

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Rehabilitation for chronic neurological disorders including acquired brain injury

NHS England has asked NICE to develop a guideline about rehabilitation for chronic neurological disorders that are expected to be long term, including acquired brain injury.

The guideline will be developed using the methods and processes outlined in [developing NICE guidelines: the manual](#).

This guideline will also be used to develop NICE quality standards.

1 Why the guideline is needed

A significant number of people live with the long-term consequences of neurological disease and disorders. These include multiple sclerosis (1 in 520 people), Parkinson's disease (1 in 37 people), neuromuscular disorders and motor neurone disease (1 in 1,000 people), traumatic brain injury (1 in 350 people), spinal cord injury and brain tumours.

Chronic (or long-term) neurological disorders refers to a large group of conditions that affect the brain, spine or peripheral nerves. These can be considered within the 5 broad categories below.

1) Acquired brain injury

This means an injury to the brain from any cause that results in neurological impairment. Causes include trauma, tumours, infections, metabolic insults and disorders of the blood supply. The resulting impairments may improve, progress or remain relatively stable over time.

2) Acquired spinal cord injury

This means an injury to the spine from any cause that results in neurological impairment. Causes include trauma, tumours, infections, metabolic insults and disorders of the blood supply. The resulting impairments may improve, progress or remain relatively stable over time.

3) Acquired peripheral nerve disorders

This includes acute-onset disorders of the peripheral nervous system that cause neurological impairment. These may include inflammatory, autoimmune or paraneoplastic causes. The resulting impairments may improve, progress or remain relatively stable over time.

4) Progressive neurological diseases

These involve a gradual progression of neurological difficulties over time. Examples include Parkinson's disease, multiple sclerosis, motor neurone disease and Duchenne's muscular dystrophy.

5) Functional neurological disorders

Functional neurological disorders can cause a range of disabling neurological symptoms, which include altered awareness, and motor and sensory changes. However, symptoms are not explained by a physical or neurological disease.

Rehabilitation

Rehabilitation is defined by the World Health Organization as 'a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment'. Functioning and disability are broad terms which are further conceptualised in the International Classification of Functioning, Disability and Health. This framework highlights the relationships and interplay between the following domains:

- health condition
- body structure and function

- activity
- participation
- environmental factors
- personal factors.

Rehabilitation is an overall process composed of individual interventions. These interventions range from the relatively simple, acting at one or a few domains, to complex interventions that may act across several domains. Rehabilitation is not a 'one size fits all' process and aims and goals should be identified and agreed with each person to fully inform personalised treatment and therapy programmes.

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.

This guideline aims to address the rehabilitation needs of people with chronic neurological disorders in all 5 categories of injury, disorder or disease set out above. It will refer to existing NICE guidelines where relevant, including on rehabilitation after traumatic injury (currently in development), stroke, rehabilitation after critical illness, cerebral palsy (in under 25s and adults), multiple sclerosis, Parkinson's disease, and spasticity in under 19s.

Current practice

Given the large number of diagnostic categories, age groups and healthcare settings, there is wide variation in the delivery of rehabilitation interventions to people with these long-term conditions.

Inpatient rehabilitation for chronic neurological conditions is delivered through a range of services based within the NHS, the private sector and the voluntary sector. Referral criteria for these services are often specific for disease or condition, symptoms, locality or age group.

In the longer term, rehabilitation may be delivered through hospital or community services, including education-based services. It may also be provided by the private or voluntary sectors. 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). Referral criteria may include diagnosis, age, or time since injury, or may depend on the purpose or setting of the intervention (for example, vocational rehabilitation). Referral criteria often inform decisions about people's access to specialist rehabilitation services.

There are significant variations in service provision and care pathways in different groups.

2 Who the guideline is for

This guideline is for:

- Health and social care professionals and practitioners
- local authorities and commissioning groups that provide or commission neurological rehabilitation services
- providers of neurological rehabilitation services in the community, including charities, third sector and private sector providers
- people who have chronic neurological disorders, their families and carers and the public.

It may also be relevant for:

- advocates for people who have chronic neurological disorders
- practitioners working in other related services, including employers, education, housing, leisure, job centres, welfare advice and legal services.

