

Rehabilitation for chronic neurological disorders including acquired brain injury

Consultation on draft scope Stakeholder comments table

08/06/2021 to 06/07/2021

Stakeholder	Page no.	Line no.	Comments	Developer's response
ACPIVR (Association of Chartered Physiotherapists Interested in Vestibular Rehabilitation)]	002	021	The draft scope currently considers 2 categories for chronic neurological disorders. We feel a third group ought to be considered capturing the associated neurological disorders, which are consequence of brain injury but may not appear immediately. These vestibular diagnoses include, (but are not exclusive) Persistent Postural Perceptual Dizziness (3PD), Chronic vestibular migraine, unilateral and bilateral vestibular failure / hypofunction, post TBI dizziness (including concussion).	Thank you for your comment. We have increased the number of categories to 5. The scope now references acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders. Regarding the vestibular diagnoses mentioned, the scope does not cover management of medical or psychiatric co-morbidities of chronic neurological disorders. However, vestibular diagnoses may be considered if they impact on areas that are covered by the scope (namely delivery of rehabilitation, effectiveness of rehabilitation interventions aimed at improving activity and maximising independence and wellbeing, and supporting access to education, employment and social participation).
ACPIVR (Association of Chartered Physiotherapists Interested in Vestibular Rehabilitation)]	005	028	The draft scope currently identifies that age related service assumptions will be reviewed. The group feel it is imperative to identify those older persons suffering chronic vestibular diagnosis are not excluded from rehabilitation due to age related discrimination and assumptions.	Thank you for your comment. We will look for evidence about a range of age related service assumptions and potentially discriminatory practices. Regarding the vestibular diagnoses mentioned, the scope does not cover management of medical or psychiatric co-morbidities of chronic neurological disorders. However, vestibular diagnoses may be considered if they impact on areas that are covered by the scope (for example delivery of rehabilitation, effectiveness of rehabilitation interventions aimed at improving activity and

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				maximising independence and wellbeing, or supporting access to education, employment and social participation)
ACPIVR (Association of Chartered Physiotherapists Interested in Vestibular Rehabilitation)]	011	005	The draft scope requests identification of barriers for people with rehabilitation needs and referral to appropriate services. The group feel that identifying chronic vestibular disorders within this guideline will improve identifications, acknowledgement, and access to specialist treatment for those with diagnosis of chronic vestibular disorders caused by Parkinson's Disease, traumatic brain injury, Meniere's Disease and Multiple Sclerosis. The referral window must also be accessible for individuals years later, when the individual returns to activities and is challenged by environmental triggers, limiting engagement, and escalating symptoms. Clear acknowledgement of chronic vestibular diagnoses will remove barriers and facilitate rehabilitation.	Thank you for your comment. The scope does not cover management of medical or psychiatric co-morbidities of chronic neurological disorders. However, vestibular diagnoses may be considered if they impact on areas that are covered by the scope (namely delivery of rehabilitation, effectiveness of rehabilitation interventions aimed at improving activity and maximising independence and wellbeing, and supporting access to education, employment and social participation). As part of the key area about identification and referral we have now included the issue of re-referral.
ACPIVR (Association of Chartered Physiotherapists	General	General	The draft scope does not specifically address chronic vestibular issues, which can both stand alone or occur as a result of known diagnoses of Parkinson's Disease, traumatic brain injury and Multiple Sclerosis. These vestibular diagnoses include, (but are not exclusive) Persistent Postural Perceptual Dizziness (3PD),	Thank you for your comment. The scope of this guideline does not cover management of medical or psychiatric co-morbidities of chronic neurological disorders, which include vestibular disorders. However, vestibular diagnoses may be

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Interested in Vestibular Rehabilitation]			Chronic vestibular migraine, Meniere's Disease, unilateral and bilateral vestibular failure / hypofunction, post TBI dizziness (including concussion). The general incidence of overall dizziness in the population is well evidenced (Furman et al 2010) and the health burden of vertigo and vestibular disorders is also well documented (Kovacs et al 2019). It is therefore our request, that based on the plethora of evidence available, clearly identifying the ability to have positive outcomes with rehabilitation (Dunlap et al 2018) that vestibular issues be included in this guidance.	considered if they affect areas that are covered by the scope (namely delivery of rehabilitation, effectiveness of rehabilitation interventions aimed at improving activity and maximising independence and wellbeing, and supporting access to education, employment and social participation).
ACPIVR (Association of Chartered Physiotherapists Interested in Vestibular Rehabilitation)]	NICE Query No 1	Comments form	Although Persistent Postural Perceptual Dizziness remains under the rubric of functional neurological disorder, we believe that is simply because the exact mechanism has yet to be evidenced. As such, functional neurological disorders should be included in the guidance. There remains significant numbers who are impacted by this condition (Popkirov et al 2017) who could and should be addressed in this context.	Thank you for your comment. Functional neurological disorders have now been included in the scope of this guideline.

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Association of British Neurologists	002	018	<p>The stated prevalence estimates for traumatic brain injury (TBI) and acquired brain injury are completely wrong.</p> <p>It is stated that 1 in 6000 people have had TBI or acquired brain injury. In fact, prevalence for TBI is estimated to be > 1 in 10 people, with 3 in 10 people under 25 having had at least one significant TBI (Maas Lancet Neurology Commission 2017).</p> <p>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 10th 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>The discrepancy between the reality of TBI prevalence and the stated prevalence in the document is very worrying as it indicates that the scale of rehabilitation required for TBI is completely unappreciated by the NICE panel.</p>	<p>Thank you for your comment. We have now made changes to the prevalence estimates. Although NICE is unable to produce a separate guideline for TBI specifically we are intending to write some specific recommendations for acquired brain injury, alongside other groups of neurological conditions, recognising that there are important differences within different groups of neurological conditions.</p>

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			<p>Long-term disability after TBI has a similar magnitude to stroke, which has its own rehabilitation recommendations.</p> <p>The importance of TBI as a cause of long-term disability and the paucity of services available for TBI sufferers should be recognised by the development of separate guidelines for TBI.</p>	
Association of British Neurologists	002	022	It is a simplistic to split conditions into acute/static and progressive. For example, conditions like TBI have a progressive component.	Thank you for your comment. We have amended the scope to reference the following categories: acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders.
Association Of British Neurologists	002	general	There is perhaps a third category or situation which needs to be included and that is either of these two groups when planned or unplanned health treatments result in temporary deterioration of their pre-existing condition e.g., with hospital admission for ill health, where it might be expected that early and intense rehab input might return them to their previous state and delay in this may lead to permanent deterioration. Acute rehab teams are scarce. Pre-op optimisation is a rarity.	Thank you for your comment. If rehabilitation is needed following relapse and/or deterioration as specified this would be covered within the scope as part of the key areas about how rehabilitation needs are identified and referred and this would include re-referral. It may also come up in terms of how rehabilitation plans are reviewed and how services are coordinated and delivered. We

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				have amended the scope to make this clearer. We have also amended the scope to reference the following categories: acquired brain injury; spinal cord injury or disorders; progressive neurological disorders; functional neurological disorders.
Association Of British Neurologists	002-003	013 – 031	There is perhaps a third category or situation which needs to be included and that is either of these two groups when planned or unplanned health treatments result in temporary deterioration of their pre-existing condition e.g., with hospital admission for ill health, where it might be expected that early and intense rehab input might return them to their previous state and delay in this may lead to permanent deterioration. Acute rehab teams are scarce. Pre-op optimisation is a rarity.	Thank you for your comment. If rehabilitation is needed following relapse and/or deterioration as specified this would be covered within the scope as part of the key areas about how rehabilitation needs are identified and referred and this would include re-referral. It may also come up in terms of how rehabilitation plans are reviewed and how services are coordinated and delivered. We have amended the scope to make this clearer. We have also amended the scope to reference the following categories: acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders..

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Association of British Neurologists	006	013	<p>'No subgroups have been identified as needing specific consideration' > As discussed above, TBI is much more prevalent than the other conditions being considered and like stroke has very specific rehabilitation issues. If TBI is included in this guideline it should have specific consideration.</p> <p>There are also specific subgroups with particularly high rates of TBI that should be considered as needing specific attention. These include:</p> <ul style="list-style-type: none"> (a) the homeless, (b) prisoners (c) domestic violence victims. (d) retired military personal (e) retired sportsmen and women. 	<p>Thank you for your comment. The guideline committee will discuss and decide what interventions to include in each question when developing the review protocols. Should the evidence allow, sub-group analysis of 5 chronic neurological disorder categories will be carried out (acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders). This will allow for recommendations about acquired brain injury to be produced discreetly to the other categories in areas where the committee feel this is important.</p> <p>We have added a note of these areas to our equality impact assessment. The committee will then consider each equality and sub group area in relation to each review question and agree which are the most important ones for any further sub group analysis.</p>

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Association of British Neurologists	006	024	<p>TBI should be included as a neurological condition for the purposes of rehabilitation guidelines.</p> <p>However, as above, consideration should be given to having separate rehabilitation guidelines for TBI because of the prevalence of the condition and the long-term impact in terms of disability.</p>	<p>Thank you for your comment. Although NICE is unable to produce a separate guideline for TBI specifically we are intending to write some specific recommendations related to acquired brain injury, as well as other neurological conditions, recognising that there are important differences within different classifications of neurological conditions.</p>
Association of British Neurologists	007	009	<p>It is unclear why A+E, Critical care units and prisons are excluded from these guidelines. This is inappropriate for TBI.</p> <p>Evidence supports early rehabilitation following TBI. Consideration should be given to evaluating interventions that are provided in A+E and critical care units.</p> <p>Rehabilitation for mild TBI routinely starts in A+E. For example, patients with mild TBI are given information sheets about TBI effects that are a key part of management. This intervention impacts on long-term outcomes and should be evaluated as part of any TBI rehabilitation guidelines.</p>	<p>Thank you for your comment. We have amended this to read "All inpatient (excluding critical care units), outpatient and community settings, including tertiary settings and care homes in which either fully or partially publicly funded rehabilitation interventions for chronic neurological disorders are provided". QS158 Rehabilitation after critical illness in adults covers early management in critical care units and we generally will not be discussing extremely early identification of rehabilitation needs and extremely early interventions in this guideline because these are covered in the soon</p>

