



Royal College
of Physicians



BSRM
British Society of Rehabilitation Medicine

Medical rehabilitation in 2011 and beyond

Report of a joint working party of the Royal
College of Physicians and the British Society of
Rehabilitation Medicine

November 2010

The Royal College of Physicians

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The British Society of Rehabilitation Medicine is the UK professional organisation for practitioners in rehabilitation medicine. It is a young, vibrant organisation devoted to promoting the development and good practice of rehabilitation medicine as a medical specialty; enhancing undergraduate and postgraduate education in rehabilitation and disability issues; supporting rehabilitation research; and working with related medical, paramedical and voluntary organisations to further these aims. Membership is open to registered medical practitioners with an interest in disability and its management.

Citation for this report: Royal College of Physicians. *Medical rehabilitation in 2011 and beyond*. Report of a working party. London: RCP, 2010.

Review date: 2013

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ISBN 978-1-86016-386-9

Printed copies of this document have been produced with the assistance of a donation to the BSRM from Irwin Mitchell Solicitors LLP.

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Typeset by Dan-Set Graphics, Telford, Shropshire

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Introduction

This is the fourth Royal College of Physicians report on rehabilitation medicine (RM). It has the following objectives:

- ▶ To clarify the specific role of RM within the broader spectrum of rehabilitation services.
- ▶ To provide an updated description of RM for commissioners, planners and providers of healthcare and social care, describing how RM expertise contributes to meeting the specialist needs of people with disabilities.
- ▶ To promote the development of high-quality, accessible, and equitable services in line with the principles of the National Service Framework (NSF) for long-term conditions,¹ specifying the basic requirements for cost-effective services.

The report appears at a time of great change in the provision of national health services, against the backdrop of a severe financial recession affecting all public services. The coalition government's white paper of July 2010 highlights the potential opportunities for 'continuously improving those things that really matter to patients' and 'empowering and liberating clinicians to innovate, with the freedom to focus on improving healthcare services.' Political devolution has permitted independent development of Welsh, Irish and Scottish health services, and English services have been subject to a series of rapid changes in organisation and funding with another, perhaps the most fundamental change in a generation, being implemented over the next few years.² At this stage, the working party cannot forecast either the effects of GP commissioning or of foundation trust status for all providers, and the report will need updating when the effect of these changes on RM commissioning becomes clearer after the planned date of full implementation of GP commissioning in April 2013.

RM physicians provide expertise in the diagnosis, assessment and management of people with disabling disorders, supporting their right to lead fulfilling, normal lives. The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) uses three dimensions to describe disablement: impairment, limitation of activity, and restriction of participation.³ The ICF also recognises the role of the environment in both producing and reducing disability, thus highlighting the potential for social attitudes, behaviours and policies to enhance participation.

The non-linear nature of a disabling illness does not fit into the 'diagnose-treat-discharge' pattern of modern hospital medicine. RM is a challenging specialty, requiring detailed knowledge of the medicine of many body systems (it is not an organ-based specialty) and of psychology, law, education and enabling technology. The clinical practice of RM divides into two broad groups: neurological rehabilitation (including spinal cord injuries), and limb loss and musculoskeletal rehabilitation, including complex trauma. There is significant overlap in all classifications of RM.

Evidence of the benefits of RM interventions has accumulated, and is summarised in Chapter 4. The detailed Cochrane reviews and the evaluation of evidence which underpinned the recommendations enshrined in the NSF have shaped current service provision. Individual patient experiences suggest that more rehabilitation interventions are required. Major trauma survivors

often have difficulty accessing specialist rehabilitation services early in their recovery when they most need it. There is evidence that access to RM services is uneven and inequitable, especially in follow-up, and attempts to provide specialist treatments in the community have not been universally successful. RM physicians highlight these needs in their daily practice. We anticipate a greater involvement in provision of specialist community services for people with long-term conditions (LTCs) after discharge from hospital.

Drivers for change in RM have included the Darzi Report⁴ and the NSF.⁵ Recently, both the critical care and the trauma care initiatives have re-emphasised the importance of early access to specialist rehabilitation services to minimise long-term disability and care costs. The Darzi report, based on patterns of service first developed in London, recommended that services for people with LTCs should be developed closer to their homes; it presented a vision of medical and therapeutic services no longer housed in their current hospital environments, but without addressing their need for a core physical structure.

The NSF produced a set of quality requirements to be achieved over a 10-year period. It was published in April 2005, co-chaired by a consultant in RM, and provides an overarching framework for all RM services. It was strongly user-led, with life-long person-centred care as its core principle. The original focus of the NSF was neurological conditions, but it is more widely applicable. Fig 1.1 illustrates how the NSF's 11 quality requirements (QRs) fit along the care pathway. It captures the flow from early access to specialist rehabilitation expertise and services into community-based rehabilitation and care services.

Funding for RM services has undergone a maelstrom of change, with centralised budgeting controlled by health authorities being displaced by primary care trust (PCT) purchasing, followed by 'Payment by results' (PbR), practice-based commissioning (PBC) and 'World class commissioning'. A new structure is being created through GP commissioning, the details of which have not yet been agreed for RM. Once known, an update to this report will be required to ensure that RM commissioning funding is in place for issues from this NSF. Ring-fenced funding has, to date, not been available for this NSF (unlike previous ones) and LTCs are not yet included in the quality outcome framework for general practice remuneration. Close monitoring will be vital to meet the NSF requirements in all areas for all people requiring these services.

Chapter 1 provides us with some patient perspectives. Chapter 2 describes the principles of RM and specifies service standards. Chapter 3 outlines clinical pathways within the principal areas of RM practice, and Chapter 4 summarises the evidence. Chapter 5 describes our standards and outcome monitoring, and Chapter 6 identifies specific issues for service commissioners. The report concludes, in Chapter 7, with an assessment of future trends. The range of services covered by rehabilitation medicine specialists is considerable, and this report cannot address each in detail. The working party has highlighted those areas of practice most commonly carried out by most specialists in the field, and which are most relevant to NHS commissioners.

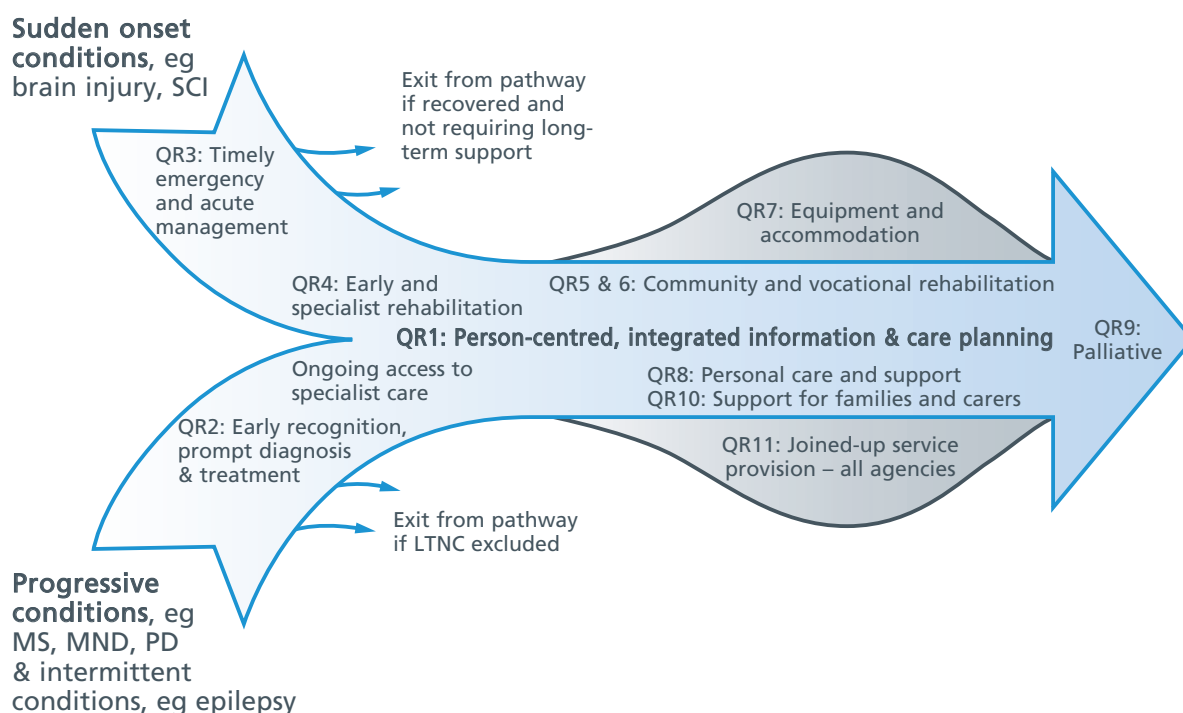


Fig 1.1 National service framework for long-term conditions care pathway.

