Optimal clinical pathway for adults: Rehabilitation for people with neurological conditions

National Neurosciences Advisory Group (NNAG)

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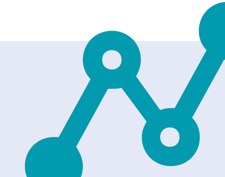


Overview: About the optimal pathway

This pathway is part of a suite of optimal neuroscience clinical pathways that have been developed by the neurological community, with the support of NHS England and the National Neurosciences Advisory Group (NNAG).

The development of this pathway was overseen by NNAG, with input from professional bodies and patient organisations. A 6 week public consultation was held to gather input, views and experience from people affected by neurological conditions and wider stakeholders.

The pathways set out what good treatment, care and support looks like. This includes treatment and support for people who may be experiencing the first symptoms of a neurological condition, right through to people who have lived with a condition for a long time. They set out the aspirations for good care, support improvement of services and enable commissioning of quality services, locally and nationally.

Optimal Clinical Neuroscience Pathways

NEUROSCIENCE

SUBARACHNOID/INTRACRANIAL HAEMMORHAGE · PITUITARY TUMOUR · BRAIN TUMOURS

MULTIPLE SCLEROSIS (MS) · EPILEPSY · AUTOIMMUNE · HEADACHE & FACIAL PAIN · NEUROMUSCULAR CONDITIONS

MOVEMENT DISORDERS · MOTOR NEURONE DISEASE (MND) · FUNCTIONAL NEUROLOGICAL DISORDER (FND) · TRAUMATIC BRAIN INJURY (TBI)

CROSS-CUTTING

TRANSITION FROM CHILDREN TO ADULT SERVICES · NEUROGENETICS · MENTAL HEALTH · REHABILITATION

FIND OUT MORE

Optimal clinical pathways and resources (NHS England and NHS Improvement. NHS log in required): www.future.nhs.uk/about

VISIT WEBSITE

Optimal clinical pathways and resources (NNAG): www.nnag.org.uk/optimum-clinical-pathways

VISIT WEBSITE

Neurological patient organisation websites & resources (Neurological Alliance): www.neural.org.uk/membership/our-members

VISIT WEBSITE

Context

Neurological conditions result in physical, sensory and cognitive impairments and are a leading cause of complex disability. Rehabilitation aims to prevent the loss of, restore, and maintain function enabling people to care for their families, and remain in the workplace. It has been identified as a priority in NHS Long Term Plan.

Reorganisation of stroke, trauma and heart attack services have led to greater numbers of survivors with significant brain injury (ischaemic, traumatic and hypoxic). Despite a 24% increase in admissions from neurological disorders in the 5 years to 2016/2017[1], rehabilitation beds have remained static over the same period. For example, to meet the needs of patients in England with major trauma alone, there is an estimated need for a further 328 specialist inpatient beds[2]. Patients experience long delays waiting for transfer to specialist rehabilitation centres, preventing efficient use of neurology, neurosurgery and trauma beds.

The majority of community rehabilitation services are uncoordinated and inconsistent. Supporting data to help improve services is lacking and the workforce is often insufficient to meet current need.

14% of the social care budget is spent on people living with neurological conditions.[1]

This pathway should be read alongside the neuroscience pathways that have been developed by NHS England and NNAG. The pathways set out good care and treatment for people with neurological conditions.

- Investment in rehabilitation for people with neurological conditions saves money and improves efficiency in the medium and long-term.
- There is now a substantial body of trial-based evidence and other research to support both the effectiveness and cost-effectiveness of rehabilitation throughout the disease trajectory.
- Vocational rehabilitation is needed by those with mild to moderate disability, for example those with newly diagnosed MS. Trial-based evidence and other research internationally, and in the NHS, support both the effectiveness and cost-effectiveness of vocational rehabilitation.
- Inpatient rehabilitation for those with moderate and severe acquired brain injury (whatever the aetiology) leads to improvements in functional abilities from inpatient which more than offset the average cost of their rehabilitation. While many of these patients still require long-term care, their dependency is reduced, with an average saving in ongoing care costs of £5151. Net life-time savings average between £680k[2] and £1 million[3].
- Every pound invested in specialist rehabilitation saved £20-£30. For example, equipment provision, orthotic provision for people with progressive neuropathies, result in cost savings where for every £1 spent on orthotic services, £4 is saved[4]. This alone represents a saving of £400m to the NHS.

