

DRAFT FOR CONSULTATION

v National Institute for Health and Clinical Excellence [document type for example, IFP, QRG] on [topic] Document cover sheet			
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28/04/21	2	LB	Post SG1
05/05/21	3	LB	For workshop and SG2
26/05/21	4	LB	1st consultation submission
27/05/21	5	SC	Edit of preconsultation scope
02/06/21	6	LB	2nd consultation submission

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NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

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Guideline scope

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Rehabilitation for chronic neurological disorders including traumatic brain injury

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The Department of Health and Social Care in England and NHS England have asked NICE to develop a guideline about rehabilitation for chronic neurological disorders including traumatic brain injury.

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

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

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1 Why the guideline is needed

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A significant number of people live with the long-term consequences of neurological disease and disorders. These include multiple sclerosis (1 in 650 people), Parkinson's disease (1 in 1,000 people), neuromuscular disorders and motor neurone disease (1 in 1,000 people), acquired or traumatic brain injury (1 in 6,000 people), spinal cord injury and brain tumours.

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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 2 broad categories below.

22

Acute and static neurological disorders

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These result from a defined injury or acute illness (such as a brain injury or spinal cord injury) with persistent subsequent neurological symptoms that either remain unchanged or progress slowly over time. Effects on people's activity, participation and quality of life may also remain static or change over

1 time (for example due to their environment, secondary complications of the
2 condition or changes in their circumstances).

3 **Progressive neurological disorders**

4 These involve a gradual progression of neurological symptoms over time.
5 Examples include Parkinson's disease, motor neurone disease or Duchenne's
6 muscular dystrophy. Progressive conditions can vary in their degree of
7 limitations on activity, participation and quality of life, their impact at an
8 individual level and their pattern of progression. Rehabilitation needs may be
9 lifelong but vary in nature among different people with the same condition, as
10 well as between different life stages and points on the disease trajectory for
11 the same person.

12 ***Rehabilitation***

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

- 20 • health condition
- 21 • body structure and function
- 22 • activity
- 23 • participation
- 24 • environmental factors
- 25 • personal factors.

26 Rehabilitation is an overall process composed of individual interventions.
27 These interventions range from the relatively simple, acting at one or a few
28 domains, to complex interventions that may act across several domains.
29 Rehabilitation is not a 'one size fits all' process and aims and goals should be

1 identified and agreed with each individual in order to fully inform personalised
2 treatment and therapy programmes. .

3 This guideline aims to address the rehabilitation needs of people with chronic
4 neurological disorders regardless of diagnostic category. It will refer to existing
5 NICE guidelines where relevant, including on stroke, rehabilitation after critical
6 illness, cerebral palsy (in under 25s and adults), multiple sclerosis,
7 Parkinson's disease and spasticity in under 19s.

8 ***Current practice***

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

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

16 In the longer term, rehabilitation may be delivered through hospital or
17 community services, including education-based services. It may also be
18 provided by the private or voluntary sectors. Rehabilitation can involve
19 impairment-focused approaches, for example to improve mobility, or a less
20 impairment-specific focus (such as that provided by community
21 neurorehabilitation teams). Referral criteria may include diagnosis, age, time
22 since injury or may depend on the purpose or setting of the intervention (for
23 example, vocational rehabilitation).

24 There are significant variations in service provision and care pathways in
25 different groups. Transition from children's to adults' rehabilitation services is
26 highly variable across the country.

27 **2 Who the guideline is for**

28 This guideline is for:

- 1 • healthcare professionals
- 2 • social care practitioners
- 3 • local authorities and commissioning groups that provide or commission
- 4 neurological rehabilitation services
- 5 • providers of neurological rehabilitation services in the community, including
- 6 voluntary and private sectors
- 7 • people who have chronic neurological disorders, their families and carers
- 8 and the public.

9 It may also be relevant for:

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

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

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

19 ***Equality considerations***

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

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

24 The guideline will look at inequalities relating to people with pre-existing
25 physical, mental health or behavioural conditions, communication impairment,
26 physical or learning disabilities, and frailty. It will also look at geographical
27 accessibility of rehabilitation services, and whether people with a lower
28 socioeconomic status are disproportionately affected. It will also consider age-

1 related service assumptions, service access, engagement and cultural
2 differences.

3 **3 What the guideline will cover**

4 **3.1 Who is the focus?**

5 **Groups that will be covered**

- 6 • Children, young people and adults with acute and static or progressive
7 chronic neurological disorders who need rehabilitation to address
8 limitations to their activity, participation and quality of life. This may include
9 people with complex rehabilitation needs because of, for example, acquired
10 or traumatic brain or spinal cord injury (excluding stroke), central nervous
11 system tumours or progressive neurodegenerative disorders, such as
12 multiple sclerosis, Parkinson's disease or motor neurone disease.