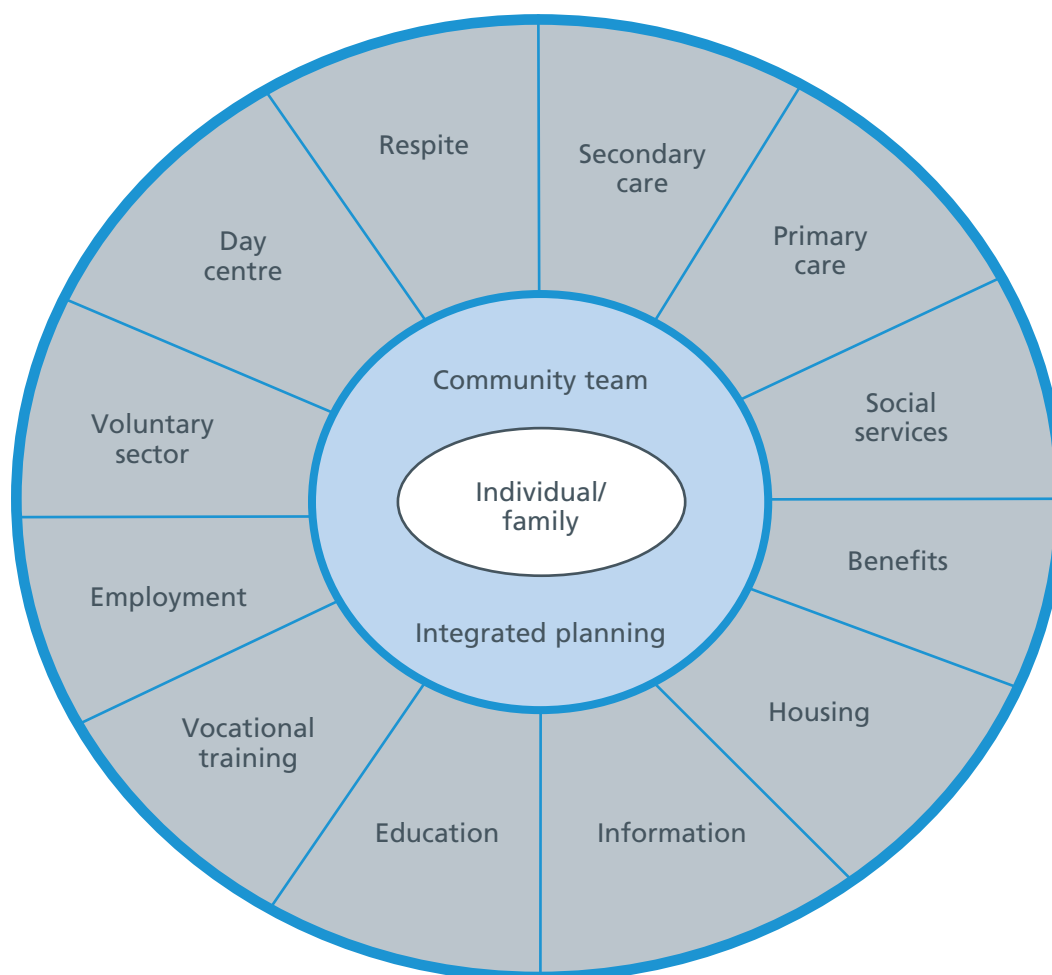


Fig 1.2 Cross-sectional cut of national service framework.

Executive summary and recommendations

This Royal College of Physicians (RCP) report on rehabilitation medicine (RM) has clarified the role of RM physicians within the wider spectrum of rehabilitation services. It demonstrates for commissioners, for our medical and surgical colleagues, and for the public, the benefits and long-term savings that can be achieved by the swift investment in and provision of access to high-quality rehabilitation services for people with newly acquired disability caused by illness or accident, and for those with long-term fluctuating or progressive disorders. It stresses the need for flexibility in care pathways, which should be seen as supportive of need and not restrictive of access.

This report revises the definitions of RM in line with current practice, and focuses on rehabilitation and disability management as the two main areas of activity. It also draws attention to the need to consider rehabilitation as a continuum of acute illness management, to prevent avoidable complications and optimise recovery and vocational status.

RM is recognised as a specialty with significant areas of overlap practice, particularly with colleagues in neurological, neurosurgical, orthopaedic, palliative care, psychiatric, psychological, rheumatological, vascular and pain medicine, not forgetting paediatric and geriatric colleagues. This is because complex disabling disorders occur at all ages, and are associated with multisystem impairments and specialised needs. Commissioning should support joint working and the development of truly interdisciplinary working practice and clinical pathways. The RM specialist is expert at coordinating individual personalised clinical pathways, which take into account complexity of need at different stages of an illness and at different stages of life.

Generic pathways developed for specific conditions such as stroke are excellent in their attention to rapid diagnosis and early treatment, and for the overall upgrading of community-based service provision after early discharge from hospital. However, they fail to capture the need for many stroke survivors to have access to a specialist rehabilitation service, with high-intensity treatments and greater consideration of individual participation in life, addressing vocational needs, needs as a parent, cognitive needs, and the need to return to as normal a life as possible. They do not address the needs of those with highly complex disability after stroke – those who are going to take longer than six weeks in a hospital or other specialist setting.

The evidence of benefit of RM interventions has been drawn from other reviews and Cochrane collaborations, and is now substantially in favour of investment in RM for people with a very wide range of disabling disorders. RM expects to produce evidence of its worth and United Kingdom Rehabilitation Outcomes Collaboration (UKROC), the national database, is providing a framework for this. Data can be a double-edged sword, and the data will not demonstrate that all of our patients get better. However, by developing the skills required to monitor goal attainment, it will be demonstrated that those with deteriorating disorders also gain benefit from rehabilitation interventions, whether it be psychosocial benefit, continuing to live with family in the community, or symptomatic relief of symptoms for those who are dying from rapidly progressive neurological conditions such as motor neurone disease. Making lives worth living remains a realistic goal, however severe the disability.

Standards of practice have been agreed and mapped on to the National Service Framework (NSF) for long-term neurological conditions. The national dataset will inform the setting of tariffs,

though present-day NHS funding cuts could slow the development of UK-wide accessible specialist rehabilitation services. Commissioners will need to be well informed and able to implement personalised clinical pathways. We recognise their need for accurate information for likely outcomes. Effective specialist rehabilitation for severe brain injury or severe Guillain-Barré syndrome can take 6 to 18 months, and can result in long-term savings in care costs, and sometimes successful return to work. This work may be possible in a good district rehabilitation service, but in some situations commissioners may need to support referral to a tertiary specialised service through a collaborative commissioning network.

The future in RM is exciting. RM physicians will have a major role in health maintenance in people with disabling illness, in preventing hospital admission wherever possible, and in maintaining commissioning support for specialist services as required. New technological solutions will include telemedicine, teletherapy, enabling technology, and smart homes. The development of disease-modifying drugs and neuroprotection will extend lives, may reduce or may attenuate and lengthen the experience of disability. Implanted prostheses will create new demands for limb loss RM specialists. Stem cell treatments and neural implants will require 'training' to gain individual functional benefit. There will be a continued and growing demand for medical expertise in RM.

Recommendations

[2.5] Commissioning requirements for disability management

Commissioners need to understand and accept the requirement for disability management and repeated packages of rehabilitation interventions for people who have complex and changing needs as a result of long-term conditions. Specialists in RM are trained to recognise the need for, and to coordinate, complex packages of intervention, in order to improve and enable the lives of people with disabilities.

[2.23] Enabling technology

Commissioners need access to guidance from specialists in RM, to evaluate and demonstrate the benefits to the individual of increased independence and well-being that can be achieved with enabling technology. Savings can be achieved, eg by reducing care needs, avoiding placements in nursing homes, or avoiding complications such as fractures. The more unique the situation, the greater the level of specialist input required. There needs to be reserve funding for unusual demands.

[3.5–3.7] RM in acute settings

We recommend that early access to acute RM specialist services is available urgently for people with newly acquired brain injury and complex disability caused by major trauma, critical illness or other causation. These RM interventions can be provided in ITU, neurosurgery and other acute settings, and will continue in specialist RM settings.

[3.13] Stroke rehabilitation

Specialist stroke rehabilitation services should be commissioned for the group of stroke survivors who were previously active, and often employed at the time of the stroke, because they have the potential to achieve a better recovery with the use of intensive and specialist techniques. Those with very complex needs also require access to specialist RM services.

[3.18] Spinal cord injury services

Standards have been devised to provide a framework for the development and monitoring of specialist spinal cord injury services, which embrace the quality requirements of the NSF and NHS aspirations.^{6,7} These standards should be followed.

[3.19–3.20] Progressive health conditions

We recommend that people with disabling new or progressive health conditions have timely access to RM specialist services to minimise their disability and enhance their quality of life.

[5.8] Consultant expansion

Based on known population patterns of growth and changing practices, we recommend that 80 new RM consultant posts are proposed and developed over a ten-year period.

[6.21] Commissioning high-quality services

Ensure that

- ▶ clear commissioning structures are in place which facilitate the understanding, coordination, redesign and development of rehabilitation services
- ▶ a commissioning framework exists to support patients individually with regard to need, complexity and local circumstances
- ▶ the benefits of consortium or collaborative commissioning arrangements for supporting existing structures are reviewed
- ▶ the benefits of case-management arrangements are reviewed to deal with gaps in service provision
- ▶ commissioning supports local specialists in the reduction of the long-term costs of disability
- ▶ medical leadership is in place to support commissioning RM services for complex patient groups, rather than relying on technological solutions.

1 Patient and carer perspectives

1.1 Rehabilitation medicine (RM) aims to enable people with disabilities to achieve and maintain a high level of physical, psychological and social well-being.