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			<p>For more severe cases of TBI rehabilitation should start in the critical care unit. Patients routinely see therapists of various types in this context and the value of early treatment should form part of the guideline evaluation.</p> <p>TBI has a major impact on the prison population. TBI is very common in offenders and impacts on recidivism, behaviour and long-term outcomes in this group. Rehabilitation interventions for inmates with TBI should form part of this evaluation.</p>	<p>to be published guideline "Rehabilitation after traumatic injury", which covers early identification of traumatic brain injury and onward referral for specialist assessment. It is not common practice for NICE guidelines to apply to the prison population because the health and care system within prisons is differently administered to that for the general population.</p>
Association of British Neurologists	007	021	<p>Areas not covered: 'diagnosis of neurological disorders' > The importance of accurately diagnosing the cause of post-traumatic problems should be considered as this is key to effective rehabilitation. An accurate diagnostic assessment and diagnostic formulation is key to delivering appropriate rehabilitation in TBI. A needs based assessment will not be effective. For example, patients have balance issues for a range of reasons after TBI, including TBI, migraine, cervical injury and vestibular impairment. These have completely different treatments, so a rehabilitation pathway that fails to make the correct diagnosis will fail the patient.</p>	<p>Thank you for your comment. This topic is focused on rehabilitation and does not cover management of medical or psychiatric co-morbidities of chronic neurological disorders. However this guideline will link to other NICE guidelines that are more concerned with diagnosis and treatment of chronic neurological disorders. This guideline will also consider how rehabilitation needs are identified and a soon to be published guideline, "Rehabilitation after traumatic injury", will cover early identification of possible TBI after injury as well as observation</p>

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				for emerging signs of TBI. This guideline will also consider a wide range of methods of identification of rehab needs and the numerous sources of identification and referral.
Association of British Neurologists	007	024	Areas not covered: 'management of medical and psychiatric co-morbidities' > This omission is very problematic for TBI. A holistic approach is necessary for successful rehabilitation of TBI. For example, psychiatric problems are extremely common after TBI. They are poorly managed and are a major cause of failure in rehabilitation. Guidelines should recognise the importance of a fully multi-disciplinary approach to rehabilitation, which includes input from neuropsychiatrists who will appropriately treat psychiatric problems in an integrated way.	Thank you for your comment. Although the recommendations about the clinical management of other conditions are outside of the scope of this guideline, recommendations will focus on a holistic approach. The guideline committee will have this mind when discussing what interventions to include for each review question protocol.
Association of British Neurologists	010	014	Economic aspects: Early multi-disciplinary rehabilitation after TBI has been shown to be cost effective and is an efficient way to improve long-term outcomes (e.g. St Georges Hospital data). This should be fully explored in the guidelines as it is key to improving rehabilitation for TBI. Currently rehabilitation services are separated from acute management in major trauma centres. This is inappropriate a more	Thank you for your comment. We will undertake the review of existing economic evidence in all key areas and undertake new economic modelling in selected areas that will be agreed with the committee. We will discuss your suggestion with the whole committee once development starts.

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			integrated approach to delivering rehabilitation through integrated teams should be considered.	
Association of British Neurologists	010	028	<p>'What works well': It should be recognised that services for TBI rehabilitation are currently poor. Patients receive limited rehabilitation from a fragmented service. Major structure services should be considered and specific recommendations made for TBI.</p> <p>This has proved very beneficial for stroke and TBI specific guidelines would have great impact.</p> <p>The need for an integrated multi-disciplinary rehabilitation for TBI should be recognised. Teams should intervene early and include access to a wide range of disciplines including neurology, neurosurgery, neuropsychiatry, neuropsychology, occupational therapy, speech and language therapy, physiotherapy etc.</p> <p>Consideration should be given to whether the existence of specific guidelines for particular conditions e.g. stroke has a detrimental effect on the availability of rehabilitation for other conditions. In a resource limited environment, the existence of</p>	<p>Thank you for your comment. We agree that the coordination and delivery of services, routes for referral and access to community rehabilitation are all important issues for this guideline to address. To deal with these issues the scope of the guideline will cover:</p> <ol style="list-style-type: none"> 1 Delivery of rehabilitation for people with chronic neurological disorders 2 Identification and referral including re-referral 3 Assessment, rehabilitation planning and review <p>In addition, and should the evidence allow, sub-group analysis of 5 chronic neurological disorder categories will be carried out (acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders).</p> <p>Stroke rehabilitation will not be covered in this</p>

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			guidelines and associated targets for conditions like stroke can have the perverse effect of limiting access to rehabilitation for conditions that do not have specific guidelines.	guideline because the topic has a separate NICE guideline.
Association Of British Neurologists	012	001	This is not very comprehensive - the effectiveness of interventions for all domains - bladder & bowel function, respiratory function, etc should be included.	Thank you for your comment. The wording provided in the guideline scope is a draft example. The exact wording and interventions included in evidence review protocols will be discussed and decided by the guideline committee.
Association Of British Neurologists	012	007	This should say "supporting people to enter, remain in, return to or exit employment". Leaving work well is a very important part of vocational rehabilitation.	Thank you for your comment. We have added 'or leave' to the referenced text.
Association Of British Neurologists	016	general	The outcome measures don't cover all domains - e.g., communication and pain are included but not mobility	Thank you for your comment. The list of outcomes provided in the scope are only examples of main outcomes that may be looked for in the evidence. The guideline committee will discuss potential outcomes, including those relating to mobility, before deciding the most suitable outcomes to include in each evidence review protocol.

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Association Of British Neurologists	general	general	FND should be included; a goal orientated rehabilitation or adjustment to disability approach in FND is just as valid as in other neurological disorders.	Thank you for your comment. Functional neurological disorders have now been included in the guideline scope and this specialty will be reflected in the guideline committee structure. If the evidence allows, rehabilitation for functional neurological disorders will also be considered for further exploration using sub-group analysis.
Association Of British Neurologists	general	general	Should there also be something in the guideline about recognising when rehabilitation is no longer appropriate and when end of life is approaching as this is often an issue with patients for example with Duchenne or Becker.	Thank you for your comment. As set out in the scope, end of life care interventions will not be included where they primarily focus on symptom control and comfort. However, there may be interventions that will be included within the context of rehabilitation towards the end of life.
Association Of British Neurologists	general	general	The guideline should consider all possible areas of inequality - race and gender aren't mentioned.	Thank you for your comment. The list of inequalities mentioned is not exhaustive, and is provided to highlight specific areas where this particular topic might have issues with inequalities. However, the recommendations within the guideline will consider health equalities in its broadest sense, including gender

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				and race and we have added reference to these to the scope.
Association of British Neurologists	General	General	The increasing digital offerings in the rehabilitation field should be considered including judgement about whether these approaches work and therefore might be useful in the near future. It is also worth including these because patients and carers (i.e. potential consumers of these apps and digital products) are already heavily targeted by marketing campaigns from companies so having some guidance might be helpful.	Thank you for your comment. The committee will consider whether digital delivery of rehabilitation will be covered in the areas of the guideline investigating the delivery of rehabilitation for people with chronic neurological disorders and supporting access to education, employment and social participation. The guideline committee will discuss which specific interventions to include in the protocols.
British Dietetic Association - Older People Specialist Group	003	014-015	Nutrition and hydration intervention are fundamental to optimising functioning. A core consideration is optimising and maintaining muscle mass. Cruz-Jentoft A et al (2018). Sarcopenia: revised European consensus on definition and diagnosis - PubMed (nih.gov) . Report of the European Working Group on Sarcopenia in Older People 2 (EWGSOP2)	Thank you for your comment. The guideline committee will discuss and decide what interventions to include in each question when developing the review protocols.
British Dietetic	003	029	Whilst the range of neurological conditions under consideration (MS, PD, MND, TBI) do have cross cutting themes regarding	Thank you for your comment. The guideline committee will discuss and decide what

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Association - Older People Specialist Group			<p>eating and drinking they do require different nutritional interventions and input from Dietitians</p> <p>ESPEN Guideline clinical nutrition in neurology (2017) https://www.espen.org/files/ESPEN-Guidelines/ESPEN-guideline_clinical_nutrition_in_neurology.pdf</p> <p>Multiple Sclerosis Society (2021) Eating and Drinking Eating and drinking Multiple Sclerosis Society UK (mssociety.org.uk) Diet and nutrition (March 2021) web.pdf (mssociety.org.uk)</p> <p>Parkinson Disease (2018) Diet & Parkinson's Diet Parkinson's UK (parkinsons.org.uk) B065 Diet and Parkinson's WEB.pdf (parkinsons.org.uk)</p> <p>Motor Neurone Disease (2020) Eating and drinking with motor neurone disease (MND) Swallowing, eating and drinking MND Association Eating-and-drinking-guide-2020-V1.pdf (mndassociation.org)</p> <p>Royal Hospital for Neuro-Disability (2016) Future Feeding Planning Pathway: https://www.rhn.org.uk/future-feeding/</p>	<p>interventions to include in each question when developing the review protocols. Should the evidence allow, sub-group analysis of 5 chronic neurological disorder categories will be carried out (acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders).</p>

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			Royal College of Physicians (March 2021) Supporting people who have eating and drinking difficulties https://www.rcplondon.ac.uk/projects/outputs/supporting-people-who-have-eating-and-drinking-difficulties	
British Dietetic Association - Older People Specialist Group	004	004	Welcome the guideline aims to address the rehabilitation needs of chronic neurological disorders regardless of diagnostic category. See above.	Thank you for your comment.
British Dietetic Association - Older People Specialist Group	004	012-020	Need to consider access and pathway to quality nutrition and dietetic assessments and education as wide variation in access and provision to expert neuro dietetic knowledge and skills	Thank you for your comment. Specific interventions will be discussed and decided by the guideline committee when designing protocols, but they are aware of the importance of nutrition, dietetics and hydration.
British Dietetic Association -	005	015	Will this include residential and nursing care homes? Will this include access for those in forensic settings?	Thank you for your comment. The guideline will include all of these settings.