Although recommendations are not intended to apply in prisons or military hospitals, this guideline may be of interest to professionals working in these settings.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#) and [Northern Ireland Executive](#).

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to race and gender and people with pre-existing physical, mental health or behavioural conditions, communication impairments, physical or learning disabilities, and frailty. It will also look at geographical accessibility of rehabilitation services, and whether people with a lower socioeconomic status are disproportionately affected. It will also consider age-related service assumptions, service access and engagement, and cultural differences.

3 What the guideline will cover

3.1 Who is the focus?

Groups that will be covered

Children, young people and adults with chronic (or long-term) neurological disorders who need rehabilitation to address limitations to their activity, participation and quality of life. The 5 categories covered in this guideline are:

- 1) Acquired brain injury. Reference will be made to existing guidelines that address aspects of these areas (cerebral palsy, stroke, trauma).
- 2) Acquired spinal cord injury. Reference will be made to existing guidelines that address the acute aspects of traumatic spinal cord injury. Early rehabilitation after spinal cord injury will be covered in the NICE guideline on rehabilitation after traumatic injury (publication expected in January 2022) and longer-term rehabilitation after spinal cord injury will be covered in this guideline.
- 3) Acquired peripheral nerve disorders. Single nerve or plexus injuries will not be considered within this scope as their management is primarily orthopaedic.

The post-acute and long-term rehabilitation of people with impairments due to the above 3 groups of conditions will be addressed in the context of their activity, participation and quality of life, with consideration given to their environment, secondary complications of the condition or changes in their circumstances.

4) Progressive neurological diseases. Progressive conditions can vary in their degree of limitations on activity, participation and quality of life; their impact at an individual level; and their pattern of progression. Rehabilitation needs may be lifelong but vary in nature among different people with the same condition, as well as between different life stages and points on the disease trajectory for the same person. These issues will be addressed in the guideline.

5) Functional neurological disorders.

Across all aspects of the guideline recommendations will be differentiated if neurological conditions and injuries need different actions and interventions. For example, if the evidence allows it, sub-group analysis will be carried out and recommendations will be focused on, and organised around, discrete areas of neurological disorder.

Groups that will not be covered

- Disorders for which interventions are primarily focused on altering body structure and functions, for example isolated peripheral nerve injuries.
- Conditions for which there is already NICE guidance on rehabilitation, including stroke, dementia, myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome and post-COVID-19 syndrome.

3.2 Settings

Settings that will be covered

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.

Settings that will not be covered

- Accident and emergency departments.
- Critical care units.
- Prisons.

3.3 *Activities, services or aspects of care*

Key areas that will be covered

We will look at evidence in the areas below when developing the guideline, but it may not be possible to make recommendations in all areas.

- 1 Delivery of rehabilitation for people with chronic neurological disorders.
- 2 Identification and referral including re-referral
- 3 Assessment, rehabilitation planning and review.
- 4 The effectiveness of rehabilitation interventions aimed at improving activity and maximising independence and wellbeing.
- 5 Supporting access to education, employment and social participation.

Areas that will not be covered

- 1 Diagnosis of neurological disorders.
- 2 End of life care (where goals are primarily focused on symptom control and comfort).
- 3 Management of medical or psychiatric comorbidities.
- 4 Transitioning of rehabilitation from children's to adults' services.

Related NICE guidance

Published

- [Brain tumours \(primary\) and brain metastases in adults](#) (2021) NICE guideline NG99
- [Rehabilitation for adults with complex psychosis](#) (2020) NICE guideline NG181
- [Cerebral palsy in adults](#) (2019) NICE guideline NG119
- [Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline NG97

- [Cerebral palsy in under 25s: assessment and management](#) (2017) NICE guideline NG62
- [Intermediate care including reablement](#) (2017) NICE guideline NG74
- [Rehabilitation after critical illness in adults](#) (2017) NICE quality standard 158
- [Parkinson's disease in adults](#) (2017) NICE guideline NG71
- [Spasticity in under 19s: management](#) (2016) NICE guideline CG145
- [Motor neurone disease: assessment and management](#) (2016) NICE guideline NG42
- [Major trauma: service delivery](#) (2016) NICE guideline NG40
- [Transition from children's to adults' services for young people using health or social care services](#) (2016) NICE guideline NG43
- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) (2015) NICE guideline NG27
- [Multiple sclerosis in adults: management](#) (2014) NICE guideline CG186
- [Neuropathic pain in adults: pharmacological management in non-specialist settings](#) (2013) NICE guideline CG173
- [Stroke rehabilitation in adults](#) (2013) NICE guideline CG162
- [Rehabilitation after critical illness in adults](#) (2009) NICE guideline CG83