1.2 Those who acquire a disability, and their families, have huge adjustments to make to their lives. These may be particularly difficult when a condition comes on suddenly, or when those involved are young. Some may go into a state of denial, refusing to accept the situation, not adapting, and blaming others for problems. Some may be overly accepting and just give in. Others achieve a more balanced attitude, accept limitations, and adapt to new ways of living and new roles in the home and community. They live and contribute to the fullest extent possible, and create new meaning and purpose in their lives. This is similar to working through bereavement, and people need the healing support of others to achieve a positive outcome.

1.3 Attitudes within society have changed dramatically, and in the UK there is now legislation which helps people with disabilities in relation to employment, transport, services and access to public places. Equipment and technologies have been developed, but they do not always reach the people who need them. It often frustrates patients, carers and their professional advisers that budgetary and administrative barriers prevent the timely solution of problems, and the patients suffer the frustrations and consequences of the delay.

1.4 Carers make a considerable contribution in supporting and enabling the person they care for in many areas of life. Carers' contributions have been estimated to be worth millions of pounds to the national economy, not to mention their immense human value. However, a carer's own health can suffer, especially if needs are not met and services are not coordinated. These services are principally in the community, and mostly within primary care, but for those with the most complex needs, RM can be vital. Proactive and integrated care can significantly reduce the impact of disability and prevent avoidable complications. This requires a well coordinated, multiprofessional team with the person and their family at the centre.

1.5 Personalised care is therefore central to the ethos of rehabilitation medicine. Patients who are knowledgeable about their condition are encouraged to negotiate the goals of their rehabilitation, and to advise on the pattern of services. Participating families or appointed health executives may assist with decision making. The RM specialist is crucial in ensuring that the patient's and family's wishes are not submerged under the contingencies of professional care.

1.6 Many people receiving rehabilitation services have highly complex needs, and it is vital to the patient and family that there is good communication with, and between, all of their rehabilitation and care staff. Communication is frequently the major issue that is identified when problems arise, and a key feature that patients and carers value when rehabilitation works well.

1.7 The specialty of rehabilitation medicine manages conditions that are complicated, expensive and likely to change markedly over the next few years with innovations in management and service delivery. These will be exciting times, but the patient and their carer/family must remain at the centre. They must be able to trust the multidisciplinary team and services responsible for them, and be assured that they will communicate well with them and with each other.

Clinical scenarios

A lady with progressive multiple sclerosis (MS) who lived alone was referred to RM by her MS nurse with painful spasms and the inability to get out of bed. A domiciliary visit led to successful treatment of spasticity, using intrathecal phenol. She was provided with electronic environmental control equipment to allow her to talk to visitors at her front door before letting them in; to answer her telephone and make calls; to switch her TV, radio and computer on and off; to close the curtains; and to switch lights on and off. She regained sitting ability, required a new powered wheelchair and other equipment (arranged by an occupational therapist) and regained control of her immediate environment. She was able to go out again.

A lady with athetoid cerebral palsy was admitted with hepatic failure after excess use of alcohol to suppress her movements. During her acute stay, her rented bungalow was given up and she was awarded continuing NHS healthcare, leading to discharge to a nursing home. Six months later, she complained of infringement of her human rights through institutionalisation and loss of access to normal, alcohol-related, social activity. RM referral led to consideration by a hospital ethics committee, a negotiated contract on alcohol consumption, a search for new accommodation, and a case worker from the community rehabilitation team.

A man was referred to an RM specialist with reduced executive skills and mild memory problems caused by hypoxia following a cardiac arrest during surgery with successful resuscitation. Clinical assessment confirmed significant emotional distress, and reduced executive skills. He was very frightened of having a further heart attack. Brain imaging was normal. Referral to a neuropsychologist in the community rehabilitation team resulted in confirmation of minor cognitive skill impairments and a severe anxiety state, which responded well to cognitive behavioural therapy. The RM consultant assisted the patient with referral to occupational health, resulting in a successful return to a modified role at work with no executive responsibilities.

2 What is rehabilitation medicine?

The definition of rehabilitation medicine

Rehabilitation medicine

2.1 Rehabilitation medicine (RM) is the medical specialty with rehabilitation as its primary strategy. It has a hospital-based four-year specialist training curriculum. RM in the UK provides services for people with complex disabilities and aims to reduce the impact of disabling conditions. Patients frequently present with a diverse mixture of medical, physical, sensory, cognitive, communicative, psychological, social and environmental problems which require specialist input from a wide range of disciplines working together as a coordinated team. Accredited RM specialists therefore work in multidisciplinary teams across the range of healthcare, both in acute and community settings. Currently, RM specialists are mainly hospital-based, with some community responsibilities. If there is a substantial move to community provision, as current policy recommends, they will be increasingly based in the community with multidisciplinary teams.

2.2 RM in the UK serves two primary groups of people: those with neurological disabilities, including those with spinal cord injuries; and those with limb loss and other musculoskeletal impairments. Musculoskeletal impairments affect all groups. RM is known as physical and rehabilitation medicine (PRM) in some parts of the world, especially continental Europe, where there is a larger element of musculoskeletal rehabilitation than exists currently in the UK. The two main aspects of RM are rehabilitation and disability management.

2.3 Rehabilitation is an active, time-limited collaboration of a person with disabilities and professionals, along with other relevant people, to produce sustained reductions in the impact of disease and disability on daily life. Interventions focus on the individual, on the physical or social environment, or a combination of these.

2.4 The principles of rehabilitation can be applied not only in time-limited programmes, but also in responding to intermittent or continuous changes in impairments and disabilities produced by progressive disorders, and also by apparently static conditions. Prevention of further disability is often an important aspect of this work. In RM, the term 'rehabilitation' is applied loosely to all of these activities, but a more accurate term would be disability management, which is defined below.

2.5 Disability management is an aspect of clinical practice which uses a collaborative rehabilitation approach in conditions which produce changing or unpredictable health needs. The aims are to work with patients and their families in preventing avoidable complications, and to minimise the effects of changing disability.

RECOMMENDATION

Commissioners need to understand and accept the requirement for disability management and repeated packages of rehabilitation interventions in people who have complex and changing needs as a result of long-term conditions. Specialists in RM are trained to recognise the need for and coordinate complex packages of intervention to improve and enable the lives of people with disabilities.

Ethical aspects and human rights

2.6 Statements from the United Nations charter through its standards (1993),⁸ the European Year of People with Disabilities 2003,⁹ and the 58th resolution of the World Health Assembly (2005)¹⁰ have all declared that access to rehabilitation is a basic human right. In addition, many European states have anti-discrimination laws which can be used to support people with disabilities and their families and carers. RM specialists are routinely involved in ethical discussions and have considerable expertise in the legal dilemmas surrounding the care and rights of their patients.

Dimensions of the International Classification of Functioning, Disability and Health

2.7 The practice of RM can also be described in the terms of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) framework.³ The central aim is to enhance a person's participation, ie the fulfilment of roles that are meaningful to the individual. This focus must take account of the personal, cultural and environmental context. An increase in participation will often come about through reduction in limitations on one or more component activities. Enhancements in activities, participation and quality of life often depend on understanding and treating health conditions and reducing impairment and its impact through medical and surgical interventions. In many situations, however, large gains can be achieved by changes in the environment, which might range from the provision of a walking aid to the facilitation of a different way of providing care. The RM specialist makes a range of contributions in the assessment and management of problems arising at all these levels, including the rights of individuals with a disability to remain in employment.

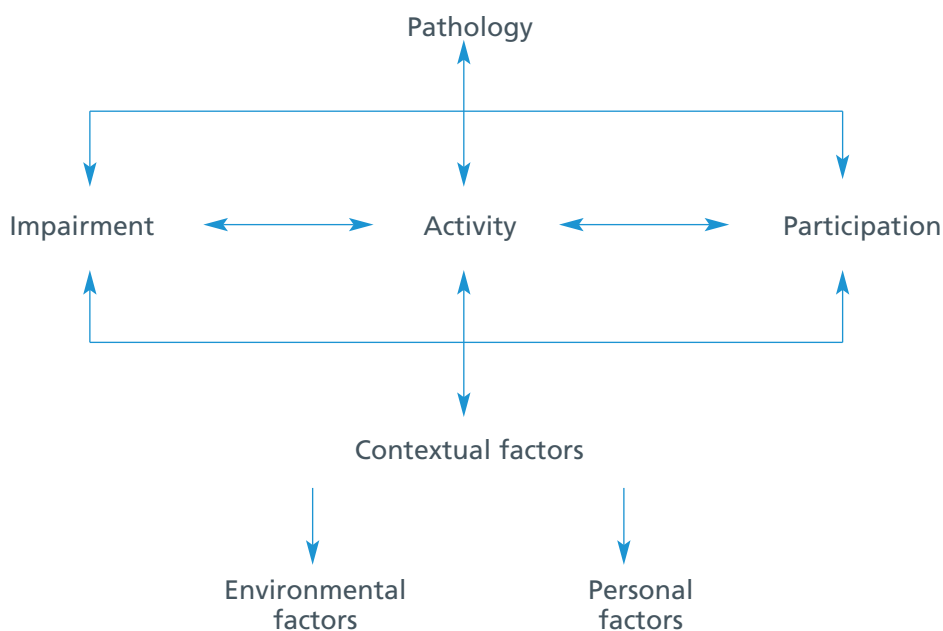


Fig 2.1 Application of the World Health Organization (WHO) international classification. 'Limitation of activity' and 'restriction of participation' are the ICF terms which replace 'disability' and 'handicap' under the previous WHO model of impairment, disability and handicap.¹¹

Example of RM practice

Following a bomb blast, a 19-year-old soldier receives a right above-knee amputation. RM assessment identifies impairments such as limb loss; pain; a previously unsuspected moderate brain injury; unilateral deafness and post-traumatic stress; limitations in activities such as walking, sleeping, concentrating; and restrictions in participation, including fulfilment of military and family roles. The outcome is enhanced by alterations in the environment, beginning with the provision of a prosthesis, specialist treatment for the brain injury and stress-related symptoms, and should eventually include adjustments made for the process of re-employment with access to vocational rehabilitation services. Continued attention to his social environment (including his family life and relationships with others in his unit), and to the bereavement aspects of his situation, are also crucial aspects of his rehabilitation.