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Older People Specialist Group				
British Dietetic Association - Older People Specialist Group	007	003	Need to consider access and pathway to quality nutrition and dietetic assessments and education as wide variation in access and provision to expert neuro dietetic knowledge and skills. Will this include residential and nursing care homes? Will this include access for those in forensic settings?	Thank you for your comment. Specific interventions will be discussed and decided by the guideline committee when designing protocols, but they are aware of the importance of nutrition, dietetics and hydration. Recommendations will apply to all settings apart from A+E departments, critical care units and prisons.
British Dietetic Association - Older People Specialist Group	007	014-019	Need to consider access and pathway to quality nutrition and dietetic assessments and education as wide variation in access and provision to expert neuro dietetic knowledge and skills and or access to e-learning / clinical supervision for generalist dietitians	Thank you for your comment. Specific interventions and phenomena of interest will be discussed and decided by the guideline committee when designing protocols, but they are aware of the importance of access nutrition, dietetics and education.
British Dietetic Association - Older People	024	006	To support outcomes on nutritional status recommend consideration of the these Nutrition related references (16.06.2021) to support	Thank you for your comment and suggestions. The guideline committee will use their expertise and other published guidance to discuss potential outcomes, including those relating to

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Specialist Group			<p>NICE Rehabilitation for chronic neurological disorder including traumatic brain injury</p> <p>National Institute for Health and Care Excellence (NICE) (updated 2017) Nutrition support in adults: Oral nutrition support, enteral tube feeding and parenteral nutrition. Clinical Guideline 32 https://www.nice.org.uk/Guidance/CG32</p> <p>National Institute for Health and Care Excellence (NICE) (2012) Nutrition support in adults Quality standard [QS24] https://www.nice.org.uk/Guidance/QS24</p> <p>PENG (2018) A Pocket Guide To Clinical Nutrition: 5th Edition A Pocket Guide To Clinical Nutrition (peng.org.uk)</p> <p>BDA (2019) BDA Outcome Guidance Document https://www.bda.uk.com/uploads/assets/562e2b60-c742-438b-93979ad5eec871a6/bdaoutcomesguidancedocument.pdf</p> <p>Rehabilitation King's College London - Post-ICU Presentation Screen (PICUPS) and Rehabilitation Prescription PICKUPS (2020). Available from:</p>	<p>mobility, before deciding the most suitable outcomes to include in each evidence review protocol. The references mentioned in your comment will be considered during this process.</p>

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			<p>King's College London - Post-ICU Presentation Screen (PICUPS) and Rehabilitation Prescription (RP) (kcl.ac.uk)</p> <p>O'Hanlon S, Smith M (2020) A Comprehensive Guide to Rehabilitation of the Older Patient 4th edition. BGS.</p> <p>Eating & drinking related Royal Hospital for Neuro-Disability (2016) Future Feeding Planning Pathway: https://www.rhn.org.uk/future-feeding/</p> <p>Royal College of Physicians (March 2021) Supporting people who have eating and drinking difficulties https://www.rcplondon.ac.uk/projects/outputs/supporting-people-who-have-eating-and-drinking-difficulties</p> <p>International Dysphagia Diet Standardisation Initiative Framework (IDDSI) (2019) https://iddsi.org/</p> <p>Consideration in neurological conditions BDA Neuroscience specialist group (NSC)</p>	

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			<p>ESPEN Guideline clinical nutrition in neurology (2017) https://www.espen.org/files/ESPEN-Guidelines/ESPEN-guideline_clinical_nutrition_in_neurology.pdf</p> <p>Multiple Sclerosis Society (2021) Eating and Drinking Eating and drinking Multiple Sclerosis Society UK (mssociety.org.uk) Diet and nutrition (March 2021) web.pdf (mssociety.org.uk)</p> <p>Parkinson Disease (2018) Diet & Parkinson's Diet Parkinson's UK (parkinsons.org.uk) B065 Diet and Parkinson's WEB.pdf (parkinsons.org.uk)</p> <p>Motor Neurone Disease (2020) Eating and drinking with motor neurone disease (MND) Swallowing, eating and drinking MND</p>	

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			<p>Association Eating-and-drinking-guide-2020-V1.pdf (mndassociation.org)</p> <p>Headway - the brain injury association Headway</p> <p>Considerations in older adults nutrition BDA Older People Specialist Group (OPSG) ESPEN Guideline on clinical nutrition and hydration in geriatrics (2018) https://www.espen.org/files/ESPEN-uidelines/ESPEN_GL_Geriatrics_ClinNutr2018ip.pdf</p> <p>SACN statement on nutrition and older adults (2021) SACN statement on nutrition and older adults - GOV.UK (www.gov.uk)</p>	
British Dietetic Association - Older People Specialist Group	General	General	Dietitians welcome a NICE for chronic neurological disorders (TBI) with a focus on rehabilitation. Optimising nutrition and hydration is key in optimising and maintain functional status and quality of life. We welcome assessing the evidence and consideration for a Dietitian to be part of the working group.	Thank you for your comment. Specific interventions will be discussed and decided by the guideline committee when designing protocols, but they are aware of the importance of nutrition and hydration in this context.

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			BDA (2019) BDA Outcome Guidance Document https://www.bda.uk.com/uploads/assets/562e2b60-c742-438b-93979ad5eec871a6/bdaoutcomesguidancedocument.pdf	
Greater Manchester Neuro-Rehabilitation Network	004	014-015	Could "symptoms" also be considered for the list e.g behavioural/cognitive symptoms that may require a specialist/MDT approach.	Thank you for your comment. This appears to refer to the section on referral criteria. 'Symptoms' has been added to the list.
Greater Manchester Neuro-Rehabilitation Network	General	general	Is it right that guidance for end of life care of people with neurological conditions is not detailed? We can still be heavily involved with patients at this stage of their condition to support with neurological symptoms and comfort. i.e secretion management and swallowing/ Neurogenic bladder and bowel/pain, spasticity and positioning management. We have come across situations where patients end up not having true MDT support as neurologists have discharged due to moving into the end of life phase and palliative care consultants feel they cannot manage neurological symptoms.	Thank you for your comment. As set out in the scope, end of life care interventions will not be included where they primarily focus on symptom control and comfort. However, there may be interventions that will be included within the context of the end of life period.

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Greater Manchester Neuro-Rehabilitation Network	Question from NICE 1	General	<ul style="list-style-type: none"> There is increasing evidence that FND is a neurological processing disorders, and therefore would benefit from being included within the guideline. "Patients with FMDs have several abnormalities in their neurobiology including strengthened connectivity between the limbic and motor networks. Additionally, there is altered top-down regulation of motor activities and increased activation of areas implicated in self-awareness, self-monitoring, and active motor inhibition such as the cingulate and insular cortex. Decreased activation of the supplementary motor area (SMA) and pre-SMA, implicated in motor control and preparation, is another finding. The sense of agency defined as the feeling of controlling external events through one's own action also seems to be impaired in individuals with FMDs. Correlating with this is a loss of intentional binding, a subjective time compression between intentional action and its sensory consequences." Taken from the abstract from 'Pathogenesis and pathophysiology of functional (psychogenic) movement disorders' José Fidel Baizabal-Carvalloab, Mark Hallett, 	<p>Thank you for your comment. Functional neurological disorders (FND) have now been included within the scope of this guideline and this specialty will be reflected in the guideline committee structure. If the evidence allows, rehabilitation for FND will be considered for further exploration using sub-group analysis. While we understand your colleagues' rationale for commissioning a new guideline specific for FND, there is a significant overlap between the rehabilitation needs of people with FND and those with other types of chronic neurological disorders. A separate guideline would duplicate effort and may cause confusion for people searching for recommendations.</p>

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			<p>Joseph Jankovica 2019 https://doi.org/10.1016/j.nbd.2019.02.013</p> <p>Neurocognitive functioning in patients with conversion disorder/functional neurological disorder - Vroege - 2021 - Journal of Neuropsychology - Wiley Online Library</p> <ul style="list-style-type: none"> • This is therefore clearly a neurological disorder, with an emerging body of evidence that the patients can be substantially improved with therapy based on the principles of neurological rehabilitation • Regarding arguing whether FND should be classified as Chronic, it is worth highlighting the relapsing and often progressive nature of the condition. Whilst some patients with mild cases get better and never struggle again, you could say the same about TBI. • FND patients are attendees of neurology clinics and are largely medically managed by neurologists; neurologists and all clinicians involved in their care would greatly benefit from FND within the scope of this guideline. 	

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			<ul style="list-style-type: none"> Although the majority of our clinicians felt FND should be within the scope of this guideline, there was a team who felt FND would benefit from a separate guideline due to the approach for working with these patients being different i.e. working collaboratively with mental health services, goals are more structured and are reviewed more regularly with the patients, they will also tend to be treated by the whole MDT rather than just working with one discipline. 	
Headway – the brain injury association	002	017	We would classify traumatic brain injury and brain tumours to be types of acquired brain injury, rather than separate conditions; furthermore, would it be possible to cite where the prevalence statistics included in this section are from?	Thank you for your comment. We have changed the scope to use the term acquired brain injury to include brain tumours and traumatic brain injury. It's NICE editorial style not to include references in scope context sections. Please also note that we have amended some of the statistics in response to stakeholders.
Headway – the brain	007	004	We would like to see the inclusion of transition from children's to adults' services. We know that this transition can be a testing time for individuals and their families with lots of change and some	Thank you for your comment. There is already a published NICE guideline "Transition from children's to adults' services for young people

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injury association			care needs can fall through the cracks. This guide could focus on the neurorehabilitation aspects of the transition.	using health or social care services (2016) [NICE guideline NG43]", which will be cross-referred as appropriate.
Headway – the brain injury association	010	014	It is encouraging to see that economic considerations will be included in the guidance. We would like to see an assessment of the economic value of community neurorehabilitation. According to the Healthcare Quality Improvement Partnership, people with traumatic brain injuries who receive rehabilitation once they have left the acute hospital setting, cost the NHS and social care £27,800 a year less than those who do not – National Clinical Audit of Specialist Rehabilitation for Patients with Complex Needs Following Major Injury . Not only does community rehab save money in long-term, it also accounts for improved outcomes for patients.	Thank you for your comment. We will undertake the review of existing economic evidence in all key areas and undertake new economic modelling in selected areas that will be agreed with the committee. We will discuss your suggestion with the whole committee once development starts.
Headway – the brain injury association	011	016	In this section we would like to see consideration given to the transition from hospital rehabilitation (both inpatient and outpatient care) to community neurorehabilitation. It is important that clinicians are aware of, and can appropriately sign-post to, community-based neurorehabilitation services that patients can access to continue their rehabilitation. This may include local	Thank your for your comment. Aside from the guidance mentioned, there is also an existing NICE guideline about transition between inpatient hospital settings and community or care home settings for adults with social care needs (NG27) as well as NG43 (Transition from children's to adults' services for young people

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			Headway support groups that are equipped to deliver rehabilitation services to clients or provide local peer support.	using health or social care services). Any additional gaps in recommendations are anticipated to be covered in evidence reviews regarding delivery of rehabilitation for people with neurological disorders.
Headway – the brain injury association	General	General	We would like to see the inclusion of assessment in relation to the impacts of the COVID pandemic on rehabilitation services. According to a study published by Headway, The Impact of Lockdown on brain injury survivors and their families , 57% of people who sustained a brain injury within the last two years had been denied vital rehab services. Consideration should be given to how we are able to 'catch up' with these lost rehab services and what additional support may be needed by those whose rehab has been negatively affected.	Thank you for your comment. In order to protect this guideline for the future, issues related to COVID-19 are outside of this scope.
Headway – the brain injury association	General	General	An assessment of geographical access to rehabilitation services should be included in the scope. The number of in-patient neurorehabilitation beds varies wildly across the country and that coupled with the disparity of access to neurorehabilitation leads to a postcode lottery for brain injury survivors.	Thank you for your comment. Geography and socioeconomic status is covered in the equality consideration section of the scope. The guideline will consider how these might affect a person's access to rehabilitation services, and how systems can decrease potential barriers.