Rehabilitation pathway

IMMEDIATE CARE

PATIENTS WITH COMPLEX REHAB NEEDS
SPECIALIST LEVEL 1 AND 2 SERVICES

ACUTE CARE
Neurosciences/ITU HDU

STEP-DOWN / TRIAGE
Early acute rehabilitation
Rehabilitation Prescription

HYPER-ACUTE REHABILITATION

Confirmation of
Category A/B needs

SPECIALIST IN-PT REHABILITATION
Multidisciplinary rehab
Consultant in
Rehabilitation Medicine

LEVEL 1/2A – TERTIARY
Specialised rehab for
Category A needs

LEVEL 2 - SECONDARY
Category B needs

LEVEL 3 LOCAL SERVICES

REHABILITATION
Level 3-inpatient services

HOSPITAL

HOME

SUPPORTED DISCHARGE
Hospital at home
Early community rehabilitation

SPECIALIST COMMUNITY REHABILITATION
Multidisciplinary rehab team
Specialist Vocational rehabilitation
Slow-stream residential rehabilitation
Specialist out-patient rehab

Rehab prescription

COMMUNITY REINTEGRATION
Enhanced participation
DEA – supported return to work
Supported self-exercise
Web-based resources

On-going
rehab needs

Source:
BSPRM Standards for specialist rehabilitation for community dwelling adults (2021)

SEVERE DISABLING NEUROLOGICAL ILLNESS OR INJURY

NO REMAINING NEEDS

Rehab prescription

INTEGRATED CARE PLANNING
Long term support
Single point of contact
Joint health and social service planning
Multi-agency care

Rehabilitation intervention examples for adults with a neurological condition

EXAMPLES OF NEUROLOGICAL DIAGNOSIS

- TRAUMATIC BRAIN INJURY
- MULTIPLE SCLEROSIS
- FUNCTIONAL NEUROLOGICAL DISORDER
- MND AND MUSCULAR ATROPHY
- MOVEMENT DISORDERS
- BRAIN TUMOURS
- INTRACEREBRAL HAEMORRHAGE

EXAMPLES OF REHABILITATION INTERVENTIONS

- VOCATIONAL REHABILITATION TO PREVENT JOB LOSS
- PHYSIOTHERAPY TO RESTORE ABILITY TO WALK AFTER A RELAPSE
- INTEGRATION OF NEUROPSYCHIATRY AND PSYCHOLOGY
- PROVISION OF EQUIPMENT INCLUDING ORTHOTICS TO PREVENT FALLS, AND FRACTURES LEADING TO ADMISSION
- MDT COMMUNITY REHABILITATION TO TREAT COMPLEX INTERACTING PROBLEMS, SWALLOW, MOBILITY, COGNITION AND CONTINENCE
- LEVEL 2 REHABILITATION BEDS TO ALLOW RAPID MULTIDISCIPLINARY INPUT AND FACILITATE INDEPENDENCE
- LEVEL 1 REHABILITATION FOR THE MOST DISABLED TO MINIMISE CARE NEEDS

IMPLICATIONS FOR CURRENT & FUTURE SERVICE PROVISION

- EARLY RECOGNITION OF INJURY
- EQUITABLE ACCESS TO COMMUNITY REHABILITATION NOT DEPENDENT ON DIAGNOSIS
- APPROPRIATE MENTAL HEALTH SUPPORT
- TIMELY ACCESS TO EQUIPMENT
- COMPREHENSIVE AND SKILLED MULTIDISCIPLINARY TEAMS
- AN INCREASE IN REHABILITATION BEDS
- ACCESS TO SPECIALIST SERVICES FOR LOW VOLUME HIGH COST SERVICES