Principles of rehabilitation medicine**Key roles and skills of the RM consultant**

2.8 Core roles of RM specialists include the diagnosis and medical management of conditions causing complex disability. One of the RM physician's key contributions to the work of the multidisciplinary rehabilitation team is to provide a holistic description of the patient's situation, from both a medical and a non-medical point of view, thus helping individuals and families to identify abilities, resources and possibilities as well as illness, disability and problems.

2.9 Disabilities can almost always be made more severe by omissions or ill-considered actions, and prevention is a fundamental principle of RM. In many situations an RM specialist can make a vital contribution through anticipation and prevention of physical, psychological and social complications, based on knowledge of a condition's natural history and prognosis. RM specialists work with and support multidisciplinary teams in healthcare and social care settings to achieve these aims.

2.10 Table 2.1 identifies eight aspects of the consultant's role, and provides examples of the tasks and skills entailed.

Table 2.1 Key roles and skills of a rehabilitation medicine consultant

Role	Tasks	Skills	Examples of problems addressed
Diagnosis and prognosis	Diagnosing pathology, identifying impairment and assessing prognosis	Generic and specialist clinical skills	<ul style="list-style-type: none"> – Identifying opportunities for interventions – Meeting information needs of patients and multidisciplinary team members
Risk assessment	Identifying and managing risks	<ul style="list-style-type: none"> – Understanding disease progression – Managing uncertainty – Education and negotiation 	<ul style="list-style-type: none"> – Accidents – Pressure sores – Contractures – Malnutrition – Relationship breakdown – Employment issues

continued

Table 2.1 Key roles and skills of a rehabilitation medicine consultant – continued

Role	Tasks	Skills	Examples of problems addressed
Medical management	Analysing impairments in relation to disabilities	Treatment of symptoms eg pain, spasticity, respiratory failure, incontinence, disorders of mood and behaviour. Involves psychologist or psychiatrist.	<ul style="list-style-type: none"> – Inadequate symptom relief – Depression, suicidal behaviour – Incontinence, pressure ulcers – Contractures
Leadership	Supporting, influencing, leading or managing multi-disciplinary teams	Managerial, team member and leadership skills	Helping a team to maintain a common purpose, often involving conflicts between multiple lines of accountability
Advocacy, mentoring	<ul style="list-style-type: none"> – Listening – Advance care planning – Family liaison – Managing expectations 	<ul style="list-style-type: none"> – Assessment of capacity and understanding of legislation – Communication techniques – Negotiation 	<ul style="list-style-type: none"> – Conflict – Inappropriate services – Inappropriate treatments
Enabling	<ul style="list-style-type: none"> – Accessing equipment – Recognising need for adaptations and involving the multi-disciplinary team – Coordinating therapy 	<ul style="list-style-type: none"> – Coordination – Advocacy – Consultation skills – Techniques such as motivational interviewing 	<ul style="list-style-type: none"> – Loss of autonomy – Loss of participation in chosen activities and roles
Counselling	Understanding and supporting individuals and families in the context of specialist medical knowledge	<ul style="list-style-type: none"> – Counselling skills – Consultation skills – Continuity of care – Understanding of multidisciplinary team working – Understanding of family dynamics 	<ul style="list-style-type: none"> – Despair – Isolation – Loss of therapeutic relationships
Public health	Advising commissioners and trusts on disability-related issues	<ul style="list-style-type: none"> – Community perspective – Political awareness of influence of health service changes on RM provision 	<ul style="list-style-type: none"> – Inequity of access to services, eg health screening for disabled people – Special needs of disabled people in hospital

The scope of rehabilitation medicine practice

Rehabilitation medicine in different phases of the rehabilitation process

2.11 Medical rehabilitation interventions are appropriate whenever there is a need (as defined above) and where an appropriate rehabilitation intervention exists. The NSF classifies medical conditions into four groups: sudden onset, intermittent, progressive and stable (see Box 2.1). These are determined by need rather than diagnosis, because people with long-term conditions

experience changing needs and will populate more than one of these four groups during their lives. RM makes contributions when new or changing needs call for medical reassessment and coordinated rehabilitative responses.

Box 2.1 NSF classification of long-term conditions

Sudden onset conditions

For example, brain or spinal cord injury, where a catastrophic onset is followed by a variable degree of recovery.

Intermittent conditions

For example, relapsing remitting multiple sclerosis, where the condition itself may fluctuate, although the problem of unpredictability is ever-present.

Progressive conditions

Impairments and disability gradually increase over a timescale, which may vary from a few months (in the case of rapidly progressive conditions) to many years (eg in secondary progressive multiple sclerosis or Parkinson's disease).

Stable conditions

For example, cerebral palsy or post-polio, where the condition itself is often static, but the additional effects of degenerative and other changes may be superimposed over time, producing new disability and new rehabilitation needs.

Example of flow of changing need in a person with a long-term condition

A man aged 48 sustains a hemiplegic stroke – a sudden onset condition requiring neurological rehabilitation to optimise functional recovery. He achieves his goals of walking independently and returning to work. At this stage his condition is stable, although still requiring long-term review of some aspects such as mobility. As he ages, his gait deteriorates because of premature degenerative changes in the hip on the paretic side caused by his impaired walking pattern. This causes pain and increased spasticity. He now requires specialist assessment and intervention again from a rehabilitation physician. He may develop osteoarthritis to a degree that would place him in the progressive category. He may develop further cerebrovascular events, which would also place him in the progressive category.

Clinical conditions served by rehabilitation medicine

2.12 RM covers many areas of practice, which can be broadly divided into: neurological rehabilitation, including brain, spinal cord and peripheral nerve conditions and injuries; and musculoskeletal rehabilitation, a large and diverse area of practice. Neurological rehabilitation serves those with all forms of complex neurological disability, whether sudden onset, progressive, intermittent or stable. Musculoskeletal rehabilitation includes services for people with congenital or acquired limb deficiencies (termed 'amputee' or 'limb loss' rehabilitation) and musculoskeletal services for people with physical impairments usually affecting the back, neck or limbs. All areas of practice include the management of pain, behaviours, emotional disturbances and cognitive issues. A list of some examples of conditions seen by RM consultants is shown in Table 2.2. While much of RM is focused on neurological rehabilitation, there is increasing recognition of the value of RM specialists in trauma and musculoskeletal rehabilitation, particularly in relation to

the development of the trauma networks, where people with complex needs following limb and truncal trauma require the input of RM services. There is potential for considerable cost savings, with the fast-tracking of people with serious disabilities out of acute services into specialist rehabilitation settings.

2.13 This report covers the services provided by rehabilitation medicine and its associated professional organisations. It describes the pathways for the provision of high-quality services for people with complex physical disabilities caused by a range of acquired and congenital health conditions. It also describes the field of competence of the specialty and its specialists, and their role in the teams in which they work. The report highlights the core features of the specialty and those where there is regular liaison with other medical disciplines and health professions. The report does not cover the whole range of health-related rehabilitation services, eg cardiac, pulmonary or psychiatric rehabilitation, for which there are clearly defined resources. RM specialists would like to see closer connections between these areas and rehabilitation medicine over the next decade, with enhanced opportunities for cross-fertilisation of services and academic interests.

2.14 The majority of RM services focus primarily on provision for adults with physical, cognitive or behavioural difficulties. Some also have a specific input for children under 16 years of age, and for people with learning difficulties, who may require the expertise of a rehabilitation team for the management of their physical or behavioural disabilities. This also applies to people with physical disabilities as well as hearing or visual impairments, and those falling under the aegis of the mental health services. This includes any adults with a disabling health condition with the potential to benefit from the specialised input of RM.

Rehabilitation medicine at different stages during life

2.15 RM makes specialist contributions at various stages in the lives of people with complex disabilities. A key component of the role involves working with other disciplines, which will vary as the individual progresses through life. Some examples are listed below.

- ▶ For disabled adolescents maturing into adulthood, RM specialists work in liaison with child health services and other specialties at the transition into adult specialist RM services. Medical issues are usually complex in addition to the social and emotional challenges of approaching adulthood with a serious disability. Intransigent epilepsy, progressive scoliosis, and neuromuscular respiratory failure are a few of the problems regularly seen. Solutions may include specialist seating,¹¹ referral for surgery, or non-invasive ventilatory support.
- ▶ RM specialists may initiate and support referral for vocational rehabilitation to promote employment opportunities for disabled adults of working age, working in liaison with occupational medicine, occupational therapists and vocational services at the job centre and in private industry.
- ▶ RM physicians work in liaison with specialists across a wide range of specialties, but especially include geriatric medicine specialists supporting older people with complex disabilities, palliative medicine specialists for the management of symptoms and disabilities in progressive neurological conditions towards the end of life (neuropalliative care), and oncologists who are treating primary and secondary disease.