NICE guidance that may also be relevant

- [Chronic pain \(primary and secondary\) in over 16s: assessment of all chronic pain and management of chronic primary pain](#) (2021) NICE guideline NG193
- [Cerebral palsy in adults](#) (2020) NICE quality standard 191
- [Trauma](#) (2018) NICE quality standard 166
- [People's experience in adult social care services: improving the experience of care and support for people using adult social care services](#) (2018) NICE guideline NG86
- [Post-traumatic stress disorder](#) (2018) NICE guideline NG116
- [Parkinson's disease](#) (2018) NICE quality standard 164

- [Intramuscular diaphragm stimulation for ventilator-dependent chronic respiratory failure caused by high spinal cord injuries](#) (2017) NICE interventional procedures guidance 594
- [Home care for older people](#) (2016) NICE quality standard 123
- [Major trauma: assessment and initial management](#) (2016) NICE guideline NG39
- [Mental wellbeing and independence for older people](#) (2016) NICE quality standard 137
- [Spinal injury: assessment and initial management](#) (2016) NICE guideline NG41
- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) (2016) NICE quality standard 136
- [Transition from children's to adults' services](#) (2016) NICE quality standard 140
- [Multiple sclerosis](#) (2016) NICE quality standard 108
- [Home care: delivering personal care and practical support to older people living in their own homes](#) (2015) NICE guideline NG21
- [Older people with social care needs and multiple long-term conditions](#) (2015) NICE guideline NG22
- [Older people: independence and mental wellbeing](#) (2015) NICE guideline NG32
- [Cancer services for children and young people](#) (2014) NICE quality standard 55
- [Metastatic spinal cord compression in adults](#) (2014) NICE quality standard 56
- [Head injury: assessment and early management](#) (2014) NICE guideline CG176
- [Head injury](#) (2014) NICE quality standard 74
- [Urinary incontinence in neurological disease: assessment and management](#) (2012) NICE guideline CG148
- [Stroke in adults](#) (2010) NICE quality standard 2
- [Depression in adults with a chronic physical health problem: recognition and management](#) (2009) NICE guideline CG91

- [Mental wellbeing in over 65s: occupational therapy and physical activity interventions](#) (2008) NICE guideline PH16

In development

- [Rehabilitation after traumatic injury](#) NICE guideline. Publication expected January 2022

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to rehabilitation for people with chronic neurological disorders:

- [Medicines optimisation](#) (2015) NICE guideline NG5
- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- [Service user experience in adult mental health](#) (2011) NICE guideline CG136
- [Medicines adherence](#) (2009) NICE guideline CG76

3.4 *Economic aspects*

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS and personal social services perspective, as appropriate.

3.5 *Key issues and draft questions*

While writing this scope, we have identified the following key issues and draft questions related to them. We use the term 'people' below to cover children, young people and adults with chronic neurological disorders. We will report and consider evidence separately for adults and children and make separate recommendations for adults and children as needed. We will also consider

evidence and recommendations separately for some questions if distinct recommendations are needed in the following areas:

- Acquired brain injury
 - Acquired spinal cord injury
 - Acquired peripheral nerve disorders
 - Progressive neurological diseases
 - Functional neurological disorders.
- 1 Delivery of rehabilitation for people with chronic neurological disorders
 - 1.1 Based on the views and preferences of everyone involved, what works well and what could be improved in the delivery of rehabilitation?
 - 2 Identification and referral including re-referral
 - 2.1 What are the barriers and facilitators to identifying people with rehabilitation needs and referring them to appropriate services, including re-referral?
 - 3 Assessment, rehabilitation planning and review
 - 3.1 What is the effectiveness of interventions, tools and approaches for assessing and reviewing rehabilitation needs and for formulating, agreeing and reviewing rehabilitation plans?
 - 3.2 Based on the views and preferences of everyone involved, what works well and what could be improved in assessing and reviewing rehabilitation needs and formulating, agreeing and reviewing rehabilitation plans?
 - 4 The effectiveness of rehabilitation interventions aimed at improving activity and maximising independence and wellbeing
 - 4.1 What is the effectiveness of interventions and approaches for improving or maintaining independence in personal care and activities of daily living?