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Headway – the brain injury association	General	General	It would be useful to include an understanding of the funding pathway for neurorehabilitation services from acute in-patient care through to community care. Understanding the relationship between the various government departments and local authorities and which fund which aspect of rehabilitation.	Thank you for your comment. The guideline committee will take funding pathways (and relationships between funding authorities) into account whilst reviewing evidence and developing recommendations.
Multiple Sclerosis Trust	003	005-006	Include multiple sclerosis as an example of progressive neurological disorders. Progressive neurological conditions may also require acute treatment – for example sudden loss of mobility due to multiple sclerosis relapse.	Thank you for your comment. We have amended the scope to include multiple sclerosis as an example of a progressive neurological disorder. Regarding your second query, , the committee may discuss recommendations for treatment if it will have consequences for a person's rehabilitation
Multiple Sclerosis Trust	004	003-004	“Regardless of diagnostic category” – would it be better to separate into acute and chronic? Should consider splitting out progressive conditions from acute/stable (e.g. SCI) as the approach and needs differ so much.	Thank you for your comment. We have amended the scope to reference the following categories: acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders. Should the evidence allow, these categories will also be used in sub-group analysis.

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Multiple Sclerosis Trust	011	001-002	<p>1.1 Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?</p> <p>This question needs clarification and more detail. For example “based on the views and preferences of everyone involved” – does this “everyone” refer to members of Guideline Committee or does it refer to evidence-based views of patients/carers/health and social care professionals. More detail of what this question encompasses is also needed – for example will this question address setting, for example in-patient/out-patient/community delivery of neurorehabilitation? Length of treatment course? Self-referral to access further courses of treatment? Effectiveness of teleconsultations and telerehabilitation? Motivational techniques?</p>	<p>Thank you for your comment. The questions listed in the scope are draft questions for evidence reviews. The full review questions will be discussed and agreed by the committee. Review protocols will further clarify the phenomena of interest and settings. Currently, this review question is a qualitative review question so any themes on barriers and facilitators to rehabilitation delivery will largely be driven by the literature findings.</p>
Multiple Sclerosis Trust	011	012	<p>Based on the views and preferences of everyone involved</p> <p>As in comment 6, what is meant by “everyone involved”? More detail required on what this question encompasses.</p>	<p>Thank you for your comment. The term 'everyone involved' refers to healthcare professionals, people with rehabilitation needs and their support networks. This will be clarified in protocols as well as recommendations where appropriate.</p>

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Multiple Sclerosis Trust	012	001	Based on the views and preferences of everyone involved As in comment 6, what is meant by "everyone involved"? More detail required on what this question encompasses.	Thank you for your comment. The term 'everyone involved' refers to healthcare professionals, social care professionals, people with rehabilitation needs and their support networks. This will be clarified in protocols as well as recommendations where appropriate.
Multiple Sclerosis Trust	012	013-014	Key issues and draft questions will be used to develop more detailed review questions Will stakeholders have an opportunity to comment on more detailed review questions?	Thank you for your comment. Stakeholders will not be able to comment on more detailed review questions. These will be agreed by the guideline committee, made up of experts in rehabilitation after chronic neurological disorders (both health and social care professionals and people with lived experience).
Multiple Sclerosis Trust	General	General	Appropriateness of including Functional Neurological Disorders (FND) We would 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. Long-term outlook for patients is poor with most continuing through their lives with long-term	Thank you for your comment. Functional neurological disorders have now been included in the scope of this guideline and this specialty will be reflected in the guideline committee constituency. If the evidence allows, rehabilitation for functional neurological disorders will also be considered for further exploration using sub-group analysis.

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			<p>disabling symptoms. There are no treatment options apart from rehabilitation and neuropsychology.</p> <p>Suspected neurological conditions: recognition and referral Quality standard QS198- Quality statement 5 https://www.nice.org.uk/guidance/qs198/chapter/Quality-statement-5-Functional-neurological-disorders-in-adults recognises the need to support adults diagnosed with FND to manage symptoms that are part of the disorder. We would argue that a specialist knowledge of neurorehabilitation is essential to support people diagnosed with FND. This consensus shows the scope for physiotherapy interventions: Nielsen G, Stone J, et al. Physiotherapy for functional motor disorders: a consensus recommendation. J Neurol Neurosurg Psychiatry. 2015 Oct;86(10):1113-9. doi: 10.1136/jnnp-2014-309255. https://pubmed.ncbi.nlm.nih.gov/25433033/.</p>	
Multiple Sclerosis Trust	General	General	<p>Is there evidence to support condition-specific specialist neurorehabilitation health professionals rather than a general neurorehabilitation health professionals? For example, is there evidence that a Parkinson's specialist neurophysiotherapist can deliver the same outcomes as a general neurophysiotherapist?</p>	<p>Thank you for your comment.</p> <p>All NICE guidelines are produced following rigorous, clear, documented methodologies. Committee members will use their collective expertise to interpret the evidence and make</p>

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				recommendations that are both general for the whole population and that are specific for particular groups where necessary and where data allow. For example, in some areas (if evidence exists), sub-group analysis of 5 chronic neurological disorder categories will be carried out (acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders).
Multiple Sclerosis Trust	General	General	The scope of this guideline is very broad and evidence is likely to be condition-specific rather than covering neurological rehabilitation in general. How does the committee intend to evaluate and extrapolate evidence from specific conditions and generate recommendations which apply across the breadth of neurological conditions?	Thank you for your comment. All NICE guidelines are produced following rigorous, clear, documented methodologies. Committee members will use their collective expertise to interpret the evidence and make recommendations that are both general for the whole population and that are specific for particular groups where necessary and where data allow. For example for some areas and subject to the evidence, sub-group analysis of 5 chronic neurological disorder categories will

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				be carried out (namely acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders).
Multiple System Atrophy Trust	003	012	We welcome the definition of rehabilitation used, recognising it is about optimisation.	Thank you for your comment.
Multiple System Atrophy Trust	007	016	Assessment of rehabilitation and review- We think the scope should explicitly address the ease of re-referral after fixed term therapy interventions. For example, people with Multiple System Atrophy may get a six week programme of physiotherapy but then, if their needs subsequently change due to worsening and progression, they often have to go through a whole process of referral again to get back into the "system".	Thank you for your comment. We have added an explicit reference to re-referral in the key area and draft question about identification and referral. So re-referral is now clearly within scope.
Multiple System Atrophy Trust	010	022	Welcome the key issues, especially 4.5 incorporating emotional health and wellbeing.	Thank you for your comment.
Multiple System	General	General	Not sure where it would fit in but we would recommend the scope includes the effective co-ordination of rehabilitation	Thank you for your comment. It is anticipated that co-ordination of rehabilitation interventions

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Atrophy Trust			interventions. People with Multiple System Atrophy may need a suite of interventions from a range of therapists such as Speech and Language Therapists, Occupational Therapists, counsellors and Physiotherapists for example. These interventions need to be effectively co-ordinated as part of a Multi-Disciplinary Team approach and we are not sure the scope presently reflects the fact that people may need this range of support and not just one therapy at a time.	will be covered by the following scope areas: Delivery of rehabilitation for people with chronic neurological disorders; Identification and referral including re-referral; Assessment, rehabilitation planning and review. As it stands, these all include a qualitative component, which is ideal to answer what co-ordination aspects work well and what can be improved.
National Hospital for Neurology and Neurosurgery	002	022	The definition of a LTNC may need to be refined- it comprises a diverse set of conditions resulting from injury or disease of the nervous system that will affect an individual for life. Dividing it into 2 categories simplifies matters but doesn't address the episodic conditions eg epilepsy and the stable conditions with/without age-related degeneration (eg polio or cerebral palsy) as being separate to the acute or the progressive conditions, perhaps more nuance is required.	Thank you for your comment. We have amended the scope to reference the following categories: acquired brain injury; spinal cord injury or disorders; progressive neurological disorders; functional neurological disorders.
National Hospital for Neurology	002	022	It needs to be very clear at the start of the document why stroke is not included (only becomes apparent by p.6) and why. Since stroke is the most common cause of chronic neurological	Thank you for your comment. NICE scopes follow a standard format where the areas excluded from the scope are listed in the

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and Neurosurger y			disability, it might be useful to include in order to highlight it has its own guidance and this is aimed at other (often neglected) conditions.	sections called "Groups that will not be covered" and "Areas that will not be covered". The first section of the scope called "why the guideline is needed" focuses on what IS included in the scope, not what is not included. We think the way this information is set out is clear and simple.
National Hospital for Neurology and Neurosurger y	002	025	We disagree with the statement that 'brain injury' (especially if it includes stroke) is 'static'. For example, at 5 years post-stroke, patients (on average) are back to where they were 2 months after stroke. This is similar for other 'single incident' conditions. Very important point as it leads to stroke/TBI services being 'front-loaded' with little available after 6 months whereas rehab needs are ongoing for many years (lifelong).	Thank you for your comment. We have removed the word 'static' from the description. The scope now references acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders
National Hospital for Neurology and Neurosurger y	003	003	We welcome the guideline and are pleased it covers all progressive neurological disorders including neuromuscular disease, It would be useful to acknowledge issues for people with rare neurological diseases accessing rehabilitation which impacts on both patients and treating teams. Colleagues may have limited experience in some rare diseases and discontinue rehabilitation if	Thank you for your comment. We anticipate that the issues you have referred to will be covered in the following areas of the guideline: delivery of rehabilitation, identification and referral of people with chronic neurological disorders. These questions will be qualitative in nature, and