2.16 There are frequent areas of overlap with other specialties, which reflect the complexity of some disabling conditions and the expertise of specialists in RM. There are a number of people with

complicated pain symptomatology who regularly need the services of specialists in pain medicine and RM. Many people with a disability who have their core needs met in RM will merit expert interventions at different times by neurological, neurosurgical, orthopaedic, psychiatric, psychological, rheumatological, urological and vascular colleagues and others. There is a growing evidence base attesting to the benefit of formal rehabilitation interventions in cardiology, respiratory medicine, orthogeriatrics, psychiatry and paediatrics, to name just a few areas of significant recent growth. This presents an opportunity to develop a broader academic framework for rehabilitation medicine in universities, to allow the sharing of philosophical and technological approaches.

What is specialist rehabilitation and which patients require it?

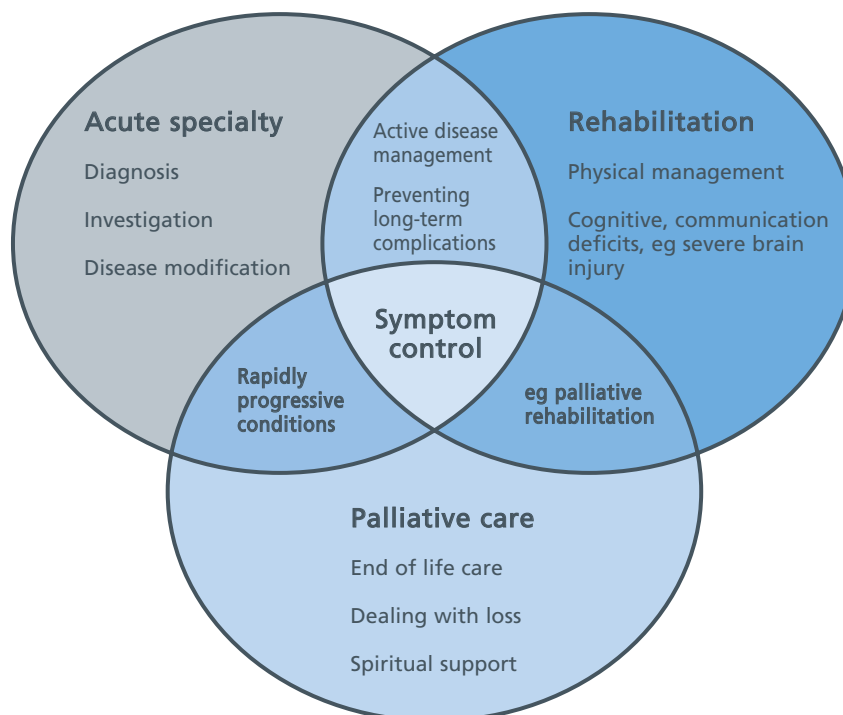


Fig 2.2 The interaction between an acute specialty, rehabilitation and palliative care services in management of patients with long-term conditions.

2.17 Specialist rehabilitation is the total active care of patients with a disabling condition, and their families, by a multiprofessional team who have undergone recognised specialist training in rehabilitation, led or supported by a consultant trained and accredited in rehabilitation medicine.

2.18 Generally, patients requiring specialist rehabilitation are those with complex disabilities. They may have a diverse mixture of medical, physical, sensory, cognitive, communicative, behavioural and social problems, which require specialist input from a wide range of rehabilitation disciplines (eg rehabilitation-trained nurses, physiotherapy, occupational therapy, speech and language therapy, psychology, dietetics, orthotics, social work etc) as well as specialist medical input from consultants trained in rehabilitation medicine, and other relevant specialties, eg neuropsychiatry.

2.19 A small number will have 'profound disability'. These severely affected patients require help for all aspects of basic care and need specialist interventions, eg spasticity management, postural support programmes and highly specialised equipment and technology, the provision of which may result in decreased care costs, reduced hospital admissions and improved quality of life.

Table 2.2 Examples of some conditions served by RM

Rehabilitation medicine specialty	NSF category			
	Sudden onset	Intermittent	Progressive	
Neurological	Brain	Relapsing-remitting multiple sclerosis	<ul style="list-style-type: none"> - Multiple sclerosis - Motor neurone disease - Parkinson's disease - Huntington's disease 	Cerebral palsy
	<ul style="list-style-type: none"> - Head injury - Stroke, subarachnoid haemorrhage - Encephalitis 			
	Spinal cord	Relapsing-remitting multiple sclerosis	<ul style="list-style-type: none"> - Spondylotic myelopathy - Hereditary paraparesis 	Spina bifida
	Traumatic spinal cord injury			
	Neuromuscular disorders	Intermittent polyneuropathies	<ul style="list-style-type: none"> - Charcot-Marie-Tooth disease - Muscular dystrophies 	Post-polio syndrome
	<ul style="list-style-type: none"> - Guillain-Barré syndrome - Critical illness neuropathy 			
Musculoskeletal	- Trauma	Spinal pain	<ul style="list-style-type: none"> - Osteoarthritis - Inflammatory arthritis 	Congenital dysmorphisms
	- Post-orthopaedic surgery			
	- Acute polymyositis			
Limb loss	Acute amputation		Diabetic and atherosclerotic peripheral vascular disease	Congenital limb deficiency
Other complex presentations	Medically unexplained conditions			

Rehabilitation services for people with different levels of complex need

2.20 The NSF recognises the need for specialist services for people with more complex needs, and therefore recommends that rehabilitation services are planned and delivered through coordinated networks in which specialist rehabilitation services work both in hospital and the community to support local rehabilitation and care support teams. The British Society of Rehabilitation Medicine (BSRM) standards recommend that there should be a local specialist rehabilitation service, led by a consultant certified on the specialist register in RM, for every 250,000 population.¹² Their activities depend, to an extent, on the geographical population they serve, on the range of conditions treated, and on their resource allocation. Commissioning arrangements are discussed in detail in Chapter 6. The work carried out in these centres also depends on the expertise of the key professionals within the multidisciplinary team, but all rehabilitation physicians are trained to treat patients across the whole range of the specialty's field of competence.

2.21 Tertiary specialised rehabilitation services such as spinal cord injury centres, by the DH definition have to serve a population of over one million, but most UK district specialist rehabilitation services will have a number of patients with very complex needs, for example motor neurone disease. Provider units for RM services negotiate with their commissioners on the level of activity and range of service.

2.22 Community-based rehabilitation teams are developing in many parts of the country, often without a specialist RM medical team member, but with intermittent input or contact and RM intervention by request of the team. Current trends suggest that more RM doctors will be working in these teams in the community in the future as the pattern of hospital-based services changes. This will create new challenges for the specialty, place extra demands on current training budgets, and require an increase in specialist numbers.

Box 2.2 Role of the RM consultant in community rehabilitation

The role of the consultant is to:

- ▶ provide advice on specialist medical issues
- ▶ organise further medical investigations and rehabilitation evaluations
- ▶ facilitate and effect medical treatments as necessary
- ▶ provide medical rehabilitation treatments and liaise with professional colleagues for provision of disability aids and equipment and assistive technologies
- ▶ liaise with primary care teams, secondary care colleagues and local authority departments to enhance patient well-being
- ▶ act as a champion for the activities of the community rehabilitation team
- ▶ promote research, education and training of community rehabilitation.

Enabling technology and rehabilitation medicine

2.23 Enabling technology is used by most people living in the modern world, but access to specialist enabling technology is crucial for people with disabling illness, to allow them both to sustain and improve their lives. Environmental controls can give people the opportunity to continue to enjoy some independence, living in their own homes and being able to lock and unlock the front door, use the phone, switch the TV on and open and close windows, all without getting out of their wheelchair. After stroke, walking can be improved and risk of falls substantially reduced by

provision of bespoke ankle–foot orthoses, or functional electrical stimulation devices. People with respiratory symptoms caused by motor neurone disease or other muscle-weakening disorders can feel fitter and be more active if they are provided with non-invasive ventilatory support. Table 2.3 describes a range of problems experienced by people with disabling illness, a variety of solutions, and the role of the rehabilitation medicine specialist in this area of practice.