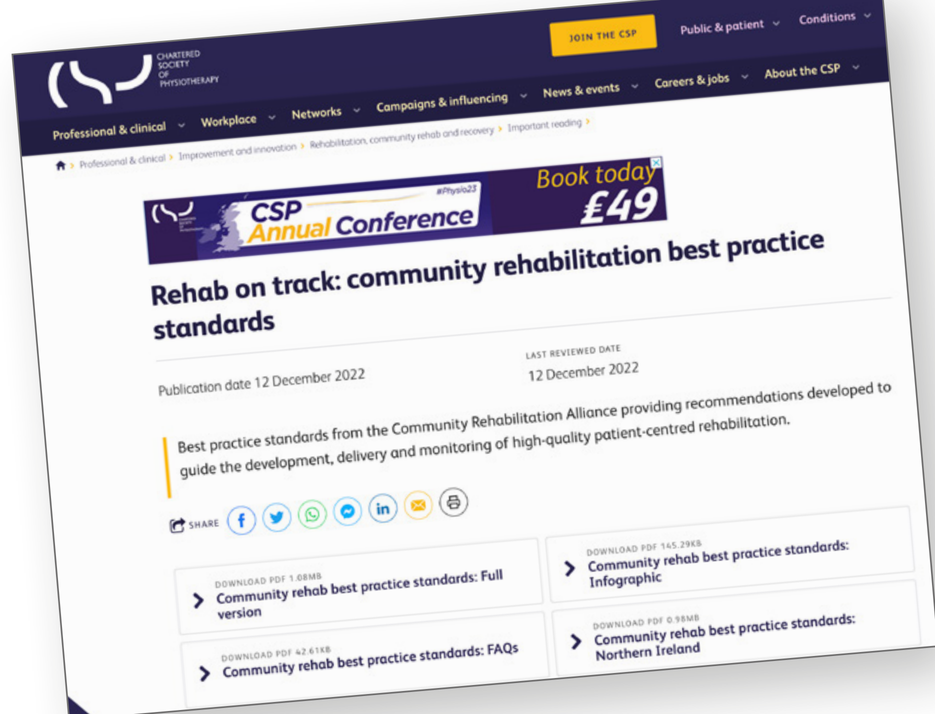
Data collection and analysis allowing quality improvement

Data collection and analysis allowing quality improvement

Overarching principles for rehabilitation of adults with neurological conditions

The overarching principles for the rehabilitative care of adults with neurological conditions correspond with the principles for all long-term conditions:

- Referral processes are explicit, easy, efficient and equitable.
- Rehabilitation interventions should be timely, co-ordinated both within and between services and prevent avoidable disability.
- Rehabilitation interventions should meet patient needs and be delivered in the format that is most effective for that patient.
- Rehabilitation pathways should address physical, cognitive communication and mental health needs, be delivered locally where possible, and allow access to specialist services.
- Every patient with complex rehabilitation needs should have a Rehabilitation Prescription and, if relevant, a FIT note completed to advise on return to work.
- The rehabilitation programme should be adequate to allow optimisation of function, incorporate teaching the skills that allow maintenance of function through self management and include regular review for people with complex disability that is likely to deteriorate.
- The rehabilitation service needs to be well led, adequately staffed in terms of range of disciplines, skill mix and expertise and supported by a rehabilitation network.
- The rehabilitation service should:, recognise the role of families, actively involve families (provided this is what the patient and the family agree to) and support families to work with patients.
- Refer to: Community Rehabilitation Alliance, Community Rehabilitation, Best Practice Guidance (2002).



- ✔ All patients with new or ongoing needs for rehabilitation should have a Rehabilitation Prescription setting out their rehabilitation needs and the plan to meet them. This information should be collated centrally for the purpose of monitoring the extent to which those needs are met.
- ✔ Patients whose Rehabilitation Prescription suggests a Level 1 or Level 2 rehabilitation, should have a timely transfer to an appropriate service in accordance with the national standards.
- ✔ Patients with neurological disability are seen annually for a rehabilitation review, or when requested by the patient and if indicated, receive a written rehabilitation prescription.
- ✔ Neuroscience centres should be part of a local rehabilitation network that works to deliver the Community Rehabilitation Alliance Best Practice Standards.

Recommendations

People with neurological conditions face inequalities in access to quality care, and there is widespread unwarranted variation in the provision and quality of appropriate rehabilitation services. The impact of the Covid-19 pandemic on people with long term neurological conditions, combined with the increased rehabilitation need, has further compounded the issues facing rehabilitation services:

Workforce challenges

- Insufficient workforce and inadequate skill mix across settings which can be less responsive to patient needs to prevent admissions to secondary care.
- Very low numbers of rehabilitation medicine consultants which have not increased in proportion with the growth in neurologists.

Inadequate numbers of specialist rehabilitation beds

- Lack of specialist rehabilitation beds leads to inappropriate management of severely disabled patients with physical & cognitive disabilities.

Inadequate provision of community neurological rehabilitation services

- Community rehabilitation services are often commissioned for specific conditions like stroke, rather than on a needs basis, which leads to fragmented systems and services with uncoordinated working. These services are inflexible and people with neurological diagnoses outside that of the commissioned conditions or those with more than one neurological conditions, struggle to access them.
- Variability in access to clinical (neuro)psychology services.

Lack of robust data and monitoring

- Inadequate data to monitor rehabilitation availability and outcomes, evaluate different models of care, and contribute to the evidence base.
- Lack of data on both quality and quantity of community rehabilitation services commissioned, with little robust data available on long-term patient outcomes.

