CNS imaging. In addition, the Clinical Guideline notes that CNS imaging is required for the following symptoms: • **Papilloedema** – this symptom may be due to raised intracranial pressure, the causes of which include a brain tumour. In the development of the HeadSmart Clinical Guideline, the Delphi panel agreed that the presence of papilloedema increases the likelihood of an underlying CNS lesion, including a brain tumour, to such an extent that CNS imaging is required even in the absence of other symptoms and signs.	Thank you for your comments. The recommendation refers to the child with squint and ataxia, vomiting or headache. This child should go to a service that can do urgent neurological assessment and imaging. A child with squint alone can see an ophthalmologist first.

Nottingham				• **Optic atrophy** – this symptom may be due to a brain tumour involving the optic pathway. In the development of the HeadSmart Clinical Guideline, the Delphi panel agreed that the presence of optic atrophy increased the likelihood of an underlying CNS lesion, including a brain tumour, to such an extent that CNS imaging is required even in the absence of other signs and symptoms. • **New onset nystagmus** – In the development of the HeadSmart Clinical Guideline, the Delphi panel agreed that CNS imaging was required for the presentation of new onset nystagmus, even where there was an absence of other symptoms and signs. • **Reduction in visual acuity not attributable to an ocular cause –** in the development of the HeadSmart Guideline, the Delphi Panel agreed that even in the absence of other symptoms and aligns a reduction in visual acuity increased the likelihood of an underlying CNS tumour to such an extent that CNS imaging is required. • **Proptosis –** the HeadSmart clinical guideline highlighted that a recent series of children with proptosis showed that over a third had malignant disease and 14% had an optic pathway tumour.	
The Migraine Trust	Full	General	General	The aim of the new NICE guideline on suspected neurological conditions must to be to clearly signpost the correct information to ensure that improvements of care happen for ALL neurological patients, including those with headache. Better management in primary care is essential and for this reason we urge NICE to include headache as a symptom within this new guideline.	Thank you for your comment. The Guideline Committee has added a cross-reference to the Headaches guideline to the recommendations in the Adults chapter of the guideline.
The Migraine Trust	Full	General	General	**Headache omission from the NICE guideline on suspected neurological conditions** A glaring omission in the draft guidance for adults over 16 is headache as a symptom. For this guideline to be practically useful, we strongly urge NICE to include headache as a separate recommendation for adults over 16. 14. As an absolute minimum the new guideline must include the following section: 15. *Headaches in Adults* *For recommendations in headache for those over the age of 12 see the NICE guideline on headaches in over 12s.* 16. Evidence base 5. Headache affects around one in seven adults. 17. 6. Headache is a special case given it is an area in which the neurology pathway could become more efficient with appropriate detection and referral. 18. 7. Headache accounts for a significant workload burden in neurology outpatient; around one third of adult neurology appointments are for headache; many of these cases can and should be managed in primary care. 19.	Thank you for your comments. The Guideline Committee have added a cross-reference to the Headaches guideline to the recommendations in the Adults chapter of the guideline.

				8. In Oxford, the following research has shown: • At the Oxford CCG-commissioned Oxford University Hospitals NHS Foundation Trust (OUHFT), general neurology outpatient department activity was 10,218 appointments contacts in the financial year 2015/16. 4,086 (40%) of these were new referrals[1]. This includes referrals from non-GP sources (such as consultant-to-consultant, and A&E outpatient referrals). • Headache is a significant burden on outpatient neurology service s. It is difficult to definitively state the true burden of headache in secondary care because outpatient activity is not coded for disease. However, the Oxford research has shown: o Choose & Book GP referrals to general neurology outpatient: the reason for referral is coded in 48% of referrals, and headache accounts for 48% of these coded referrals (Figure 2). o An internal audit of rapid access clinic referrals at OUHFT showed that 48% of all referrals were for headache (Figure 2). o Nationally, we know that headache referrals to neurology outpatient account for more than 25% of all referrals[2]. o Internal audit within the OUHFT general neurology outpatient has shown that they receive approximately 90 GP and other clinician referrals alone for headache per month (1,104 per annum) o The follow-up rate within the OUHFT general neurology outpatient clinic is 98%[3]. 20. In summary, neurology clinics are over-burdened with headache presentations, many of which would be more appropriately managed elsewhere. It is estimated that general neurology only needs to see 18% of the headache referrals being sent to it. 50% could be managed in the community), 6% could be managed with MRI without appointment, and 10% could be managed with advice directly back to the referrer. Improving triage of headache referrals centrally and making community headache clinics and MRI-without-appointment available has the potential to improve neurology outpatient capacity for other neurological conditions and reduce waiting times. 21. [1] OUHFT Neurosciences Data Extrapolated from 10 months of 2015-16 SLAM Data for all of Neurology. 10m data is: 8,515 total contacts, of which 3,369 first attends (which includes 356 non-consultant FAs). [2] Patterson & Esmonde (1993); Sender J (2004) [3] OUHFT Neurology Outpatient Activities in 2015-16 for OCCG Outpatient (SUS Data) 4World Health Organization. Headache disorders. Fact sheet no.277, 2012. 5 Neurological Alliance 'Parity of esteem for people affected by neurological conditions.' 2017 22. 23.	