Table 2.3 Examples of enabling technology and the RM specialist role

Clinical scenario	Equipment needed	RM specialist role
<ul style="list-style-type: none"> – Paralysed – Spends time alone at home – Unable to answer door, telephone, open window, switch on computer, make phone calls 	<ul style="list-style-type: none"> – Bespoke environmental control system (eg Possum) to promote independence – Powered and specialist wheelchair provision 	<ul style="list-style-type: none"> – Review diagnosis and prognosis – Assess ability of person to use equipment, vision, cognition, physical skills – Assess urgency of need – Make equipment recommendation
<ul style="list-style-type: none"> – Risk of falls because of leg weakness – Drags foot because of weakness – Spastic foot inversion on walking 	<ul style="list-style-type: none"> – Orthotic devices for foot drop – Off-the-shelf or bespoke ankle–foot orthosis – Functional electrical stimulation device – Lycra or silicone garment – Walking aids 	<ul style="list-style-type: none"> – Review diagnosis and prognosis – Assess current walking ability – Assess suitability for specific orthoses and walking aids – Make equipment recommendation – Agree and review desired outcomes
<ul style="list-style-type: none"> – Limited access to IT for leisure or vocational purposes – Loss of ability to feed because of upper limb impairment 	<ul style="list-style-type: none"> – Mobile arm supports, adaptive software, voice recognition systems, robotic solutions, implanted devices – Arm orthoses – Functional electrical stimulation – ‘Neater Eater’ feeding devices 	<ul style="list-style-type: none"> – Review cause – Signpost solutions – Recommend access to employment and vocational services and funding – Link up innovators of new technology
Communication difficulties	<ul style="list-style-type: none"> – Simple ‘point to it’ guides, language- or icon-based – Electronic, eg ‘Say it Sam’, Dynavox – Language-based talking aids, eg Litewriter, and amplification devices 	<ul style="list-style-type: none"> – Review diagnosis and prognosis – Analyse communication impairments – Identify solutions – Liaise with speech and language therapist to trial and select communication aid
Unable to stand, at risk of osteoporosis contractures and renal complications	Standing frame, standing wheelchair	<ul style="list-style-type: none"> – Review and assess loss of ability to stand – Assess ability to benefit from the intervention – Recommend how it can be achieved

continued

Table 2.3 Examples of enabling technology and the RM specialist role – *continued*

Clinical scenario	Equipment needed	RM specialist role
Severe spasticity inadequately responsive to physical and pharmacological treatments	Intrathecal baclofen therapy, with insertion of pump and delivery system	<ul style="list-style-type: none"> – Review of need in people attending spasticity management services run by RM specialists and multidisciplinary teams – Selection and referral of those most likely to benefit
Muscular weakness causing treatable respiratory failure, eg motor neurone disease or muscular dystrophy	<ul style="list-style-type: none"> – Non-invasive ventilatory support equipment – Cough assist devices – Rocking beds 	<ul style="list-style-type: none"> – Diagnose need and ability to benefit from intervention – Joint working with respiratory services
Sexual and sphincter dysfunction caused by spinal cord disease	Implantation of sacral root stimulators	<ul style="list-style-type: none"> – Assess need – Prioritise against background of overall disability severity, referral
Complex limb loss related disability with specialist requirements eg multiple limb loss, athlete, occupational needs	<ul style="list-style-type: none"> – Neuromodular prostheses – Specialised sports prostheses 	<ul style="list-style-type: none"> – Assess need and ability to benefit from complex bio-engineering solutions – Make recommendation

RECOMMENDATION

Commissioners need access to guidance from specialists in RM to evaluate and demonstrate to the individual the benefits of increased independence and well-being that can be achieved with enabling technology. Savings can be achieved, eg by avoiding complications such as fractures, reducing care needs or avoiding placements in nursing homes. The more unique the situation, the greater the level of specialist input required. There needs to be reserve funding for unusual demands.

Rehabilitation medicine and vocational services

2.24 The responsibility of physicians and health professionals to support patients at work has been neglected in the UK since the 1980s,¹³ with the loss of many services, in contrast with North America.¹⁴ The UK situation has been changing since 2008, with the publication of the ‘Health-care professionals consensus statement’,¹⁵ which commits to continue to educate the healthcare community, employers and people of working age about the benefits that work can provide and, as appropriate, to do all it can to help people to enter, stay in, or return to work.

2.25 Vocational rehabilitation (VR) enables people with physical, psychological, developmental, cognitive and emotional impairments or health conditions to overcome barriers to accessing, maintaining or returning to employment or other useful occupation.^{16–18} It encompasses not only job retention,¹⁹ a general term for the processes that enable an employee to remain at work with their same employer, but also prepares individuals for work – either because they were

disadvantaged during their formative years (eg with cerebral palsy)²⁰, or because of job loss. The term 'return to work' (RTW) is sometimes preferred.²¹ The value of rehabilitation in facilitating RTW following injury or illness and maintaining people with disabilities in work is high on government agendas. There is government support for RTW programmes, in which RM specialists play an important role.²² This applies across the UK, and VR is one of the three priority areas within Scotland's rehabilitation strategy.²³

Box 2.3 The role of RM specialists in vocational rehabilitation

The role of the specialist is to:

- ▶ optimise the health and abilities of potential disabled employees
- ▶ provide support and expert reports for the individual and their present or future employers, or the vocational service working on behalf of the individual
- ▶ promote knowledge of and access to specialist vocational services
- ▶ promote knowledge of and access to work-related benefits and services within job centres and social services
- ▶ assist the individual in any reasonable way and within the RM specialist's skills and expertise to achieve a successful work withdrawal strategy
- ▶ facilitate participation in the world of work in any possible way.

3 Clinical pathways in rehabilitation medicine in various conditions

Introduction

3.1 This chapter provides an overview of clinical pathways in rehabilitation medicine (RM). These may be delivered in a variety of ways. Inpatient services are usually provided through specialist neurological rehabilitation units supported by specialist multidisciplinary teams. In addition to conventional medical outpatient units, RM consultants often also provide multidisciplinary clinics. Community services may be provided by RM consultants through one or more of the following:

- ▶ personal outreach (satellite clinics and home visits)
- ▶ multidisciplinary outreach
- ▶ community-based multidisciplinary teams either supported or led by RM consultants.

3.2 Three areas of RM activity are described:

- ▶ neurological and spinal cord injuries rehabilitation
- ▶ rehabilitation following limb loss
- ▶ musculoskeletal rehabilitation.

Neurological and spinal cord injuries rehabilitation

Sudden onset neurological conditions

3.3 Fig 3.1 summarises generic features of clinical pathways for people with sudden onset neurological conditions.

3.4 Early rehabilitation in sudden onset conditions is initiated in trauma units, critical care units and acute medical wards, where the role of the RM physician is supportive and advisory. People with stroke are increasingly receiving integrated services within stroke units. Survivors of acquired brain injury who require further inpatient rehabilitation are admitted to neurological rehabilitation units. These units also serve patients with complex needs arising from other acute onset conditions, including stroke. Many (but not all) of those with spinal cord injuries are served by specialist supraregional centres now known as spinal cord injury centres (SCICs). The highly complex needs of some patients may be served through regional or supraregional facilities (for example units for people with severe behavioural disorders), but many neurological rehabilitation units provide for patients with both complex and highly complex conditions. In each of these settings, the RM physician plays a leading role within the multidisciplinary team, supervising inpatients and providing outpatient follow-up.

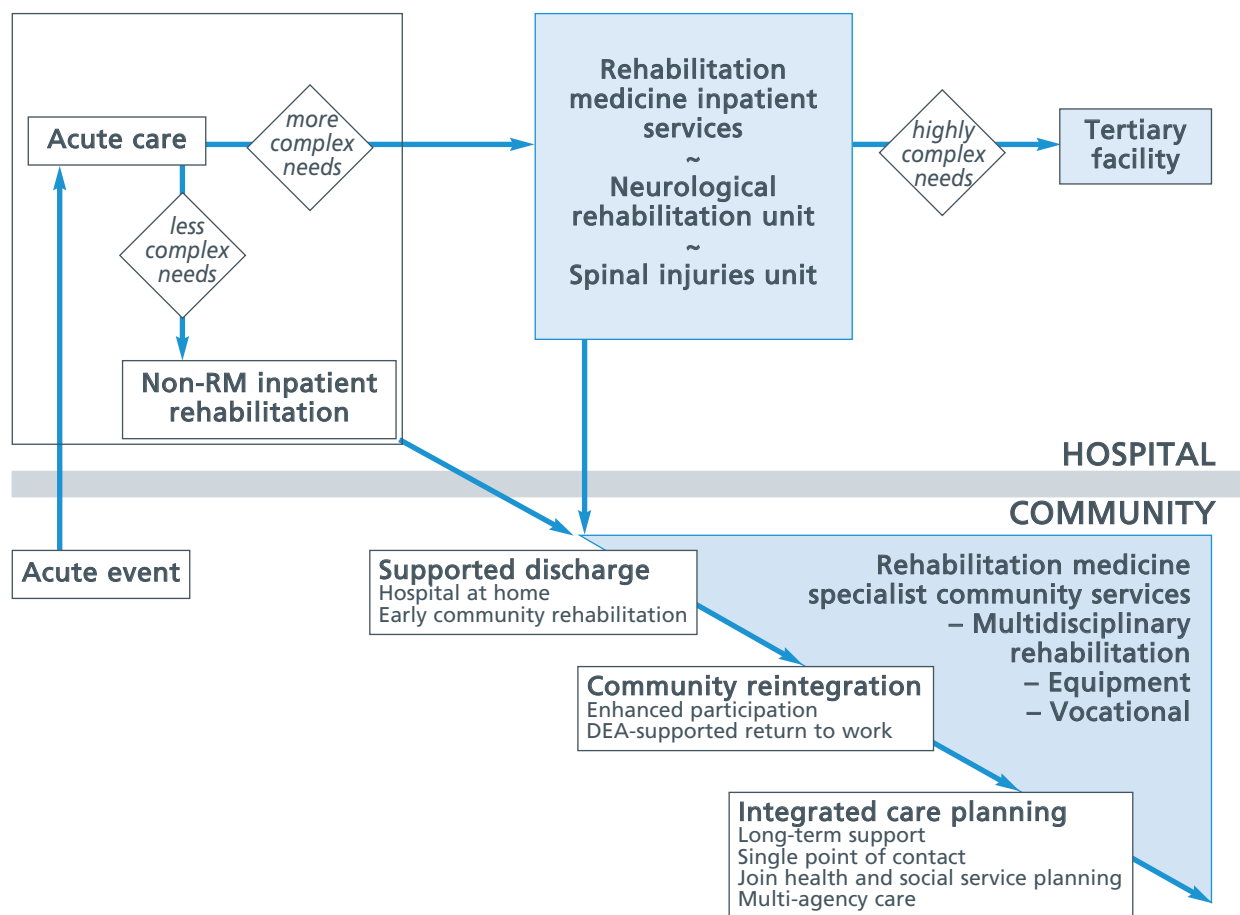


Fig 3.1 Generic features of clinical pathways for sudden-onset conditions. Shaded panels indicate rehabilitation medicine services.