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			they are not clear what interventions can help that person. Also, people with rare neurological diseases lose trust in some local rehabilitation services if they perceive that there is limited knowledge of their condition. Accessing specialist national services needs to be included.	will include the views of people with chronic neurological rehabilitation needs and healthcare professionals involved in their rehabilitation. The guideline will include reference to all rehabilitation services including specialist national services
National Hospital for Neurology and Neurosurgery	003	011	The needs of people with LTNCs who have another acute illness eg fall and fracture or infection and being seen in A&E / acute care should be included as they frequently deteriorate at that time if their rehab needs are not tailored to the neuro condition.	Thank you for your comment. This guideline will consider the rehabilitation needs of people with pre-existing conditions, disabilities or who are frail. A soon to be published, NICE guideline, Rehabilitation after traumatic injury, also covers the holistic assessment of people based on individual rehabilitation needs as well as type of injury.
National Hospital for Neurology and Neurosurgery	004	020	(such as that provided by community neurorehabilitation teams) seems an inappropriate example, community services may look at impairment level of functional goals. Suggest change to (functional goals such as managing personal care or preparing a meal).	Thanks for your comment. We agree and have amended the scope to say "Rehabilitation can involve impairment-focused approaches, for example to improve mobility, or a less impairment-specific focus towards functional goals (such as managing personal care or preparing a meal)"

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National Hospital for Neurology and Neurosurgery	005	024	We are disappointed that they have skirted around the issue of race and ethnic background here. There is evidence that health inequalities for people from ethnic minority groups go hand in hand with structural racism that manifests as "gatekeeping" of specialist services that could include rehabilitation. A different skin colour is not the same as cultural differences, as there can be cultural differences within white minority groups. We would welcome this aspect be considered too.	Thank you for your comment. The list of inequalities mentioned is not exhaustive, and is provided to highlight specific areas where this particular topic might have issues with inequalities. However, the recommendations within the guideline will consider health inequalities in its broadest sense, including gender and race and we have added reference to these to the scope.
National Hospital for Neurology and Neurosurgery	005	024	A further area of health inequality that must be considered is the artificial barriers put up between for example stroke community neuro support and neurological (all non-stroke) community support. This is an artificial boundary and results in vastly different services in terms of quality, resources and timeliness of intervention despite often similar clinical need. Likewise the artificial boundary between patients with neurological conditions and learning disability vs those with the same complex needs but an IQ of >70.	Thank you for your comment. The committee will consider how services are delivered and how rehabilitation needs are identified and people referred as part of key areas 1 and 2. The committee will consider evidence about what works well and what could be improved. Where we have evidence we will consider health inequalities between different groups including people with learning disabilities.
National Hospital for	006	003	What about Functional Neurological Disorders (FND)? These should be included as they benefit for the same structures	Thank you for your comment. Functional neurological disorders have now been included

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Neurology and Neurosurgery			rehabilitation approach but perhaps may be better suited to their own guidance?	in the guideline scope and this specialty will be reflected in the guideline committee structure. If the evidence allows, rehabilitation for functional neurological disorders will also be considered for further exploration using sub-group analysis.
National Hospital for Neurology and Neurosurgery	007	003	Exclusion of Critical care units means those with severe TBI / brain injury, GBS, myaesthesia etc will not have a guideline on their acute rehabilitation needs and prevention of complications if critical illness, immobility etc. Or are these covering in a different guideline?	Thank you for your comment. There already is an existing guideline on Rehabilitation after critical illness in adults (2017) [NICE quality standard 158], which will be referred to where appropriate.
NICE-Quality standards and indicators	General	General	The draft scope notes some NICE quality standards related to or of relevance to the topic. There are additional quality standards that include quality statements on rehabilitation of chronic neurological disorders that may be of relevance: stroke QS2, cancer services for children and young people QS55, metastatic spinal cord compression in adults QS56, head injury QS74, multiple sclerosis QS108, Parkinson's disease QS164 and cerebral palsy in adults QS191.	Thank you for your comment. We have added these quality standards to the 'Related NICE guidance' section of the scope.
NICE-Quality	General	General	Quality statement 6 on inpatient rehabilitation for people with traumatic brain injury in QS74 on head injury uses SIGN 130 as	Thank you for your comment. Identification, referral and assessment of traumatic brain injury

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standards and indicators			source guidance. SIGN 110 was withdrawn as source guidance when the guideline was withdrawn by SIGN. The statement was retained based on expert opinion. It would be helpful if the proposed guideline on rehabilitation for chronic neurological disorders including traumatic brain injury could consider development of recommendations on assessment for inpatient rehabilitation for people with traumatic brain injury.	will be covered in this guideline as part of acquired brain injury, including inpatient settings.
NICE- Quality standards and indicators	General	General	Quality standard QS74 on head injury contains a placeholder statement on post-acute phase rehabilitation for children and young people. The draft scope suggests that this population will be covered in the guideline, and recommendations may be used as source guidance to develop a quality statement in this area.	Thank you for your comment. This guideline will cover the rehabilitation needs of children and young people (and adults) after acquired brain injury outside of A+E departments and critical care units.
Recolo UK Ltd	005	005	Is this guideline <u>not</u> for use in privately run rehabilitation services? Please can this be made clear.	Thank you for your comment. Yes, this guideline is intended to be used in privately run rehabilitation services as long as they are at least partly funded by public service funding. This is covered by the bullet point 'providers of neurological rehabilitation services in the community, including charities, third sector and private sector providers'

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Recolo UK Ltd	006	005	<p>Groups that will be covered: as your comment in covering instructions, a difficult decision whether to include Functional Neurological Disorders.</p> <p><i>FNDs are neurologically represented in the brain therefore could be considered candidates for neurological rehabilitation. However our experience is that this would require a high level of psychological/neuropsychiatric input. A formulation-based approach looking at clusters of symptoms, addressing these with appropriate treatment is necessary. Such intervention will need psychological supervision due to the psychological, systemic and transference factors involved in development and maintenance of (and treatment for) the condition. Conceptualisation of each case should include information from neuropsychological and neuropsychiatric assessment, formulation of the bio-psycho-social factors and symptom-based treatments, but with understanding in the team of the psychological dynamics involved in treating people with a 'functional disorder' – and ways to manage them.</i></p> <p>We also note that there is some controversy over the very existence and diagnosis of such conditions. This means a position</p>	<p>Thank you for your comment. While we understand your rationale for a separate guideline on functional neurological disorders (FND), we have decided to extend the scope on this guideline to include rehabilitation for FND. While the causes and diagnosis of FND may be different from other chronic neurological disorders, there is significant overlap between the rehabilitation needs of both populations. A separate guideline would duplicate effort and may cause confusion for people searching for recommendations.</p>

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			<p>should be agreed on in relation to FND as a diagnosis, and acknowledgment given to other understandings.</p> <p><i>Having said that, regarding provision of clinical guidelines, good input for non-functional disorder involves such conceptualisation and intervention e.g. psychogenic and maintenance factors acknowledged and managed in the treatment.</i></p> <p>Given these factors, it may be simpler not to include FND but have specific links to a document on FND presentations and management.</p>	
Recolo UK Ltd	006	005	<p>What ages does this guidance relate to, will there be differences in guidance for children versus adults, versus young people?</p> <p>If you are going to write guidelines to cover children and young people, please make sure it's written in a way that is child-focused and specific to the needs of children and young people with brain injury. The approach will be different in many ways than in adults (addressing developmental issues, systemic factors as well as the immediate clinical issues experienced by the individual).</p>	<p>Thank you for your comment. We appreciate the differences in the rehabilitation needs of those with chronic neurological conditions between paediatric and adult populations. We have appointed a paediatric specialist in neurological rehabilitation as a topic advisor and will recruit a number of roles to the committee with paediatric expertise. Evidence about children and young people will be reported separately to</p>

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			<p>Therefore –please note and mark the overlaps in the guidelines and signpost the additional considerations.</p> <p>We are particularly concerned that children are not just treated as 'small adults'.</p> <p>Another key factor relates to young adults where issues of identity, transition, independence etc are at the fore – and clinical guidelines need to give particular consideration and professionals to have competencies in this service delivery.</p>	<p>evidence about adults within the evidence reports and the committee will have opportunities to write recommendations for different age groups</p>
Recolo UK Ltd	006	005	<p>Can you clarify whether Cerebral Palsy is not included here and referred to in separate guideline? As some of conceptualisation (CP can result from an ABI), formulation and interventions will overlap.</p>	<p>Thank you for your comment. The NICE guideline Cerebral palsy in adults NG119 already covers some aspects of rehabilitation, as does Cerebral palsy in under 25s: assessment and management (NG62). We recognise however that this guideline may include aspects of rehabilitation that those guidelines do not, for example in relation to the example you include here. Therefore, the coverage of cerebral palsy</p>

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				as a result of acquired brain injury will be discussed by the committee when they develop the detailed elements of the review questions and protocols. . Should the evidence allow, sub-group analysis of 5 chronic neurological disorder categories will be carried out (acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders).
Recolo UK Ltd	007	003-005	Does this only cover publicly funded rehabilitation settings? There are many private companies / charities that deliver rehab.	Thank you for your comment. We have amended this to read "All inpatient (excluding critical care units), outpatient and community settings, including tertiary settings and care homes in which either fully or partially publicly funded rehabilitation interventions for chronic neurological disorders are provided".
Recolo UK Ltd	007	011	Are Mental Capacity and Deprivation of Liberty Safeguarding going to be key areas covered?	Thank you for your comment. This is covered by existing NICE guidance ("Decision-making and mental capacity", NG108) and will be cross-referenced where appropriate.