The Neuro Foundation tion	General	General	General	Unfortunately there are no dedicated guidelines for neurofibromatosis (NF) on the NICE website. Placing the term "neurofibromatosis" into the search engine for the neurology guideline links with just autism and with EOS2D/3D imaging only. This is a major deficiency as neurofibromatosis is common and often presents initially to a neurologist.	Thank you for your comment. The guideline is designed to facilitate recognition and referral of neurological conditions, rather than as a diagnostic tool for individual diseases. Reference

					to specific conditions is therefore minimised throughout.
The Neuro Foundation	General	General	General	**Neurology & Neurofibromatosis** The neurofibromatoses are inherited conditions that have a major impact on the nervous system and predispose to benign and malignant tumour formation. Although NF2 and schwannomata's are rare disorders (birth incidence 1 in 33,000 and 1 in 50,000), they cause significant morbidity and NF1 is a common multi-system condition occurring in between 1 in 2,000-2,500 births with a prevalence of 1 in 3-4,000. The hallmark of NF1 is the neurofibroma, a peripheral nerve sheath tumour. The management of neurological complications in NF1 frequently differs from the general population.	Thank you for your comment.
The Neuro Foundation	General	General	General	**Neurological problems associated with neurofibromatosis 1 (NF1) include** • Central nervous system tumours (optic pathway glioma and brain and spine glioma, dysembyroplastic neuroepithelial tumour) • Malignant peripheral nerve sheath tumour • Cerebrovascular disease including stenosis, haemorrhage and aneurysm formation • Multiple sclerosis • Epilepsy • Cognitive and behavioural impairment (specific learning problems, impaired executive function, autism, attention deficit hyperactivity disorder) • Distal symmetrical sensorimotor axonal neuropathy As a secondary consequence of: • Malformations of the brain (aqueduct stenosis), skull (sphenoid wing dysplasia) and skeleton (kyphoscoliosis) Neurofibromas causing pressure on peripheral nerves, spinal nerves or the spinal cord	Thank you for your comment. The guideline is designed to facilitate recognition and referral of neurological conditions, rather than as a diagnostic tool for individual diseases. Reference to specific conditions is therefore minimised throughout.
The Neuro Foundation	General	General	General	**NF2** is associated with bilateral vestibular, cranial, spinal and peripheral nerve schwannomas. Brain or spinal meningiomas, ependymoma and glioma occur and amyotrophy, mononeuropathy of the facial nerve and distal sensorimotor axonal neuropathy are also encountered. NF2 often presents to a paediatric neurologist with mononeuropathy, epilepsy or focal neurological loss.	Thank you for your comment. The guideline is designed to facilitate recognition and referral of neurological conditions, rather than as a diagnostic tool for individual diseases. Reference to specific conditions is therefore minimised throughout.
The Neuro Foundation	General	General	General	**Schwannomatosis** is characterised by multiple, frequently painful schwannomas that do not usually involve the vestibular nerve.	Thank you for your comment. The guideline is designed to facilitate recognition and referral of neurological conditions, rather than as a diagnostic tool for individual diseases. Reference to specific conditions is therefore minimised throughout.
The Neurological Alliance	Appendices	General	General	We note that many appendices are empty and assume this is due to inadequate evidence. This is indicative of a broader issue in neurosciences in that investment in research is inadequate meaning evidence of 'what works' is sparse, particularly for rarer conditions, and particularly in primary care settings. In some cases, this is also due to lack of service infrastructure to support research. One example of this is the lack of research into adults with Duchenne Muscular Dystrophy. This is clearly an issue for NIHR and other bodies than NICE. However, NICE's focus on what is deemed 'high quality evidence' hampers development of neurological guidance. For many rarer conditions double blind randomised controlled trials are not only unethical, but also impracticable, given the small pool of patients that are potential participants for such research. We would urge NICE to more widely adopt a consensus based approach to what is deemed adequate evidence.	Thank you for your comment and for highlighting the issues around research in neuroscience. However, the reason there wasn't much evidence included in this guideline was not due to the fact that the Guideline Committee had restricted their searches to high quality randomised trials, but to the fact that there was no evidence that specifically answered our clinical questions. The type of study design we look for depends on the type of question being asked. In this guideline we were mainly looking for clinical prediction studies

					with multivariate analyses that accounted for at least some of the key confounders identified by the committee. This would provide evidence that the association of specific signs and symptoms for example headaches with dizziness is indicative of a specific neurological condition. Unfortunately, there was a lack of such evidence and therefore not many studies were included in the guideline.