Traumatic brain injury

3.5 Traumatic brain injury poses some of the most complex challenges for rehabilitation. RM consultants have input at all points in the pathways shown in Fig 3.2, in liaison with multidisciplinary teams.

3.6 In the acute stage, RM consultants advise the ITU department regarding such issues as behavioural problems and postural management. They facilitate subsequent rehabilitation on orthopaedic or neurosurgical wards and then take over management of the most complex patients following transfer to a neurological rehabilitation unit. In the acute stage, RM consultants advise acute teams – including the ITU – about behavioural problems, postural management and other specific issues, and facilitate subsequent rehabilitation on orthopaedic or neurosurgical wards.

3.7 The patients with the most complex conditions are then transferred to a neurological rehabilitation unit where the RM consultant takes over management. Following discharge either from an inpatient rehabilitation unit or from an acute ward, care should be coordinated by a specialist brain injury team, although this resource is not available in all areas. Those with complex and changing needs are often managed by an RM consultant, supported by a neuropsychologist or neuropsychiatrist if the dominant problems are behavioural. In a few areas neuropsychiatrists will lead specialist brain injury teams for people with behavioural disorders. These problems are often the main cause of the long-term disability due to brain injury. In too many areas, mental health teams remain uninvolved. Less specialised needs are served by a range of community-based services which may be led or supported by an RM consultant.

Example of practice we do not like

What happened: A 20-year-old man is admitted with herpes simplex encephalitis complicated by temporal lobe haemorrhage, resulting in severe cognitive impairment, lack of insight, but little physical disability. He is prioritised for inpatient rehabilitation from his acute medical ward, but is allowed to return home by the acute team when he asks to go. At home he is uncooperative and moody, and refuses to get out of bed, eat or wash. He is seen urgently in the RM outpatient unit one week later. An interpreter is provided to facilitate communication with his mother. No community service is available to support the family immediately. The family cannot manage his difficult behaviour; the police become involved and return him to hospital. He moves after a further week, to an RM bed. He becomes increasingly disturbed and is sectioned and moved to a neurobehavioural unit.

What should have happened: He should have had direct transfer to the RM service from his acute bed. His lack of mental capacity was not sufficiently considered when he chose to go home. Social services were not alerted by the acute team. Insufficient rehabilitation resources prevented both his early acute transfer to RM when needed, and adequate family support from a specialist RM team in the community.

Box 3.1 The specialist's role in acquired brain injury

The specialist's role is to:

- ▶ assess and provide a statement of need wherever the patient is
- ▶ assess and treat specific impairments eg epilepsy, spasticity
- ▶ manage acute rehabilitation needs in a specialist RM setting with a multidisciplinary team
- ▶ provide a holistic family-centred approach in the chosen setting for the longer term
- ▶ promote the removal of boundaries between health, social services, educational and vocational services, to move towards seamless input
- ▶ provide a coordinated approach to the involvement of other specialists as required, eg specialist neurobehavioural and neuropsychiatric services.

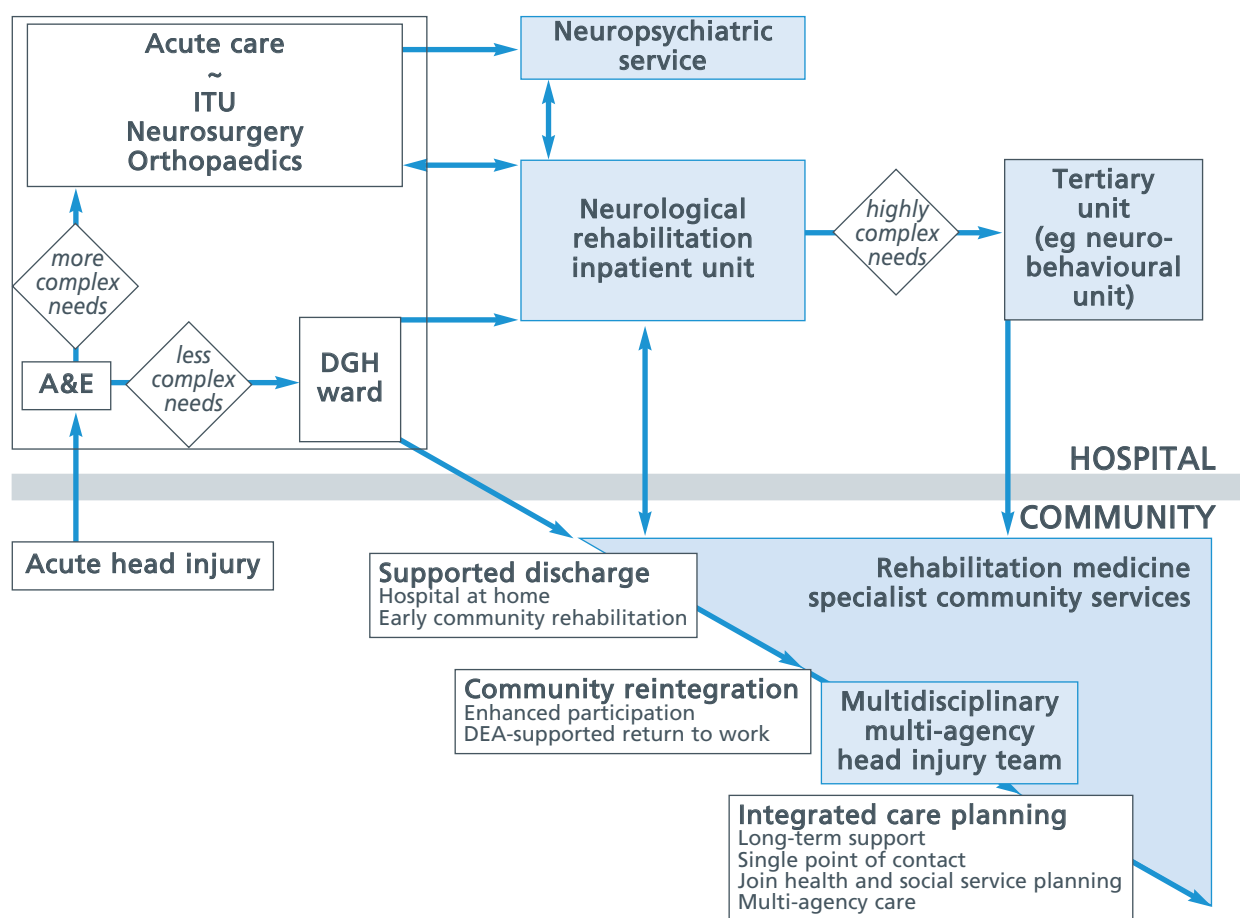


Fig 3.2 Clinical pathways for traumatic or acquired brain injury.

Stroke

3.8 The number of people and their families who experience the consequences of stroke is increasing.^{24–27} Clinical pathways for stroke, shown in Fig 3.3, take account of National Clinical Guidelines for stroke.²⁸

3.9 Stroke services are currently going through a period of radical change, led by developments in acute care. The specialty of stroke medicine is developing, and a more comprehensive network of stroke rehabilitation units (SRUs) is becoming established. There is now a comprehensive network of acute stroke units (ASUs), where the emphasis is on management of patients during the early phase of their condition. However, the delivery of stroke rehabilitation remains patchy, and is delivered in a non-systematic way. Acute stroke physicians agree that there is a gap in the delivery of expert stroke rehabilitation, and this is not only an area that requires correction, but also one in which RM can play a significant role. RM physicians have the skills to train stroke physicians and to deliver services as required (see also 3.13).

3.10 In some ASUs, RM consultants function as supervising consultants. They also function as advisors on complex problems later on in stroke rehabilitation, for example severe spasticity. However, the standard model is inadequate for stroke survivors with complex needs, including those where the aims of rehabilitation are oriented towards regaining paid employment or parenting. Enabling them to resume active participation in society – including returning to work – reduces social costs as well as maximising well-being. The annual incidence of stroke survivors in this category of complexity may be around 2 per 1,000 of the population per annum. Incidence