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Recolo UK Ltd	007	014-019	<p>Consideration of interventions to support family adjustment and their own psychological needs is required. This is because they are a key part of the environment for the rehabilitation of the individual regardless of age. As family, caregivers should be an essential part of the rehab team, their competencies, abilities to be collaborative partners in the rehab are essential.</p> <p>Ref: Ylvisaker & Feeney (1998) Collaborative brain injury intervention: positive everyday routines. San Diego: Singular Publishing</p>	<p>Thank you for your comment. We anticipate that the issues you have referred to will be covered in the following areas of the guideline: Delivery of rehabilitation for people with chronic neurological disorders; and supporting access to education, employment and social participation.</p>
Recolo UK Ltd	007	019	<p>Do you have Educational Psychologists on the NICE advisory panel to advise on supporting access to education? Do you have Organisational Psychology or Vocational Case Managers to advise on employment?</p> <p>Are Social Services involved? (we know some Social Work settings have been deficient in knowledge about Mental Capacity)</p>	<p>Thank you for your comment. The intended constituency for the committee includes education experts, for example in special educational needs, case managers including those with vocational expertise, social workers and care workers.</p>
Recolo UK Ltd	010	026	<p>Change the wording: it is <u>essential</u> that separate reviews of evidence be undertaken for CYP and adults. As above many</p>	<p>Thank you for your comment. We appreciate the differences in chronic neurological conditions</p>

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			different factors and trajectories involved are reflected in the different evidence bases. For example there is a much more sparse evidence base for interventions in CYP than in adults. However this should not preclude the provision of clinical guidelines. Where there is a lack of evidence, rigorous attempts should be made to address this to provide 'good enough' rehabilitation.	rehabilitation needs between paediatric and adult populations. Evidence about children and young people will be reported separately to adults within the evidence reports and the committee will have opportunities to write recommendations for different age groups. Additionally, we have appointed a paediatric specialist in neurological rehabilitation as a topic advisor and will recruit a number of roles to the committee with paediatric expertise
Recolo UK Ltd	011	009-011	As we are constantly reviewing the evidence base to guide our practice, we are always aware of the inadequacy of the evidence base around rehabilitation for CYP and young adults. This means that 3.1 is difficult to answer for this age range. Please can we be clear that this issue is not 'fudged' and that the NICE team can push for better resources to fund this gap.	Thank you for your comment. We appreciate the differences in rehabilitation needs between paediatric and adult populations with chronic neurological disorders.. Evidence about children and young people will be reported separately to evidence about adults within the evidence reports and the committee will have opportunities to write recommendations for different age groups. If the evidence is not available for children and young people the committee can consider extrapolating from the

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				adult evidence and use their expertise to write recommendations. In addition they can make research recommendations to address any evidence gaps.. Additionally, we have appointed a paediatric specialist in neurological rehabilitation as a topic advisor and will recruit a number of roles to the committee with paediatric expertise. NICE is unable to invest in research directly but NICE research recommendations can be influential in attracting funding from the NIHR.
Royal College of Paediatrics and Child Health	General	General	The reviewer believes that functional neurological disorders should be addressed in a separate guideline as the cause of functional disorders and its management can be quite different to those addressed in this guideline. Even-though some aspects of the rehabilitation will overlap between these two groups, including functional disorders in this guideline might lead to confusion among users.	Thank you for your comment. While we understand your rationale for a separate guideline on functional neurological disorders (FND), we have decided to extend the scope on this guideline to include rehabilitation for FND. While the causes and treatment of FND may be different from other chronic neurological disorders, there is significant overlap between the rehabilitation needs of both populations. A separate guideline would duplicate effort and

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				may cause confusion for people searching for recommendations.
Royal College of Paediatrics and Child Health	General	General	The reviewer supports the rationale for including Functional Neurological Disorders's (FND) in the guideline. Patients understanding and acceptance of the disease is important. Taking unnecessary medications can also negatively affect prognosis. Interdisciplinary collaboration and neurological care is required to improve the QoL of these patients. Promising evidence has accumulated for the benefits of specific physical rehabilitation and psychological interventions alone or in combination for patients with FNDs this can be achieved by including functional neurological disorder in the scope of the guideline.	Thank you for your comment. Functional neurological disorders have now been included in the scope of this guideline.
Royal College of Paediatrics and Child Health	General	General	In the UK, approximately 35,000 children per annum were seen in the accident and emergency departments due acquired brain injury (ABI), and 5% of them were classified as having moderate to severe brain injury. These children need ongoing care to manage their movement difficulties, weakness, abnormal muscle tone, fatigue and other comorbidities. The reviewers strongly believe that functional neurological disorders and acquired brain injury (traumatic and non-traumatic) should be included in the scope of	Thank you for your comment. Acquired brain injury and functional neurological disorders have been included in the guideline scope. If the evidence allows, rehabilitation for acquired brain injury and functional neurological disorders will also be considered for further exploration using sub-group analysis.

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			<p>the NICE guideline for rehabilitation for chronic neurological disorders.</p> <p>The reviewers have recently written to the journal of Developmental Medicine and Child Neurology (Letter to editor, Paediatric neurorehabilitation: we must do better https://www.mackeith.co.uk/wp-content/uploads/2016/12/Rathinam-LET.pdf) explaining their views and urge NHS England to prioritise neurorehabilitation for ABI in children. The content of the communication is highly relevant and merit the justification for the support for the above said topic.</p>	
Royal College of Paediatrics and Child Health	General	General	<p>Important areas to be addressed in the guideline should include:</p> <ul style="list-style-type: none"> a. Preventive strategies/resilience b. Lack of reliable epidemiological data <p>Serious research underfunding</p>	Thank you for your comment and for highlighting these important issues, which the committee are likely to consider in their discussions.
Royal College of Speech &	004	002	RCSLT recommend specifically adding remote therapy and virtual therapy delivered digitally.	Thank you for your comment. It is anticipated that remote and virtual therapy will be covered in the areas of the guideline investigating the delivery of rehabilitation for people with chronic

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Language Therapists			During the pandemic digital and remote consultation was extensively used and continues to play a big part. This should be reflected in the Guideline.	neurological disorders and supporting access to education, employment and social participation. However, the guideline committee will discuss which specific interventions to include in the protocols.
Royal College of Speech & Language Therapists	005	027-028	RCSLT recommend that you look at the impact of remote therapy and if it can disadvantage certain groups of people.	Thank you for your comment. We have included a section on the delivery of rehabilitation, which will look at modes of delivery. This will be further specified by the committee within the review question protocols.
Royal College of Speech & Language Therapists	007	003	Please confirm if tertiary rehabilitation settings are in scope.	Thank you for your comment. Tertiary rehabilitation settings will be covered in this scope, and amendments to include this have been made.
Royal College of Speech & Language Therapists	011	001-002	Will this include people/family feedback as well as clinician's feedback? People with CNS may need support with communication to take part and express their views.	Thank you for your comment. Questions will include the views of people with rehabilitation needs pertaining to chronic neurological disorders, their friends and family (where appropriate) and health and social care professionals.

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Royal College of Speech & Language Therapists	011	006	Within this search question on identifying services, it would be worthwhile to search for barriers and facilitators with regard to (1) availability of services and (2) access criteria of services.	Thank you for your comment. As it stands, this question is designed to be a qualitative question and therefore the results will largely be driven by the data. It is likely that relevant studies will cover the types of issues you mention.
Royal College of Speech & Language Therapists	011	008	Please add a search on the effectiveness of remote therapy or therapy delivered remotely. This is increasingly being used as a method of delivery across the NHS and would be useful to capture these new approaches.	Thank you for your comment. It is anticipated that remote therapy delivery of rehabilitation will be covered in the areas of the guideline investigating the delivery of rehabilitation for people with chronic neurological disorders and supporting access to education, employment and social participation. However, the guideline committee will discuss which specific interventions to include in the review protocols.
Royal College of Speech & Language Therapists	011	017	We recommend that you add an add a further sub-question 4.6 "What is the effectiveness of interventions and approaches for improving or supporting eating, drinking and swallowing (dysphagia)?"	Thank you for your comment. Rehabilitation interventions to help eating, drinking and swallowing will be considered as part of drafting detailed review protocols for the following three review areas. More details will be decided by experts on the committee: 4.2 What is the effectiveness of interventions

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				and approaches for improving and sustaining physical functioning including strength, mobility and balance? 4.3 What is the effectiveness of interventions and approaches for improving or supporting speech, language and communication? 4.4 What is the effectiveness of interventions and approaches for improving and maintaining cognitive function?
Royal College of Speech & Language Therapists	011	026	RCLST recommends this is worded as “speech, language and communication”, and that specific communication disorders commonly experienced in this area are also considered in searching and assessing the evidence. Searches only focussed on “communication” may not always relate to specific speech, language and communication needs which potentially require intervention as part of rehabilitation.	Thank you for your comment. We have amended the wording in the list of possible main outcomes that the committee may consider when assessing the evidence.
Royal College of Speech & Language Therapists	012	001	We recommend adding a question to ask what are the barriers to enter, remain in or return to work or education.	Thank you for your comment. Barriers to enter, remain in or return to work or education will be covered in the draft review question 'Based on the views and preferences of everyone involved, what works well and what makes it difficult to

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				access support for education, employment and social participation?'
Royal College of Speech & Language Therapists	012	006	Within this question it would be beneficial to look at interventions that are led through employers and workplace support, not only focus on NHS interventions.	Thank you for your comment. The guideline committee will discuss which specific interventions to include in the protocols, and will take your suggestion into account.
Royal College of Speech & Language Therapists	012	021	RCLST recommends this is worded as "speech, language and communication", and that specific communication disorders commonly experienced in this area are also considered in searching and assessing the evidence. Searches only focussed on "communication" may not always relate to specific speech, language and communication needs which potentially require intervention as part of rehabilitation.	Thank you for your comment. We have amended the wording in the list of possible main outcomes that the committee may consider when assessing the evidence.
Royal College of Speech & Language Therapists	012	024	Nutrition status could be expanded to include eating, drinking and swallowing needs.	Thank you for your comment. The list of outcomes provided in the scope are only examples of main outcomes that may be looked for in the evidence. The guideline committee will discuss potential outcomes, including those relating to nutrition (for example eating, drinking and swallowing needs), before deciding the most