The Neurological Alliance	Full	67	1-30	Section 5.4, 'Gait unsteadiness', refers to a number of specific neurological conditions for investigation in relation to unsteadiness of gait. The NICE MND Guideline (NG42) notes that "MND causes progressive muscular weakness that can present as isolated and unexplained symptoms", including "loss of dexterity, falls or trips" (p.5), yet MND is not covered here.	Thank you for your comment. The guideline is not intended to provide comprehensive information about particular conditions. It is a guide only to the need for referral. Moreover, there is a separate NICE guideline on MND (NG42)
The Neurological Alliance	Full	72-73	4	We are concerned that in many places the Guideline refers to one or two conditions in relation to specific symptoms – often without obvious logic as to why some very rare conditions are included but not other more common conditions. This may delay appropriate referral of a patient. For example, in relation to recommendations 26, 27 and 33 – all three signs and symptoms could be indicative of a rarer condition such as Transverse Myelitis. Other examples are outlined below.	Thank you for your comment. The Guideline Committee has revised the recommendations and link to evidence tables to rationalise the references to rarer conditions.
The Neurological Alliance	Full version	104	16	Getting timely information and support is very important to people affected by neurological conditions yet our recent patient experience survey found 45% of patients were dissatisfied with information they had received about their condition, 63% were dissatisfied with information they had received about sources of emotional support, and 53% dissatisfied with information they had received about third sector support available. (See *Falling Short, Neurological Alliance, 2017)* The only advice the Guideline recommends is to check the DVLA notification guidelines and to consider telling their employer, school or college. We are concerned with both of these pieces of advice being given in isolation to additional information and support. • Telling an employer, school or college about a suspected neurological condition can have huge implications for individual patients and it may not always be appropriate to do so before a diagnosis has been confirmed. Indeed, until diagnosis is confirmed, patients/employees do not have legal protection under the Equality Act 2010. Patients will often benefit from additional support in informing an employer or education institution, and patient organisations – such as Neurological Alliance member charities – provide a wealth of support and information in areas such as this. Patients must be made aware of this broader support in parallel to being advised to consider telling an employer or education institution about a suspected neurological condition. • Similarly, while safety concerns are paramount in relation to DVLA notification, surrendering a driving license can have a huge impact on an individual's life, for which they may benefit from additional support – and indeed signposting to financial support that may be available to help with alternative transport. Again, third sector organisations are ideally placed to provide such support. See for example Epilepsy Action's advice and information about driving and epilepsy. We welcome the inclusion here of the principles in the NICE Guideline on Patient Experience in Adult NHS Services. Yet, without specific reference to the importance of information and an individualised approach to services in the neurological conditions guideline, we feel GPs may miss the opportunity to sign post patients to information, helplines and support groups available. The committee notes that it was concerned about unduly worrying patients before diagnosis was confirmed. Our experience is patients are more likely to worry without appropriate information and support, particularly while waiting for a neurologist appointment. Third sector organisations are highly skilled in supporting patients at every stage on the care pathway – even before diagnosis. Indeed, many provide support in understanding the next steps such as what will happen at a neurologist appointment, what tests may be carried out and why. Many third sector organisations work closely together in relation to patients who have similar symptoms or may be incorrectly diagnosed. Much of the information developed by third sector organisations is peer reviewed and developed with reference to academic research, medical expertise and has the NHS England information standard.	Thank you for your comments. The Guideline Committee appreciates that there are many excellent examples of supportive information for people with specific diagnoses. Unfortunately NICE guidelines cannot refer to information from third party organisations because these can change after publication of the NICE guidance. If there are specific pieces of information which you would like to be highlighted, these could be considered separately by referring them to the NICE endorsement programme: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement. The advice on employment and driving is made with care. The recommendation on informing employers only suggests considering this, and refers to the situation where the person may have difficulty in carrying out their job. The other part of this recommendation only suggests that the person should look at the DVLA website to decide whether it is

					necessary to inform the DVLA. We agree in both instances that it would also be useful to point the person towards other lines of support, although for reasons given in the preceding paragraph we cannot specify this support within the guideline.