Lack of awareness and clinical leadership

- Lack of strong rehabilitation leadership across the country.
- Clinicians and people with long term neurological conditions are unaware of benefits of rehabilitation.

Key recommendations for the Integrated Care Board (ICB)

- Appoint a rehabilitation director at executive level within the integrated care system[5].
- Within the ICB there should be a director whose portfolio includes responsibility for rehabilitation (this could be at executive or non–executive level)[5].
- Establish a rehabilitation network with input of all local providers of rehabilitation services including primary, secondary, tertiary health care, mental health, social care, vocational, independent and third sector providers[5].
- Collection of nationally agreed data to enable the publication of comparative datasets to support service delivery[5].
- Publish an annual reports on rehabilitation with a directory of rehabilitation services within each Integrated Care System and an annual report[5].
- Ensure adequate access to specialist equipment across all rehabilitation services.
- Support the appointment of allied healthcare professionals with specialist experience in rehabilitation.
- Support the appointment of a dedicated workforce with specialist experience in the substantial psychological morbidity associated with neurological conditions - clinical psychology/neuropsychologists and associate/assistant staff together with specialist practitioners in mental health provision including access to neuropsychiatric expertise, specialist counselling and NHS talking therapies services.
- Expand community rehabilitation services to meet population need.
- Increase or improve access to the numbers of level 1 and level 2 specialist rehabilitation beds. Mandate level 2 in-patient of 24 beds rehabilitation unit for every 250, 000 – 500, 000 staffed to guidance.
- Mandate the rehabilitation prescription.

Resources to support local pathways

Community Rehabilitation Alliance December 2022 Community Rehabilitation Best Practice Standards

VISIT WEBSITE

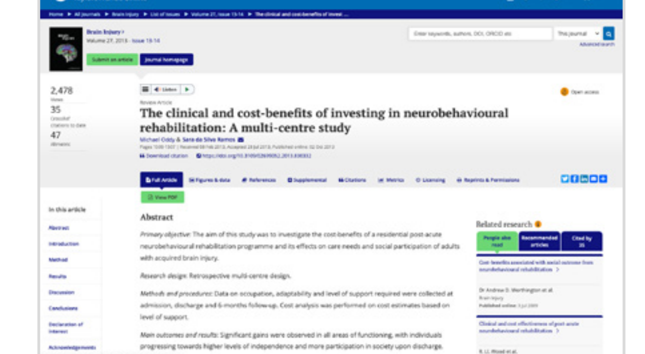
Cost-efficiency of specialist inpatient rehabilitation for working-aged adults with complex neurological disabilities: a multicentre cohort analysis of a national clinical data set

VISIT WEBSITE

Estimated Life-Time Savings in the Cost of Ongoing Care Following Specialist Rehabilitation for Severe Traumatic Brain Injury in the United Kingdom

OPEN PDF ONLINE

The clinical and cost-benefits of investing in neurobehavioural rehabilitation: A multi-centre study



VISIT WEBSITE

NHS England 2019 NHS RightCare Community rehabilitation toolkit

NHS England 2016 Commissioning guidance for rehabilitation

Resources to support local pathways

Community Rehabilitation Alliance 2022 Best Practice Standards

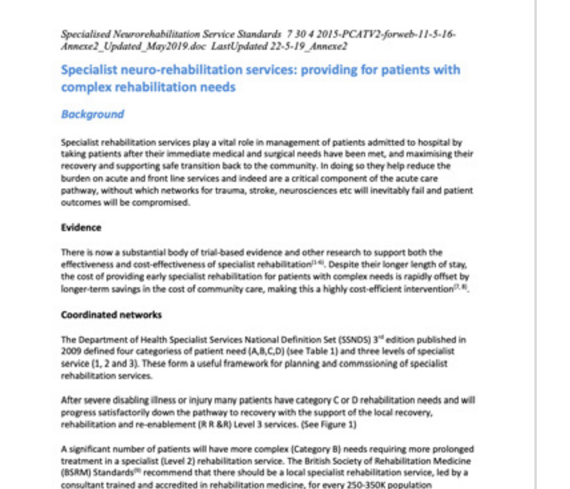
OPEN PDF ONLINE

BSPRM 2021 2021 Standards for specialist rehabilitation for community dwelling adults – updated 2002 standards

OPEN PDF ONLINE

BSPRM 2019 Specialist neurorehabilitation services

OPEN PDF ONLINE



Specialised Neurorehabilitation Service Standards 7 30 4 2015-PCATV2-forweb-11-5-16-Annexe2_Updated_May2019.doc LastUpdated 22-5-19_Annexe2

Specialist neuro-rehabilitation services: providing for patients with complex rehabilitation needs

Background

Specialist rehabilitation services play a vital role in management of patients admitted to hospital by taking patients after their immediate medical and surgical needs have been met, and maximising their recovery and supporting safe transition back to the community. In doing so they help reduce the burden on acute and front line services and indeed are a critical component of the acute care pathway, without which networks for trauma, stroke, neurosciences etc will inevitably fail and patient outcomes will be compromised.