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				suitable outcomes to include in each evidence review protocol.
Spinal Injuries Association	002	018	There is no mention of disease prevalence for Spinal Cord Injury, but disease prevalence has been given for Parkinson's, MND etc. This omission should be corrected.	Thank you for your comment. As the numbers were relatively small and as we are looking at injuries to the spine that also cause neurological impairment we decided to leave the figures out of the scope rather than risk any inaccuracies.
Spinal Injuries Association	002	026	The effects on people's lives after sustaining a Spinal Cord Injury vary greatly. Those with paraplegia or tetraplegia are paralysed for life, and with life-changing consequences for themselves, their families and their friends.	Thank you for your comment. We agree that spinal cord injury affects people to different extents. Therefore, recommendations from this guideline will cover longer-term rehabilitation after spinal cord injury, regardless of prognosis. Should the evidence allow, spinal cord injury will be investigated as a sub-group in order to determine potential differences in the rehabilitation needs of people with spinal cord injury. Further recommendations on spinal cord injury rehabilitation exists in 2 NICE guidelines (NG41 Spinal injury: assessment and initial management and Rehabilitation after traumatic

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				injury (to be published 2022)) and will be cross-referenced where appropriate.
Spinal Injuries Association	003	028	Those who sustain a Spinal Cord Injury need complex intervention that requires intervention across several psychosocial domains.	Thank you for your comment. The guideline committee will discuss and decide what interventions to include in each question when developing the review protocols. Should the evidence allow, sub-group analysis of 5 chronic neurological disorder categories will be carried out (acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders). It will therefore be possible for the committee to write discrete recommendations about spinal cord injury in areas where this is seen as important and in areas which complement the recommendations on general and specific rehabilitation for spinal cord injury in the new NICE guideline on rehabilitation after traumatic injury.

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Spinal Injuries Association	004	007	If (they are available) are there any NICE guidelines on Spinal Cord Injury? It would be suitable to develop specific NICE guidelines on Spinal Cord Injury.	Thank you for your comment. Apart from this guideline when published, there are 2 other NICE guidelines addressing management of spinal cord injury: Spinal injury: assessment and initial management (NG41) and Rehabilitation after traumatic injury (to be published). Both of these are listed with hyperlinks in the related NICE guidance section of the scope.
Spinal Injuries Association	004	021	Referral criteria may also include location and access to specialist services therein.	Thank you for your comment. We have added addressed this by adding the line to the scope 'Referral criteria often inform decisions about people's access to specialist rehabilitation services'.
Spinal Injuries Association	004	025	Transition from hospital to community settings is also highly variable for those with Spinal Cord Injury and other degenerative brain disorders.	Thank you for your comment. We agree that transition from hospital to community settings is very variable for people with spinal cord injury and other degenerative brain disorders. This is acknowledged within the equality impact section and any recommendations (specifically within the delivery of rehabilitation section) will take into account the potential impact of geography,

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				socioeconomic status, age-related service assumptions and cultural differences.
Spinal Injuries Association	005	012	Practitioners may also include charities with a specialist interest.	Thank you for your comment. We have amended the 'Who the guideline is for' section to include charities.
Spinal Injuries Association	005	027	Specialist Spinal Centres e.g. the National Spinal Injuries Centre at Stoke Mandeville also should be considered, as many people who sustain a Spinal Cord Injury and are referred for specialist treatment are unable to receive in-patient care and rehab in a specialist Centre.	Thank you for your comment. All settings except A+E departments, critical care units and prisons will be considered.
Spinal Injuries Association	007	018	Referrals to onward services e.g. physiotherapy or psychological support should also be considered. Many people who sustain a brain injury (including Spinal Cord Injury) then go onto suffer depression, and mental health issues, excluding this criteria from this section limits the scope of the study.	Thank you for your comment. We anticipate that your concerns will be addressed in key areas 2 and 3 of the scope (Identification and referral including re-referral; Assessment, rehabilitation planning and review).
Spinal Injuries Association	011	009	The "appropriateness" as well as the "effectiveness" of intervention tools and approaches should be considered.	Thank you for your comment. Appropriateness may be seen as part of effectiveness, depending on what the outcome measures are for a particular review question. Appropriateness will also be widely picked up in the qualitative evidence reviews which will look at supporting

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				access to education, employment and social participation, delivery of rehabilitation and assessment.
Spinal Injuries Association	012	014	Access to services should also be considered when searching for and assessing the evidence as well as experience of services. For those who sustain a Spinal Cord Injury, many people are referred for specialist treatment but are unable to receive in-patient care and rehab in a specialist Centre.	Thank you for your comment. It is anticipated that this will be covered in the section regarding delivery of rehabilitation for people with chronic neurological disorders.
Spinal Injuries Association	012	014	Accessibility related requirements should also be considered when searching for and assessing the evidence.	Thank you for your comment. The guideline committee will discuss and decide which specific interventions to include when developing evidence review protocols.
The Disabilities Trust	002	general	The term "static" is not quite the right word to refer to acquired neurological conditions such as brain injury. We are concerned that this may potentially lead to misunderstanding and problems in ensuring that this "type" of neurological conditions is recognised and taken into account throughout a person's lifetime, and at all points of contact with healthcare and other agencies. It is noted that the draft scope acknowledges that "effects on peoples' activity, participation and quality of life may also remain static or change over time", but there is the risk of failing to	Thank you for your comment. We have removed the word 'static' from the description. The scope now references acquired brain injury, acquired spinal cord injury or disorders, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders.

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			acknowledge that these may result in rehabilitation needs throughout the person's life-span.	
The Disabilities Trust	004	general	By using the term "private" the draft scope excludes charities and the third sector, who are key providers of services for people with chronic neurological conditions. This could result in lack of awareness of the full range of services and expertise available to respond to the heterogeneous needs of people with neurological conditions by users of the guideline.	Thank you for your comment. The text has been amended to reference 'charities, third sector and private sector providers'.
The Disabilities Trust	006	010	The draft scope excludes people with stroke, presumably because there is NICE guidance on stroke rehabilitation in adults. We would argue that this group should not be excluded automatically, as the current stroke guideline is not accounting for people with stroke who have cognitive profiles with features which resemble those seen in traumatic brain injuries (TBI), such as lack of self-awareness into difficulties, poor initiation, memory and learning problems, and which may affect the engagement in, and effectiveness of, interventions delivered in line with the current stroke guideline. In other words, for some people with stroke, an approach to rehabilitation focused addressing limitations to activity, participation and quality of life, will be more appropriate than a "standard" stroke rehabilitation approach. This is supported	Thank you for your comment. We have already amended the text referenced from 'regardless of diagnostic category' to 'chronic neurological disorders in all 5 categories of injury, disorder or disease as set out above'. While we understand your rationale for including stroke in this guideline, we believe that your concerns should instead be considered in future stroke guideline updates.

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			by clinical outcome data collected over the past 10 years within our organisation, which shows that the needs' profiles of people with haemorrhagic strokes (using the Mayo-Portland Adaptability Inventory, Malec & Lezak, 2003) are more similar to the profiles of those with TBI, and also by considering the brain-behaviour relationships for the areas and networks of the brain likely to be damaged as a result of a ischaemic stroke, versus haemorrhagic stroke. We would suggest that the terminology used on page 4 of the current draft scope (i. e. "This guideline aims to address the rehabilitation needs of people with chronic neurological disorders regardless of diagnostic category."), is maintained throughout the document, and that it remains reflected throughout the development of the full guideline. However, for clarity, we are not suggesting that the new rehabilitation for chronic neurological disorders guideline should be recommended for all people with stroke. In a similar vein, the guideline on rehabilitation of chronic neurological disorders should include all forms of acquired brain injury with profiles of need similar to traumatic brain injury.	
The Disabilities Trust	012	018-027	We suggest that the outcome "nutrition status" is modified to focus on general self-care. We also propose that the following outcomes should be included: fatigue, subjective perception of	Thank you for your comment. The list of outcomes (and wording) provided in the scope are only examples of main outcomes that may be

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			change (global impression of change), cognitive factors (including self-awareness, initiation, utilization of compensatory strategies), psychological outcomes (including mood, anger, self-esteem, emotion regulation, wellbeing) and functional neurological symptoms. All of these, but cognitive factors in particular, can affect both the nature of the interventions that can be delivered, and the effectiveness of those interventions, therefore measuring levels of self-awareness, initiation and use of compensatory strategies is key to understand what works for whom, and what adaptations may be needed.	looked for in the evidence. The guideline committee will discuss potential outcomes (including those relating to nutrition, fatigue, perception of change, cognitive and psychological factors and functional neurological symptoms) before deciding the most suitable outcomes to include in each evidence review protocol.
The Disabilities Trust	04	025	The extent to which the existing NICE guideline on transition from children's to adults' services for young people using health or social care services (NG 43) is fully appropriate in the context of rehabilitation for chronic neurological disorders, may need further consideration. It may be that specific recommendations would be required under the new guideline (e. g. transition to adult brain injury rehabilitation services following an injury acquired in childhood).	Thank you for your comment. Aside from the guidance mentioned, there is also an existing NICE guideline about transition between inpatient hospital settings and community or care home settings for adults with social care needs (NG27), as well as NG43 Transition from children's to adults' services for young people using health or social care services. Any additional gaps in recommendations are anticipated to be covered in evidence reviews

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				regarding delivery of rehabilitation for people with neurological disorders.
The Disabilities Trust	Question from NICE 1	general	There is high co-morbidity of functional neurological disorders (FND) and chronic neurological disorders (CND), and in many cases the diagnosis of a CND triggers FNDs. It would be important for the new rehabilitation of CND guideline to recognise that FNDs need treatment, but any specific recommendations for the treatment of FNDs should be covered on a separate guideline. We propose that one way of ensuring integration and a joint approach to working with people with FND, CND or both, would be to incorporate functional neurological symptoms as outcomes to be considered and monitored when evaluating the evidence, and the results, in clinical practice, of rehabilitation for chronic neurological disorders.	Thank you for your comment. While we understand your rationale for a separate guideline on functional neurological disorders (FND), we have decided to instead extend the scope of this guideline to include rehabilitation for FND. There is significant overlap between rehabilitation needs of people with FND and those with other types of chronic neurological disorders. A separate guideline would duplicate effort and may cause confusion for people searching for guidance. However, in a number of instances, we recognise distinct recommendations will be needed for people with FND as opposed to other conditions. These will be signposted as appropriate.
The Disabilities Trust	Question from NICE 2	general	In our experience, while there is some research in this area, there is still insufficient evidence on cost saving interventions and innovative approaches that would allow recommendation for	Thank you for your comment. The use of technology in the delivery of rehabilitation interventions is likely to be an area for the