The Neurological Alliance	Full version	26	1-43	We welcome the development of a Guideline on suspected neurological conditions in primary care. As noted in your introduction, our patient experience research demonstrates the time taken from first GP visit to diagnosis can be highly variable across conditions and across different geographies. While some variation is expected; delays in referral often impacts adversely on patient outcome. For example, Motor Neurone Disease (MND) is a rapidly progressing terminal conditions and a third of people with MND will die within a year. Early diagnosis is essential as it enables patients to begin receiving treatment to enable them to extend their life and maintain wellbeing as long as possible. Variation in length of time to referral and diagnosis can also be indicative of inefficiencies within the health system. For example, around a third of outpatient neurology appointments are for headache; many patients with headache and migraine can be managed in primary care. The Neurological Alliance and its members are keen to work with NICE to ensure this Guideline addresses delays in detection and referral of neurological conditions, as well as inefficiencies in the pathway. To this end, we want to ensure the final Guideline is comprehensive in its content, easy to use for primary care professionals, and widely taken up by the health system. At present, we feel the draft Guidance has serious shortcoming which we note in our response below and would like to see significant changes made before a final document is published.	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned.
The Neurological Alliance	Full version	27	10-15	The range and complexity of neurological symptoms and conditions make it challenging for GPs and other primary care professionals to recognise and refer patients with suspected neurological conditions. We feel that even with this additional guidance, non-specialists working in primary care may still, in some cases, require additional support and a second opinion. The new models of care set out in NHS England's GP Forward View – primary care networks or hubs – will mean access to greater expertise across a 'hub' area, which may include GPs with a special interest in neurological conditions and specialist nurses. Primary care networks or hubs could also facilitate the development of areas of expertise amongst primary care professionals. These new models of care will increase the pool of knowledge across GP surgery hubs, as the number of neurological cases seen across a hub area will be greater than for an individual GP surgery. The Guidance does not currently make any reference to hubs or network models of care and how this could facilitate implementation of this new Guidance. Furthermore, pilot schemes to enable GPs to speak to neurologists on the phone or via video conference have been successful in improving appropriate referral rates – see for example the Walton Centre Vanguard, or the work by the neurology strategic clinical network. Such schemes might be included in the shared learning database to support implementation. We would also urge the Guidance development group to speak to these pilot projects about findings from their work to understand more about the sorts of questions GPs are asking in relation to neurological conditions, to inform the development of this Guidance. Would it possible to consider adding another category to the 'refer urgently', 'refer immediately', 'refer' criteria which stipulates seeking a second opinion? – a phone call to a neurologist is far more efficient than a wasted neurology outpatient appointment – and more likely to lead to the better pathway for the patient.	Thank you for your comments. The Guideline Committee agrees that there may well be value in some of the implementation methods you suggest such as Primary Care hubs. However, consideration of these was not part of the remit or the scope of the Guideline. We also agree that phone calls can be useful, but we cannot recommend this within the guideline since access to neurologists is beyond our control and will require local negotiation.
The Neurological Alliance	Full version	31	30-33	The draft Guidance notes that the wide range of neurological conditions has meant the scope concentrated on 'more common presentations of neurological symptoms'. We believe that several common presentations of neurological symptoms are missing from this guidance – or not given the emphasis required to effectively detect conditions - which may lead to (even relatively common) neurological conditions being missed or misdiagnosed. Similarly, if one of the intentions of this guideline is to increase referrals of rarer conditions, rarer symptoms must be included to ensure timely diagnosis. We suggest the following signs and symptoms of neurological conditions are added to the Guidance and would be happy to supply further evidence and information in these areas. While some of these symptoms are mentioned in passing in the Guidance, they are not always experienced in tandem with the symptoms listed in the draft Guidance which may lead to them being missed. We believe each of these areas should be covered as separate recommendations given they are common symptoms of several neurological conditions. • Disturbance of bladder and bowel function, sexual dysfunction	Thank you for your comments. The guideline was necessarily limited in scope and had to concentrate on areas where practice was variable or unsatisfactory. The GC recognised that autonomic signs and symptoms and are often significant and require onward referral, but decided that for the most part current practice is satisfactory. A recommendation on Headache has now been added, linking to current NICE

				These are also symptoms that patients may be embarrassed or reluctant to mention to their GP. This makes it even more paramount that primary care professionals are aware of their link to neurological conditions so they can ask appropriate questions during consultations. The Guidance should encourage GP's to ask about such symptoms. • Headache A glaring gap in the draft Guidance is the absence of headache as a symptom included in the recommendations for adults over 16. Headache (and migraine) is only referred to in relation to other symptoms meaning an opportunity to detect and appropriately refer (or not refer) patients presenting with headache may be missed. Headache affects around one in seven adults. Headache is a special case given it is an area in which the neurology pathway could become more efficient with appropriate detection and referral. Around one third of adult neurology appointments are for headache; many of these cases can and should be managed in primary care. We urge NICE to include headache as a separate recommendation for adults over 16, with reference to the existing NICE Guideline on headache in over 12s. • Facial pain Facial pain (which is a symptom of neurological conditions such as trigeminal neuralgia) often presents to the dental profession who are not skilled in this area and so result in irreversible treatments and delay in diagnosis and management. Other symptoms not adequately covered are respiratory symptoms and autonomic failure.	guidelines. Facial pain is covered in recommendation 5.3.5 of the Full version and 1.3 of the Short version. Respiratory symptoms other than those related to sleep disorders are not covered. The GC does not believe that these are currently mismanaged and they were not prioritised for inclusion.
