Suspected neurological conditions

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

	Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly. We would like to hear your views on the draft recommendations presented in the short version and any comments you may have on the evidence presented in the full version. We would also welcome views on the Equality Impact Assessment. We would like to hear your views on these questions: 1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. 2. Would implementation of any of the draft recommendations have significant cost implications? 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) 4. [Insert any specific questions about the recommendations from the Developer, or delete if not needed] See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.
Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	FND Hope UK

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NICE National Institute for Health and Care Excellence

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Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	None
Name of commentator person completing form:	Dawn Golder
Type	[office use only]

Comment number	Document (full version, short version or the appendices	Page number Or 'general' for comments on the whole document	Line number Or 'general' for comments on the whole document	Comments Insert each comment in a new row. Do not paste other tables into this table, because your comments could get lost – type directly into this table.
Example 1	Full	16	45	We are concerned that this recommendation may imply that ……..
Example 2	Full	16	45	Question 1: This recommendation will be a challenging change in practice because ……
Example 3	Full	16	45	Question 3: Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact…….
1	Full	General	General	We are concerned that the proposed NICE guidelines for suspected neurological conditions do not make reference to

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				or discuss Functional Neurological Disorder (FND) as a condition in its 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 endeavor). 4. Enable patients with functional neurologic disorders to more easily access neurology-based treatments, such as specialist neurological physiotherapy, which may benefit them. 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. **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 **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]).

2	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. **Reference:** **Graham A**., Functional Neurological Symptoms in North East Neurology Services: A HealthCare Needs Assessment, Public Health England North East Centre. 2016
3	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)
4	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
5	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
6	Full	11	37-39	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 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
7	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. **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

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8	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 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
9	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].
10	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 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 (Minneap Minn). 21(3 Behavioral Neurology and Neuropsychiatry): 818-37. doi: 10.1212/01.CON.0000466669.02477.45
11	Full	16	9-11	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 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
12	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
13	Full	26	15-16	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 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
14	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.
15	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.
16	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
17	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 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.
18	Full	58	Recommendation 8	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 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
19	Full	64	Table 11	Other Outcomes: functional disorders Functional Neurological Disorder is a disorder in its own right and should be named appropriately.
20	Full	75	Recomm	Functional symptoms are not necessarily related to anxiety or a mental health comorbidity. The new DSM-5 criteria

			endation 31	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.

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21	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 appropropriate multidisciplinary treatmetn (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
22	Full	78	Recommendation	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),

			36,37	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.

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23	Full	80	Table 12 Population	We argue that Functional Neurological Disorder should also be included
24	Full	85	5 Outcomes	Other Outcomes: functional disorders Functional Neurological Disorder is a disorder in its own right and should be named appropriately.
25	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.
26	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.
27	Full	86	52	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 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

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28	Full	88	Recommendation 53	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), 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

				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
29	Full	96	Recommendation 72	Other Outcomes: functional disorders Functional Neurological Disorder is a disorder in its own right and should be named appropriately.
30	Full	101	Table 13	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 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
31	Full	102	5.14.5 3	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 it's 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
32	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
33	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.
34	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
35	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
36	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
37	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.

Insert extra rows as needed

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- Complete the disclosure about links with, or funding from, the tobacco industry.
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