Evidence

There is now a substantial body of trial-based evidence and other research to support both the effectiveness and cost-effectiveness of specialist rehabilitation[1-6]. Despite their longer length of stay, the cost of providing early specialist rehabilitation for patients with complex needs is rapidly offset by longer-term savings in the cost of community care, making this a highly cost-efficient intervention[7, 8].

Coordinated networks

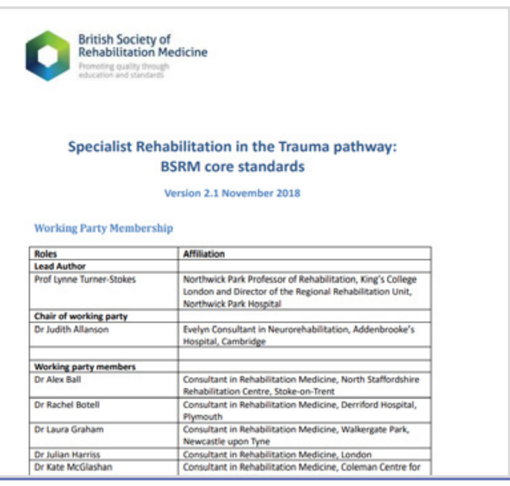
The Department of Health Specialist Services National Definition Set (SSNDS) 3rd edition published in 2009 defined four categoriess of patient need (A,B,C,D) (see Table 1) and three levels of specialist service (1, 2 and 3). These form a useful framework for planning and commssioning of specialist rehabilitation services.

After severe disabling illness or injury many patients have category C or D rehabilitation needs and will progress satisfactorily down the pathway to recovery with the support of the local recovery, rehabilitation and re-enablement (R R &R) Level 3 services. (See Figure 1)

A significant number of patients will have more complex (Category B) needs requiring more prolonged treatment in a specialist (Level 2) rehabilitation service. The British Society of Rehabilitation Medicine (BSRM) Standards[9] recommend that there should be a local specialist rehabilitation service, led by a consultant trained and accredited in rehabilitation medicine, for every 250-350K population

BSPRM 2018 BSPRM Core standards for Major Trauma (Rev 2.1-Nov2018)

OPEN PDF ONLINE



British Society of Rehabilitation Medicine

Promoting quality through education and standards

Specialist Rehabilitation in the Trauma pathway: BSRM core standards

Version 2.1 November 2018

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BSPRM 2021 BSPRM brief guidance on vocational rehabilitation

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British Society of Rehabilitation Medicine

Vocational Rehabilitation: BSRM brief guidance

Community Rehabilitation Alliance 2022 Making Community Rehabilitation Data Count

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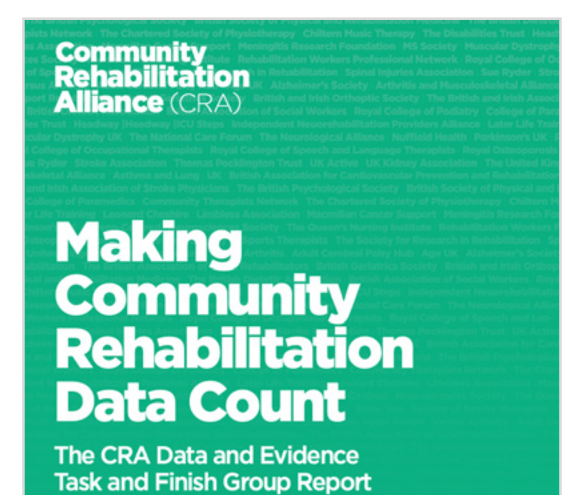

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- Adine Adonis, Clinical Specialist Physiotherapist Neurology, Imperial College NHS Trust. Chair, The Association of Chartered Physiotherapiss interested in Neurology (ACPIN)
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National Neurosciences Advisory Group c/o The Neurological Alliance (England)
www.nnag.org.uk

The Neurological Alliance is a coalition working together to improve treatment, care and support for people affected by neurological conditions. Together we campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.

www.neural.org.uk

Email: info@neural.org.uk

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