The Neurological Alliance	Full version	General	General	The draft Guidance is attempting to make the demand side of neurology outpatient appointments more effective and efficient. One of the major problems in this approach is that without any action to also address the supply side of neurology services, it is likely to fail. It is well documented that there is huge geographical variation in neurology services: • Not all GPs can refer directly for MRI scans meaning an outpatient neurology appointment is required to get referral for imaging. • There is a national shortage of neurologists, with some areas carrying long standing vacancies. • In other specialisms such as neuropsychiatry and neuropsychology, access is even more patchy across the country. • Brexit is likely to make recruitment issues worse in areas such as neuroradiology and other related specialisms. • The complexity of many neurological conditions requires care by a multi-disciplinary team and our research shows health care professionals do not consistently work collaboratively in providing care for neurological patients. See our 2017 report *Falling Short.* • There are frequent references in the Guidance to 'functional symptoms'. Services for people with functional neurological disorder are very patchy. It is paramount that work is undertaken by Health Education England, NHS England, the Association of British Neurologists and others to address the supply side in relation to access to neurology services across the country. We would welcome conversations with other agencies about how the Neurological Alliance could support initiatives to address these issues.	Thank you for your comments. The Guideline Committee appreciates the problems you describe, but resource and recruitment issues in the system at large are beyond the control of this Guideline Committee.
The Neurological Alliance	Full version	General	General	An overall comment is that for several conditions (headache and migraine, as well as rarer conditions such as Transverse Myelitis), there is a greater urgency in the children's guideline than in the adult's guidance. The children's Guideline is also clearer in places. We feel overall that this Guidance may be more effective as two sets of Guidance – one for children and one for adults – ensuring each piece of Guidance is comprehensive.	Thank you for your comment. The recommendations will be separate for adults and children when the final version is published on the NICE website.
The Neurological Alliance	Full version	General	General	We do not feel this guidance is appropriately pitched for generalist health professionals working in primary care. An example of this include the way in which functional symptoms are referred to within the guidance. Indeed, leading neurologists often struggle to correctly identify functional symptoms as distinct from an organic neurological condition. Another example is that the Guidance recommends 'urgent referral for adults whose blackout is accompanied by features that are strongly suggestive of epilepsy seizures', but does not indicate what these features might be. We do not believe non-neurological specialists working in primary care – not just GPs but also health visitors, pharmacists, dentists, optometrists and others - will be able to effectively use this Guidance to identify and appropriately refer patients with suspected neurological conditions without significant amendments. Furthermore, the Guidance is not suitable for use by patients and carers.	Thank you for your comments. The guideline is not intended primarily as a guide to diagnosis, and a high level of diagnostic acumen is not expected of a general physician. It is designed to guide the need for referral to neurology. The Guideline Committee agrees that diagnosis of functional symptoms can be difficult, but the relevant recommendations in the guidance refer to recurrent, rather than first, presentation. The Guideline Committee

					has added the description of epileptic seizures.