13 No subgroups of people have been identified as needing specific
14 consideration.

15 Note: early rehabilitation after spinal cord injury will be covered in the NICE
16 guideline on rehabilitation after traumatic injury (publication expected in
17 January 2022) and longer-term rehabilitation after spinal cord injury will be
18 covered in this guideline.

19 **Groups that will not be covered**

- 20 • Disorders for which interventions are primarily focused on altering body
21 structure and functions, for example isolated peripheral nerve injuries.
- 22 • Conditions for which there is already NICE guidance on rehabilitation,
23 including stroke, dementia, myalgic encephalomyelitis (or
24 encephalopathy)/chronic fatigue syndrome and post-COVID-19 syndrome.
25 However, where it is appropriate to extrapolate to the groups that will be
26 covered, we may use evidence from some of these groups that will not be
27 covered.

1 **Settings**

2 **Settings that will be covered**

3 All inpatient (excluding critical care units), outpatient and community settings
4 in which publicly funded rehabilitation interventions for chronic neurological
5 disorders are provided.

6 **Settings that will not be covered**

- 7 • Accident and emergency departments.
8 • Critical care units
9 • Prisons.

10 **3.2 *Activities, services or aspects of care***

11 **Key areas that will be covered**

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

- 14 1 Delivery of rehabilitation for people with chronic neurological disorders
15 2 Identification and referral
16 3 Assessment, rehabilitation planning and review
17 4 The effectiveness of rehabilitation interventions aimed at improving
18 activity and maximising independence and wellbeing.
19 5 Supporting access to education, employment and social participation

20 **Areas that will not be covered**

- 21 1 Diagnosis of neurological disorders
22 2 End of life care (where goals are primarily focused on symptom control
23 and comfort)
24 3 Management of medical or psychiatric comorbidities
25 4 Transitioning of rehabilitation from children's to adults' services

1 **Related NICE guidance**

2 ***Published***

- 3 • [Brain tumours \(primary\) and brain metastases in adults](#) (2021) NICE
4 guideline NG99
- 5 • [Rehabilitation for adults with complex psychosis](#) (2020) NICE guideline
6 NG181
- 7 • [Multiple sclerosis in adults: management](#) (2019) NICE guideline CG186
- 8 • [Motor neurone disease: assessment and management](#) (2019) NICE
9 guideline NG42
- 10 • [Cerebral palsy in adults](#) (2019) NICE guideline NG119
- 11 • [Dementia: assessment, management and support for people living with
12 dementia and their carers](#) (2018) NICE guideline NG97
- 13 • [Neuropathic pain in adults: pharmacological management in non-specialist
14 settings](#) (2018) NICE guideline CG173
- 15 • [Cerebral palsy in under 25s: assessment and management](#) (2017) NICE
16 guideline NG62
- 17 • [Intermediate care including reablement](#) (2017) NICE guideline NG74
- 18 • [Rehabilitation after critical illness in adults](#) (2017) NICE quality standard
19 158
- 20 • [Spasticity in under 19s: management](#) (2016) NICE guideline CG145
- 21 • [Major trauma: service delivery](#) (2016) NICE guideline NG40
- 22 • [Transition from children's to adults' services for young people using health
23 or social care services](#) (2016) NICE guideline NG43
- 24 • [Transition between inpatient hospital settings and community or care home
25 settings for adults with social care needs](#) (2015) NICE guideline NG27
- 26 • [Stroke rehabilitation in adults](#) (2013) NICE guideline CG162
- 27 • [Rehabilitation after critical illness in adults](#) (2009) NICE guideline CG83

28 ***NICE guidance that may also be relevant***

- 29 • [Chronic pain \(primary and secondary\) in over 16s: assessment of all
30 chronic pain and management of chronic primary pain](#) (2021) NICE
31 guideline NG193