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			inclusion in a clinical guideline. We have been evaluating the potential of technology, including smart home technology and virtual reality, for creating more cost-effective ways for rehabilitation and support of people with acquired brain injury. However, we are also aware that the appropriateness, acceptability and effectiveness of those options partly depends on the needs profile of the individual, the features that the technology offers, and the context or purpose for its use (for example, people with poor self-awareness or initiation difficulties might not respond to prompts, or initiate technology use. A period of trial and training is likely to be required, technology may successfully support someone in specific settings, such as at home or school, but may not enable full independence in other settings, such as work, or social situations). We suggest that interventions of this nature for acquired brain injury, are considered under recommendations for research under the new guideline. However, we acknowledge that the evidence base for other neurological conditions may be more robust.	committee to consider across a range of reviews. Where the evidence is lacking in these areas the committee will use its collective expertise and experience to make recommendations. They can also agree to make recommendations for future research to plug those gaps.
The Neurological Alliance	002	018	The stated prevalence estimates should be reviewed.	Thank you for your comment. We have now made changes to the prevalence estimates. Although NICE is unable to produce a separate

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			<p>Prevalence for TBI is estimated to be > 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 10th 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>guideline for TBI specifically we are intending to write some specific recommendations for acquired brain injury, alongside other groups of neurological conditions, recognising that there are important differences within different groups of neurological conditions.</p>

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			Further information about prevalence and incidence of neurological conditions is available in our report 'Neuro Numbers, 2019' https://www.neural.org.uk/wp-content/uploads/2021/04/neuro-numbers-2019-1.pdf	
The Neurological Alliance	002 - 003	022 - 011	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.	Thank you for your comment. The scope now references acquired brain injury, acquired spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders.
The Neurological Alliance	003	012	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.	Thank you for your comment. A sentence has been added to the introductory section to say, "Rehabilitation can reduce demand on the most costly and intensive parts of the health and social care system. It also supports people and their families and carers to participate economically in society."
The Neurological Alliance	006	004	The care and support needs of informal carers should be considered as part of the guideline and who it is for.	Thank you for this comment. We agree that care and support needs of informal carers are very important. As there is already a separate NICE

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				guideline on this issue (NG150 Supporting adult carers), this will be cross-referenced where appropriate.
The Neurological Alliance	006	020-021	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.	Thank you for your comment. Any transient event that leads to chronic neurological disorder is included, which has been clarified by the inclusion of acquired brain injury in both the title of the guideline and as a named neurological disorder category. Traumatic brain injury has been included as an example of acquired brain injury in the opening portion of the scope.
The Neurological Alliance	007	011	Support available for informal carers should be considered here.	Thank you for this comment. We agree that the care and support needs of unpaid or 'informal' carers are very important. As there is already a separate NICE guideline on this issue (NG150 Supporting adult carers), this will be cross-referenced where appropriate.
The Neurological Alliance	007	016	Ease of re-referral after fixed term therapy should also be included	Thank you for your comment. We have added an explicit reference to re-referral in the key area and draft question about identification and

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				referral. So re-referral is now clearly within scope
The Neurological Alliance	007	020	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.	Thank you for your comment. While we appreciate that accurate diagnosis and management of co-morbidities are important factors for people with chronic neurological disorders (and their future rehabilitation needs), this is outside of the scope of this rehabilitation guideline. However, the guideline will consider rehabilitation needs of different sub groups of the population, including older people and those with disabilities and we anticipate that these areas will be addressed in review questions on rehabilitation planning of people with chronic neurological disorders.
The Neurological Alliance	011	001	Please clarify the term 'everyone involved'	Thank you for your comment. The term 'everyone involved' refers to healthcare professionals, people using services and their support networks. This will be clarified in protocols as well as recommendations where appropriate.

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The Neurological Alliance	012	001	Please clarify the term 'everyone involved'	Thank you for your comment. The term 'everyone involved' refers to healthcare professionals, social care professionals, people with rehabilitation needs and their support networks. This will be clarified in protocols as well as recommendations where appropriate.
The Neurological Alliance	012	007	Please include 'remain in, return to or exit from employment and volunteering?'	Thank you for your comment. We have added 'or leave' to the referenced text.
The Neurological Alliance	012	015	Outcomes related to mobility, cognition and emotional health should be included here.	Thank you for your comment. The list of outcomes provided in the scope are only examples of main outcomes that may be looked for in the evidence. The guideline committee will discuss before deciding the most suitable outcomes to include in each evidence review protocol.
The Neurological Alliance	General	General	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	Thank you for your comment. Functional neurological disorders have now been included in the scope of this guideline .

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			<p>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>	
The Neurological Alliance	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</p>	<p>Thank you for your comment.</p> <p>All NICE guidelines are produced following rigorous, clear, documented methodologies. Committee members will use their collective expertise to interpret the evidence and make recommendations that are both general for the whole population and that are specific for particular groups where necessary and where the data allow. For example, in some areas (and where evidence exists), sub-group analysis of 5 chronic neurological disorder categories will be carried out (acquired brain injury, acquired</p>

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			<p>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>	<p>spinal cord injury, acquired peripheral nerve disorders, progressive neurological diseases and functional neurological disorders).</p>
The Neurological Alliance	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>	<p>Thank you for your comment. The list of inequalities mentioned is not exhaustive, and is provided to highlight specific areas where this particular topic might have issues with inequalities. However, the recommendations within the guideline will consider health equalities in its broadest sense, including gender and race and we have added reference to these to the scope. We have also included reference to geographical accessibility of rehabilitation services.</p>

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The Neurological Alliance	General	General	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.	Thank you for your comment. Multi-disciplinary teams will be included in review question protocols where appropriate.
The Neurological Alliance	General	General	The committee and guideline should also consider the potential of digital solutions and the integration of telemedicine.	Thank you for your comment. It is anticipated that digital therapy and telemedicine will be covered in the areas of the guideline investigating the delivery of rehabilitation for people with chronic neurological disorders and supporting access to education, employment and social participation. However, the guideline committee will discuss which specific interventions to include in the protocols.
The Royal College of Psychiatrists	008	001	Although this guideline will not consider psychiatric comorbidity, reference to Depression in adults with a chronic physical health problem: recognition and management (CG91) is recommended as mood disorders are extremely common in neurological rehabilitation settings and have a significant impact on the	Thank you for your comment. This reference has been added to the scope in the 'Relevant NICE guidance' section.

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			success of rehabilitation. There is no reference to depression guidelines although PTSD guidelines are cited.	
The Royal College of Psychiatrists	012	015	Cognitive outcomes need to be included.	Thank you for your comment. The list of outcomes provided in the scope are only examples of main outcomes that may be looked for in the evidence. The guideline committee will discuss potential outcomes, including cognitive outcomes, before deciding the most suitable outcomes to include in each evidence review protocol.
The Royal College of Psychiatrists	General	General	It is imperative that Functional Neurological Symptoms/Disorder (FND) is included in the scope of this guideline. FND is common (15% of new neurology outpatients) and comorbid functional symptoms alongside other long term neurological conditions are highly prevalent, cause as much distress and disability as their neurological counterparts (long term outlook poor for 40% and similar levels of disability and poor quality of life to Parkinson's and MS) and require careful diagnosis and specific rehabilitative interventions. As these conditions present in neurology and rehabilitation settings all the time, to exclude them from the scope sends a divisive and dualistic message regarding	Thank you for your comment. Functional neurological disorders have now been included in the scope of this guideline.

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			rehabilitation of long-term neurological conditions. Rehabilitation is essentially a holistic treatment approach that utilises a bio-psychosocial model. Any attempt to separate out a neurological condition on the basis that it is 'not neurological but psychological' would inherently undermine that holistic approach and run the risk of sending a strong message from NICE that the guideline is not adopting an integrated model as is commonly utilised in clinical practice by rehabilitationists. The guideline committee have an opportunity to provide holistic and integrated guidance that spans the brain and mind interface without adopting an outdated, dualistic approach to 'physical' and 'mental' that will quickly become obsolete. Excluding people with FND from the guideline would demonstrate an inequality of access to rehabilitation as described in the Equality Impact Assessment.	
The Royal College of Surgeons of Edinburgh	General	General	<p>There are three topics that we do not see addressed.</p> <ol style="list-style-type: none"> 1. Co-morbidities. Rehabilitation requires comprehensive care to function optimally. How will the management of co-morbidities be integrated? 2. Duration of rehabilitation services. There are increasing data to indicated that recovery persists for many months after the 	<p>Thank you for your comment and suggestions. The guideline will consider co-morbidities in the context of rehabilitation needs of the individual, of different age ranges and people with different disabilities and long term health conditions. The committee may wish to consider the optimum timing and duration of rehabilitation</p>

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			<p>begin some time after injury. There are parallel data showing that rehabilitation after injury can have measurable beneficial effects even if started late, and certainly if continued for periods as long as two years after stroke, for example. How are these observations incorporated into the guidelines?</p> <p>3. We live in a time of data capture and analysis. It is critically important to have the data around the clinical course of patients with chronic neurological disorders including traumatic brain injury captured and analysed to continue refining guidelines over time as new rehabilitation modalities are introduced and practiced.</p>	<p>with regards to assessment and planning for different groups and the factors to consider. They will agree this as part of protocol development.</p> <p>NICE committees are made up of a wide range of practitioners working directly in rehabilitation today as well as people with lived experiences. Where real world data is available and relevant the committee will consider how it might inform their recommendations.</p>
United Kingdom Multiple Sclerosis Specialist Nurse Association (UKMSSNA)	General	General	<p>The draft is very comprehensive and it is to its advantage that it covers both children and adults. and the different rehab structures. It may be beneficial to give time scales as to when rehab interventions should occur if it is for an outpatient, although this may be condition specific for example for a patient with Multiple Sclerosis who suffered a relapse there will be a window of time in which rehab is more beneficial to help to improve function.</p>	<p>Thank you for your comment. Time frames will be specified within evidence review protocols, which will be developed with experts on the guideline committee.</p>

[Registered stakeholders](#)

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