The Neurological Alliance	Full version	General	General	Given the complexity of this area of health care, and length of even the short version of the Guidance, we are concerned that it will not be widely taken up by primary care professionals; especially given there are few contractual incentives in primary care relating to neurology. This Guidance is being launched in a vacuum; • Neurology is not a priority for many Clinical Commissioning Groups and Sustainability and Transformation Partnerships. Our 2016 CCG audit found that only 21% of CCGs have made an assessment of the number of people using neurological services in their area. • Survey data produced for our 2016 report *Neurology and Primary Care* found that 84% of GPs feel that they could benefit from further training on identifying and managing people presenting with neurological conditions. Consequently, while we believe that the development this guideline is an important and welcome initiative, there needs to be additional work alongside the launch of the Guideline to ensure if it effective. Professional education, an awareness campaign, ongoing audit as part of accountability frameworks, and a simple algorithm are all tools that would support the intentions behind this Guideline to be realised. We would welcome a further conversation with NICE (the Royal College of General Practitioners, Primary Care Neurology Society, and others) about how the Neurological Alliance can support this Guidance to be used. We would also like to understand more about the role of the NICE implementation team in relation to ensuring this Guidance is used.	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned. The Guideline Committee appreciates the problems you describe, but resource and recruitment issues are beyond the control of this Guideline Committee.
The Neurological Alliance	Full version	General	General	We would be interested to explore the extent to which other (non-neurological) NICE Guidance refers to potential neurological conditions (and in time should cross refer to this new guidance). Neurological patients often find themselves 'stuck' in the wrong part of the health service, for example in ear nose and throat clinics or continence services – without appropriate referral to neurology. This new guidance is an opportunity to review the representation of neurology in other guidance beyond neurology, where symptoms may be indicative of neurological condition.	Thank you for your comment. This guideline refers to other NICE guidance where appropriate. As other relevant NICE guidance is updated, there will be an opportunity to review how they might best link to this guideline The guidance is directed mainly at presentations in primary care, but the Guideline Committee would anticipate that it might be consulted by non-neurologists working in secondary care.
The Neurological Alliance	Full version	General	General	We note that mental health is mentioned only twice in the whole Guideline – in relation to tic disorder. Our recent report *Parity of Esteem for people affect by Neurological Conditions* (2017) found that around 50% of neurological patients (and as high as 86% of patients with Tourette's Syndrome and 80% of patients with multiple system atrophy) have co-morbid mental health conditions. This is higher than for the general long-term condition patient population, where 30% of patients have a mental health condition. This is due to the complex interplay between a neurological conditions and mental health condition (see our report for further detail). These patients would benefit from a multidisciplinary approach including liaison psychiatry and clinical psychology. The omission of any mention or consideration of co-morbid mental health conditions in this Guidance is a missed opportunity for early detection of mental health conditions in neurological patients.	Thank you for your comments. The Guideline Committee has added a reference to depression and coincident psychiatric disorder in the introduction to the Full version. However, the remit of the guideline is to address the need for referral of primary presentations of symptoms suggestive of a neurological cause, not treatment of that presentation or any psychological sequelae or co-existing mental health problems.
The Neurological Alliance	Short version	31	12-15	This recommendation refers only to cauda equine syndrome. These symptoms could reflect other conditions, for example Multiple System Atrophy. Overall, we recommend NICE reviews the parts of the Guidance that refer only to one or two specific conditions and where there is evidence that symptoms may be indicative of other conditions, adding these conditions to the list. Alternatively, there should be a note in the Guidance explaining that other rarer neurological conditions should also be considered in relation to recommendations which stipulate one or two conditions. This is important not only so that patients are not stuck on the incorrect pathway, but also to ensure patients have as much information as possible about their potential diagnosis when leaving the GP surgery. Patients can and do research possible diagnoses online and should be given the broadest possible amount of information at this stage.	Thank you for your comments. It is not the purpose of the guideline to mention every possible cause of each presentation. It is aimed at ensuring that referral is appropriate, so that the detailed diagnostic work can then take place.

				A more general, but related point, is that in many places the Guidance is written around a handful of more common conditions and it is hard to see how rarer conditions would fit in. In other places, the Guidance refers to very rare conditions. It is hard to follow the logic of why some conditions are included but not others.	
Transverse Myelitis Society	Full Version	104	16	Advising the patient to tell their employer, school or college about a suspected neurological condition could be premature. Doing so can have huge implications for individual patients and it may not always be appropriate to do so before a diagnosis has been confirmed. Indeed, until diagnosis is confirmed, patients/employees do not have legal protection under the Equalities Act. Patients must be made aware of broader support available to them from patient organisations in parallel to being advised to consider telling an employer or education institution about health issues which may affect their ability to work or study.	Thank you for your comment. The Guideline Committee agrees that informing an employer before diagnosis may not always be appropriate, and the recommendation therefore does not mandate this but advises considering it.