- 4.2 What is the effectiveness of interventions 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?
 - 4.5 What is the effectiveness of interventions and approaches for improving and sustaining emotional health and mental wellbeing?
- 5 Supporting access to education, employment and social participation
- 5.1 Based on the views and preferences of everyone involved, what works well and what makes it difficult to access support for education, employment and social participation?
 - 5.2 What is the effectiveness of interventions or approaches for supporting people to enter, remain in, return to or leave education and training?
 - 5.3 What is the effectiveness of interventions or approaches for supporting people to enter, remain in, return to or leave employment and volunteering?
 - 5.4 What is the effectiveness of interventions or approaches for supporting people's social participation (for example leisure, family life, sex and relationships)?

The key issues and draft questions will be used to develop more detailed review questions, which guide the systematic review of the literature.

3.6 Main outcomes

The main outcomes that may be considered when searching for and assessing the evidence are:

- 1 quality of life (including physical and mental health-related, and social care-related)
- 2 personal goal attainment

- 3 speech, language and communication
- 4 participation and inclusion (including in social, educational and work activities)
- 5 degree of pain
- 6 nutrition status
- 7 carer quality of life
- 8 care contacts (both planned and unplanned, and emergency)
- 9 experience of services

4 NICE quality standards and NICE Pathways

4.1 NICE quality standards

NICE quality standards that may need to be revised or updated when this guideline is published

- To be confirmed

NICE quality standards that will use this guideline as an evidence source when they are being developed

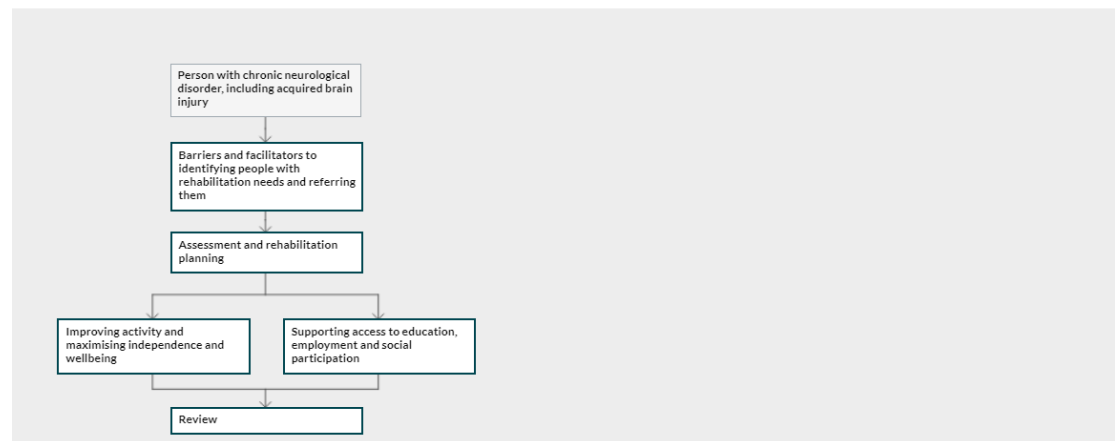
- To be confirmed

4.2 NICE Pathways

[NICE Pathways](#) bring together everything we have said on a topic in an interactive flowchart. When this guideline is published, the recommendations will be included in the NICE Pathway on rehabilitation for chronic neurological disorders including acquired brain injury (in development).

An outline based on this scope is included below. It will be adapted, and more detail added as the recommendations are written during guideline development.

Rehabilitation for chronic neurological disorders including acquired brain injury overview



5 Further information

This is the final scope, which takes into account comments from registered stakeholders during consultation.

The guideline is expected to be published in August 2023.

You can follow [progress of the guideline](#).

Our website has information about [how NICE guidelines are developed](#).

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