- 1 • [Head injury: assessment and early management](#) (2019) NICE guideline
- 2 CG176
- 3 • [Trauma](#) (2018) NICE quality standard 166
- 4 • [People's experience in adult social care services: improving the experience](#)
- 5 [of care and support for people using adult social care services](#) (2018) NICE
- 6 guideline NG86
- 7 • [Post-traumatic stress disorder](#) (2018) NICE guideline NG116
- 8 • [Intramuscular diaphragm stimulation for ventilator-dependent chronic](#)
- 9 [respiratory failure caused by high spinal cord injuries](#) (2017) NICE
- 10 interventional procedures guidance 594
- 11 • [Parkinson's disease in adults](#) (2017) NICE guideline NG71
- 12 • [Home care for older people](#) (2016) NICE quality standard 123
- 13 • [Major trauma: assessment and initial management](#) (2016) NICE guideline
- 14 NG39
- 15 • [Mental wellbeing and independence for older people](#) (2016) NICE quality
- 16 standard 137
- 17 • [Spinal injury: assessment and initial management](#) (2016) NICE guideline
- 18 NG41
- 19 • [Transition between inpatient hospital settings and community or care home](#)
- 20 [settings for adults with social care needs](#) (2016) NICE quality standard 136
- 21 • [Transition from children's to adults' services](#) (2016) NICE quality standard
- 22 140
- 23 • [Home care: delivering personal care and practical support to older people](#)
- 24 [living in their own homes](#) (2015) NICE guideline NG21
- 25 • [Older people with social care needs and multiple long-term conditions](#)
- 26 (2015) NICE guideline NG22
- 27 • [Older people: independence and mental wellbeing](#) (2015) NICE guideline
- 28 NG32
- 29 • [Urinary incontinence in neurological disease: assessment and](#)
- 30 [management](#) (2012) NICE guideline 2012
- 31 • [Mental wellbeing in over 65s: occupational therapy and physical activity](#)
- 32 [interventions](#) (2008) NICE guideline PH16

1 ***In development***

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

4 **NICE guidance about the experience of people using NHS services**

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

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

14 **3.3 *Economic aspects***

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

22 **3.4 *Key issues and draft questions***

23 While writing this scope, we have identified the following key issues and draft
24 questions related to them. We use the term 'people' below to cover children,
25 young people and adults with chronic neurological disorders. It is likely that
26 separate reviews of the evidence would be undertaken for children and young
27 people and for adults.

28 1 Delivery of rehabilitation for people with chronic neurological disorders:

- 1 1.1 Based on the views and preferences of everyone involved, what
2 works well and what could be improved in the delivery of rehabilitation?
3
- 4 2 Identification and referral:
- 5 2.1 What are the barriers and facilitators to identifying people with
6 rehabilitation needs and referring them to appropriate services?
7
- 8 3 Assessment, rehabilitation planning and review:
- 9 3.1 What is the effectiveness of interventions, tools and approaches for
10 assessing and reviewing rehabilitation needs and for formulating,
11 agreeing and reviewing rehabilitation plans?
12 3.2 Based on the views and preferences of everyone involved, what
13 works well and what could be improved in assessing and reviewing
14 rehabilitation needs and formulating, agreeing and reviewing
15 rehabilitation plans?
16
- 17 4 The effectiveness of rehabilitation interventions aimed at improving
18 activity and maximising independence and wellbeing:
- 19 4.1 What is the effectiveness of interventions and approaches for
20 improving or maintaining independence in personal care and activities of
21 daily living?
22 4.2 What is the effectiveness of interventions and approaches for
23 improving and sustaining physical functioning including strength, mobility
24 and balance?
25 4.3 What is the effectiveness of interventions and approaches for
26 improving or supporting communication?
27 4.4 What is the effectiveness of interventions and approaches for
28 improving and maintaining cognitive function?
29 4.5 What is the effectiveness of interventions and approaches for
30 improving and sustaining emotional health and mental wellbeing?
31
- 32 5 Supporting access to education, employment and social participation:

1 5.1 Based on the views and preferences of everyone involved, what
2 works well and what makes it difficult to access support for education,
3 employment and social participation?

4 5.2 What is the effectiveness of interventions or approaches for
5 supporting people to enter, remain in or return to education and training?

6 5.3 What is the effectiveness of interventions or approaches for
7 supporting people to enter, remain in or return to employment and
8 volunteering?

9 5.4 What is the effectiveness of interventions or approaches for
10 supporting people to begin, continue with or resume social participation
11 (for example leisure, family life, sex and relationships)?

12

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

15 **3.5 Main outcomes**

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

18 1 quality of life (including physical and mental health-related and social
19 care-related)

20 2 personal goal attainment

21 3 communication

22 4 participation and inclusion (including social, education and work)

23 5 degree of pain

24 6 nutrition status

25 7 carer quality of life

26 8 care contacts (both planned and unplanned, emergency)

27 9 experience of services

1 **4 NICE quality standards and NICE Pathways**

2 **4.1 NICE quality standards**

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

- 5 • To be confirmed

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

- 8 • To be confirmed

9 **4.2 NICE Pathways**

10 **This section is completed by the digital team pathways editors.**

11 **This section will include a draft outline of the pathway based on the scope. It**
12 **will also include details of other NICE guidance that will be in the pathway –**
13 **for example, any interventional procedures or technology appraisals that are**
14 **directly relevant to the topic and that will appear as source guidance or any**
15 **guidelines that overlap with the topic in development.**

16 [Type here; use 'NICE normal' style]

17 **5 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 8 June to 6 July 2021.

The guideline is expected to be published in August 2023.

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

[After consultation, delete the first paragraph above and replace it with 'This is the final scope, which takes into account comments from registered stakeholders during consultation'.]

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