Transverse Myelitis Society	Full Version	127	4	Recommendation 116 on pg. 127 – Floppiness of the limbs can also indicate Acute Flaccid Myelitis (AFM), a sub-type of Transverse Myelitis. This should be mentioned as AFM has arisen in clusters in the UK (Wales, Scotland) among children.	Thank you for your comment. The Guideline Committee agrees, but the predominant symptom is weakness and loss of function which would be covered under the current recommendation for urgent referral of the child with new onset limb or face weakness.
Transverse Myelitis Society	Full Version	128	4	Recommendation 117 on page 128 & 129 – The referral for children is 'immediately' (same day) but doesn't feel that way for adults. Why is the reason for that? The urgency regarding referral of potential neuro-inflammatory conditions in children is clearly urgent in these draft guidance notes, but doesn't appear to be that way for the same symptoms in the adult section. Why is that?	Thank you for your comment. It is less easy to make a diagnosis in children as they may not be able to describe symptoms well., Tthe presentation is much less common in children and so people lack confidence in making a diagnosis, and there is more likelihood of a progressive disorder that requires urgent assessment.
Transverse Myelitis Society	Full Version	131	5	Recommendation 121 on pg. 132 – TM, ADEM, NMO, AFM can all result in new-onset gait abnormality and this should be mentioned. I have heard of issues in A&E and with paramedics that they did not believe when a child said s/he could not walk properly or at all and it turns out they were experiencing the onset of TM, ADEM or NMO.	Thank you for your comment. The Guideline Committee acknowledges your point, but this is not a diagnostic guideline. These diagnoses will be considered once the child has been referred urgently.
Transverse Myelitis Society	Full Version	138	3	Recommendation 130 – Tingling in children can also indicate TM, ADEM, and NMO. Given there is a difference from GBS, these rare neuro-inflammatory conditions should be mentioned. Overall, recommendations for children experiencing symptoms indicative of rare neuro-inflammatory conditions feel clearer and have a greater urgency about them than the recommendations for the same symptoms in adults. As an example, recommendations 128 to 32 for children. Recommendation 131 on pg. 139 – Tingling can also be caused by demyelination.	Thank you for your comment. The Guideline Committee has added "and other neuro-inflammatory conditions" to the following recommendation: *Be aware that tingling in children may be the first symptom of an acute polyneuropathy (Guillain-Barré syndrome) or other neuro-inflammatory conditions. If the child has features suggesting motor impairment, refer urgently for neurological assessment.*
Transverse Myelitis Society	Full Version	145	1	There are no references to ophthalmological issues which can appear in children (or adults) with NMO and ADEM.	Thank you for your comment. The guideline is based on presentations, not specific conditions, and within each presentation the Guideline Committee has not attempted to produce a full list

					of the possible causes which would be beyond the remit of the guideline.
Transverse Myelitis Society	Full Version	154	1	Insert acronyms and abbreviations for Transverse Myelitis and ADEM, NMO and AFM as appropriate.	Thank you for your comment. The Guideline Committee has added the appropriate acronyms on p. 129 and 154 of the consultation version.
Transverse Myelitis Society	Full Version	156	3	Insert acronyms and abbreviations for Transverse Myelitis and ADEM, NMO and AFM as appropriate.	Thank you for your comment. The Guideline Committee has added the appropriate acronyms on p. 129 and 154 of the consultation version.
Transverse Myelitis Society	Full Version	26	1-43	We welcome the development of a Guideline on suspected neurological conditions in primary care. As noted in your introduction, the Neurological Alliance patient experience research demonstrates the time taken from first GP visit to diagnosis can be highly variable across conditions and across different geographies. While some variation is expected; delays in referral often impacts adversely on patient outcome. For example, with rare neurological inflammatory conditions like Transverse Myelitis (TM), Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO) and Acute Flaccid Myelitis (AFM), early diagnosis and treatment is essential to maximise outcomes. The Transverse Myelitis Society is keen to work with NICE to ensure this Guideline addresses delays in detection and referral of neurological conditions, as well as inefficiencies in the pathway. To this end, we want to ensure the final Guideline is comprehensive in its content, easy to use for primary care professionals, and widely taken up by the health system.	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned.
