



**The Neurological Alliance's Response to the NICE scope on Rehabilitation for Chronic Neurological Disorders Including Traumatic Brain Injury**

	<p><b>Please read the checklist for submitting comments at the end of this form.</b> We cannot accept forms that are not filled in correctly or arrive after the deadline.</p> <p>In addition to your comments below, we would like to hear your views on these questions:</p> <ol style="list-style-type: none"> <li>1. We are uncertain about the appropriateness of including functional neurological disorders in the scope of the guideline. Please let us have your views, with a supporting rationale, on whether functional neurological disorders should be included or excluded from the scope of this guideline.</li> <li>2. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?</li> </ol> <p><a href="#">Developing NICE guidance: how to get involved</a> has a list of possible areas for comment on the draft scope.</p>
<p><b>Organisation name – Stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p><b>The Neurological Alliance</b></p>
<p><b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.</p>	<p><b>Nothing to declare</b></p>
<p><b>Name of person completing form:</b></p>	<p><b>Georgina Carr</b></p>

Type		[for office use only]	
Comment No.	Page number or ' <u>general</u> ' for comments on the whole document	Line number or ' <u>general</u> ' for comments on the whole document	Comments Insert each comment in a new row. Do not paste other tables into this table, as your comments could get lost – type directly into this table.
Example	3	55	The draft scope currently excludes people who have already been diagnosed. We feel this group should be included because....
	General	General	<p>If the guideline is to encompass all chronic neurological disorders, we strongly support the inclusion of FND in the scope of this document. FND is one of the most common causes of referrals to neurologists, it is probably as common as Parkinson's Disease and multiple sclerosis (MS). A goal orientated rehabilitation or adjustment to disability approach in FND is just as valid as in other neurological disorders.</p> <p>Importantly, the NICE Quality Standards for 'Suspected neurological conditions: recognition and referral' contains a specific Quality Standard on FND, recognising the need to support adults with FND appropriately, which could include occupational therapy, physiotherapy and mental health support.</p>

	General	General	<p>We consulted with our membership in the development of our response to this consultation. Our membership constitutes more than 80 organisations, including patient groups, regional Alliance's and professional groups.</p> <p>Some members expressed concerns about a guideline that encompasses all chronic neurological disorders. For example, concerns were raised about the specificity of specialist skills and knowledge required for different conditions given the different symptom presentations, aetiologies and prognosis. There is a risk of the guideline being very general, thereby limiting its effectiveness. In addition, there is a risk we lose the specialist skills required to allow for optimum results.</p> <p>Furthermore, evidence suggests the effectiveness of rehab is likely to be condition-specific rather than covering neurological rehabilitation in general. We would welcome clarity from the Committee as to how it intends to evaluate and extrapolate evidence from specific conditions and generate recommendations which apply across the breadth of neurological conditions.</p>
	General	General	<p>All aspects of health inequalities should be considered in the development of this guideline, including possible inequalities in access, experience, outcome, prevalence and incidence of chronic neurological conditions in relation to race and ethnicity, residential status and digital literacy and digital confidence.</p>
	General	General	<p>Many people with neurological conditions will require support from an integrated, multi-disciplinary team of healthcare professionals, underpinned by excellent care coordination. This should be recognised throughout the guideline, as it is in many of the relevant guidelines listed in the scoping document.</p>
	General	General	<p>The committee and guideline should also consider the potential of digital solutions and the integration of telemedicine.</p>

1	2	18	<p>The stated prevalence estimates should be reviewed.</p> <p>Prevalence for TBI is estimated to be &gt; 1 in 10 people, with 3 in 10 people under 25 having had at least one significant TBI (Maas Lancet Neurology Commission 2017). The high prevalence is coupled with very high long-term disability following TBI. For example, a single cause of TBI (road traffic accidents) is the 10<sup>th</sup> most important cause of long-term disability across all medical conditions. This indicates the massive long-term clinical impact of TBI (Lancet 2012), which should be reflected in specific guidelines for long term management and rehabilitation.</p> <p>Approximately 1 in 500 people live with multiple sclerosis (MS) (Public Health England (2020) Multiple sclerosis: prevalence, incidence and smoking status - data briefing), (MS Society (2020), MS in the UK)</p> <p>The lifetime risk of being diagnosed with Parkinson's is 2.7%. This is equivalent to 1 in every 37 people being diagnosed with Parkinson's at some point in their life. (Parkinson's UK (2018) The incidence and prevalence of Parkinson's in the UK)</p> <p>Further information about prevalence and incidence of neurological conditions is available in our report 'Neuro Numbers, 2019' <a href="https://www.neural.org.uk/wp-content/uploads/2021/04/neuro-numbers-2019-1.pdf">https://www.neural.org.uk/wp-content/uploads/2021/04/neuro-numbers-2019-1.pdf</a></p>
2	2 - 3	(2)22 – 3(11)	It may be overly simplistic to consider just two categories, and these categories can of course be interlinked. For example, TBI may have a progressive element. Progressive conditions may also require acute rehab support, for example after a relapse.
3	3	12	In addition, robust evidence demonstrates that quality rehabilitation reduces demand on the most costly and intensive parts of health and social care systems and supports people and their carers to participate economically in society. This should be recognised here.
4	6	4	The care and support needs of informal carers should be considered as part of the guideline and who it is for.
5	6	20-21	This requires clarification. Concern that at present this would exclude conditions which have a perhaps transient event associated e.g., trauma, when in fact a neurological disability is a lifelong consequence which can ebb / flow. This may become more pronounced as other factors diminish compensatory systems e.g., aging.
5	7	11	Support available for informal carers should be considered here.

6	7	20	The omission of both diagnosis and co-morbidities is likely to be problematic. For example, the importance of accurately diagnosing the cause of post-traumatic problems in TBI should be considered as this is key to effective rehabilitation. Psychiatric problems are also common after TBI – if poorly managed, they can be a root cause of failure of rehab.
7	7	16	Ease of re-referral after fixed term therapy should also be included
8	11	1	Please clarify the term ‘everyone involved’
9	12	1	Please clarify the term ‘everyone involved’
10	12	7	Please include ‘remain in, return to or <b>exit from</b> employment and volunteering?’
11	12	15	Outcomes related to mobility, cognition and emotional health should be included here.

Add extra rows if needed

#### Checklist for submitting comments

- Use this comment form and submit it as a **Word document (not a PDF)**.
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- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include **page and line number (not section number)** of the text each comment is about.
- Combine all comments from your organisation into 1 response. **We cannot accept more than 1 response from each organisation.**
- Do not paste other tables into this table – type directly into the table.
- Ensure each comment stands alone; do not cross-refer within one comment to another comment.
- **Clearly mark any confidential information or other material that you do not wish to be made public. Also, ensure you state in your email to NICE that your submission includes confidential comments.**
- **Do not name or identify any person or include medical information about yourself or another person** from which you or the person could be identified as all such data will be deleted or redacted.
- Spell out any abbreviations you use
- For copyright reasons, **do not include attachments** such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.
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