Transverse Myelitis Society	Full Version	72	4	Recommendations 22 and 26 assumes the issues could be stroke or cancer. Sudden-onset and/or progressive weakness of a single limb or hemiparesis can be a symptom of TM and NMO. We have a concern that only referring to the NICE guidance on stroke and brain and central nervous system cancers may limit the doctor's focus and could result in the patient being put on the incorrect pathway and delayed diagnosis. Referring to only one condition within a recommendation where the symptoms being referred to is characteristic of a number of neurological conditions is an issue throughout these draft guidelines.	Thank you for your comment. The Guideline Committee understands your point, but felt that some of the recommendations to refer needed explanation since they might not be apparent to some in primary care. These brief mentions of the reasoning are not essential but the Guideline Committee thinks they will enhance take up of the recommendations. The key is to get people referred with an appropriate degree of urgency; if the suspected diagnosis is incorrect the patient will still be in the neurology system and the correct management of the true condition will follow.
Transverse Myelitis Society	Full Version	72	4	Recommendations 28 on pg. 73 – Same issue as in comment 1 but this time only MND is referred to and the symptom can appear in TM.	Thank you for your comment. Please see response to your comment 1 (immediately before this response).
Transverse Myelitis Society	Full Version	72	4	Recommendations 33 on pg. 73 - Same issue as in comment 1 but this time only Cauda Equina is referred to and the bladder, bowel and sexual dysfunction is a key red flag for TM, NMO and ADEM.	Thank you for your comment. Please see response to your comment 1 (immediately before this response).
Transverse Myelitis Society	Full Version	72	4	Recommendation 26 on pg. 74 – The reference to NICE CG150 seems to be a mistake as that NICE guidance is in reference to headaches.	Thank you for your comment. The Guideline Committee has amended this reference so that now it correctly links to CG186.

Suspected neurological conditions

Consultation on draft guideline - Stakeholder comments table
07 August 2017 – 19 September 2017

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Transverse Myelitis Society	Full Version	72	4	Recommendation 27 on pg. 74 – Same issue as in comment 1. Rapidly progressive symmetrical weakness can also be an indication of Transverse Myelitis, not just Guillain-Barre Syndrome	Thank you for your comment. Please see response to your comment 1.
Transverse Myelitis Society	Full Version	85	1	Recommendation 55 on pg. 86 – Adults (and children) experiencing the onset of Transverse Myelitis can also experience rapidly progressive (within hours to days) of numbness and weakness or imbalance on one side of the body. This is not mentioned in the recommendations.	Thank you for your comment. The Guideline Committee acknowledges your point, but transverse myelitis is a less common cause of this presentation than tumour. The key issue is to get people referred with an appropriate degree of urgency; if the suspected diagnosis of a brain tumour is incorrect the patient will still be in the neurology system and the correct management of the true condition will follow.
Transverse Myelitis Society	Full Version	85	1	Recommendation 51 on pg. 88 – Could also mention TM, ADEM and NMO along with MS to highlight that rare neuro-inflammatory conditions also have this symptom. Bladder, bowel and sexual dysfunction can also appear alongside sensory disturbance. On the whole, bladder and bowel dysfunction are not mentioned as fully for adults as being an indicator of physical neurological disease as it is in the children's section. Sexual dysfunction should also be stressed for adults as an indicator.	Thank you for your comments. The guideline covers recognition and referral and is not designed as a detailed diagnostic aid. The guideline was necessarily limited in scope and had to concentrate on areas where practice was variable or unsatisfactory. The Guideline Committee recognised that autonomic signs and symptoms and are often significant and require onward referral, but decided that for the most part current practice is satisfactory.
Transverse Myelitis Society	Full Version	85	1	Recommendation 55 on pg. 89 – I appreciate this recommendation relates to GBS. I would like to highlight that cervical lesions in TM and NMO can also result in respiratory issues and failure and it would be good to see this mentioned so a GP's focus isn't solely on peripheral neuro conditions.	Thank you for your comment. Although the Guideline Committee mentions GBS in the recommendations and link to evidence table the recommendation itself does not. It appropriately recommends immediate referral for those with rapidly progressive limb weakness, and should be applied whatever diagnosis the referrer is suspecting.
Transverse Myelitis Society	Full Version	General	General	It is recommended to implement these guidelines with supportive mechanisms to enable GPs to use the guidelines effectively. • Having the guidelines set up as an easily accessible interactive web tool may support GPs in determining when to make a referral. Having a named neurologist a GP can call to discuss a case could prevent unnecessary referrals and facilitate referrals for urgent cases (e.g., NHS England's GP Forward View – primary care networks or hubs; pilot schemes to enable GPs to speak to neurologists as they have done at the Walton Centre Vanguard).	Thank you for your comments. Your comments will be considered by NICE where relevant support activity is being planned. However, provision of named neurologists is beyond our control and will require local negotiation.
Transverse	Short	General	General	All comments on the recommendations in the full version made below also apply to the short version.	Thank you for your comment.

Myelitis Society	Version				