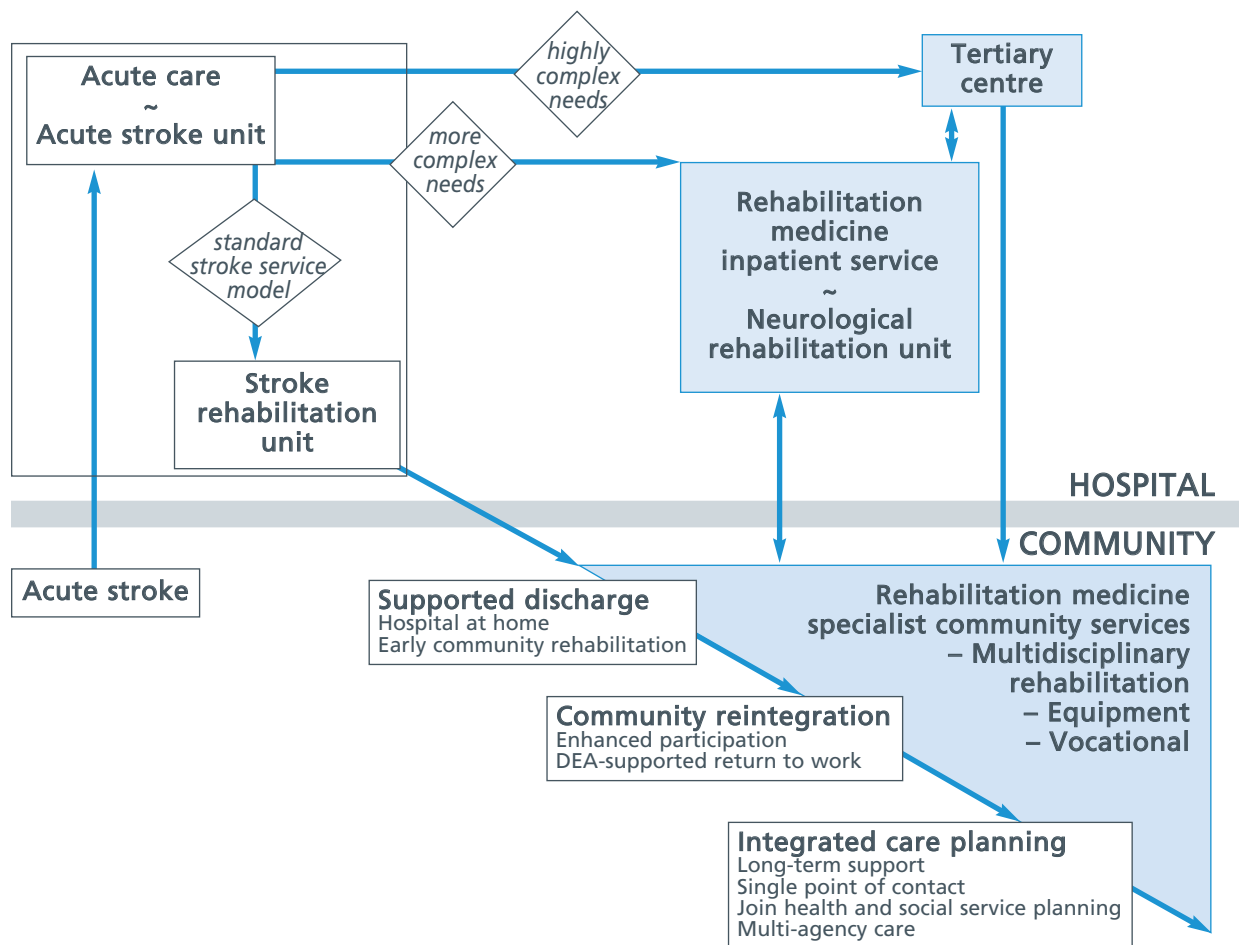


Fig 3.3 Clinical pathways for stroke.

rises sharply with age, from around 1.4 per 1,000 adults aged 55–59, to 5.1 per 1,000 of those aged 65–69, and increasing further thereafter.²⁹

3.11 These people require admission to a specialist neurological rehabilitation unit and specialist outpatient rehabilitation medicine support, as do those with complex neurobehavioural problems, for example following subarachnoid haemorrhage.

3.12 Early specialist intensive input promotes better long-term outcomes. Early input using specific specialist techniques to reduce motor impairment has been shown to improve outcome. A systematic review identified a range of interventions, including high-intensity training and constraint-induced therapy, that showed statistically significant improvement in motor recovery.³⁰ Techniques using biofeedback, robotics and mental imagery for improving motor recovery are still being explored. People with little motor disability may also require specialist cognitive assessment and interventions, eg to support successful reintegration into the workforce.

3.13 Many of the new approaches depend on equipment and specialist supervision from hospital-based rehabilitation units. Moreover, patients with complex needs require competent specialised assistance in the context of a specialist rehabilitation milieu. Continuing to commission specialist inpatient rehabilitation can produce further improvements in stroke rehabilitation. There is demonstrable evidence for cost-efficiency of specialist rehabilitation for stroke survivors with highly complex needs.

RECOMMENDATION

Specialist stroke rehabilitation services should be commissioned for the group of stroke survivors who were previously active, and often employed at the time of the stroke, because they have the potential to achieve a better recovery with the use of intensive and specialist techniques. Those with highly complex needs also require access to specialist RM services.

Other acquired brain injury

3.14 Pathways for other causes of acquired brain injury resemble those for traumatic brain injury. Conditions such as encephalitis are less common, but tend to produce diffuse brain injury. These patients typically have highly complex and challenging rehabilitation needs because of a combination of physical, cognitive and behavioural impairments, requiring admission to a specialist neurological rehabilitation unit.

Spinal cord injury

3.15 There is now a National Spinal Cord Injury Strategy Board (NSCISB) with commissioners and clinicians. The current pathways for spinal cord injury are shown in Fig 3.4.

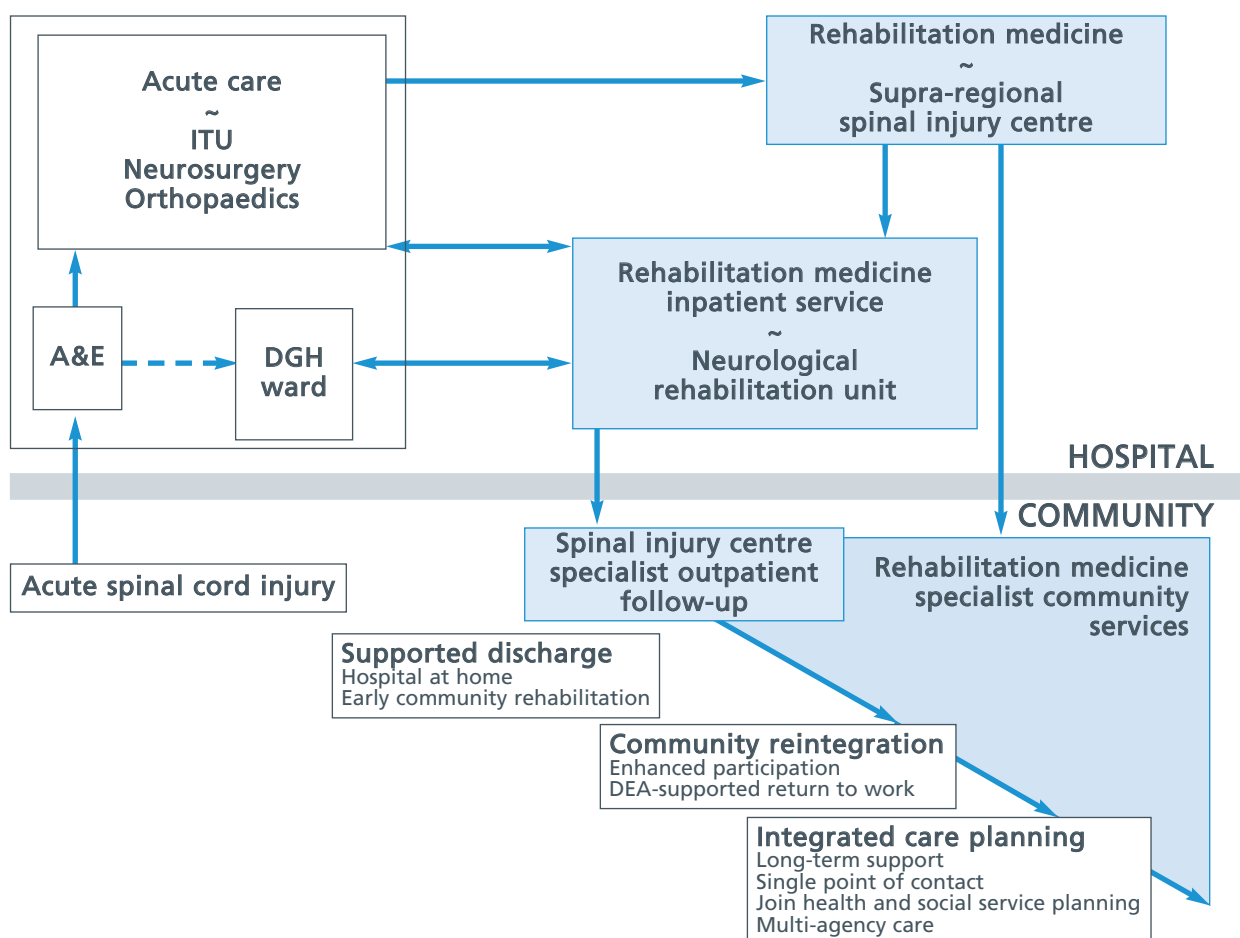


Fig 3.4 Clinical pathways for traumatic spinal cord injury.

3.16 There is a supraregional network of spinal cord injury centres with the expertise and range of services required to manage individuals from injury, through rehabilitation and reintegration, to long-term follow-up and management. Transfer to one of these centres is advised as soon as practicable following injury, although, in practice, capacity does not currently allow for this.

Clinical scenarios

A 24-year-old man was admitted to the SCIC from A&E following a fall from a wall. His spine was surgically stabilised. He had a complete cord injury causing paraplegia. He was mobilised and started his rehabilitation, which included a full education programme on preventing complications and maintaining long-term health. He remained in hospital for 12 weeks and was discharged home, fully independent as a wheelchair user. He had been encouraged to set vocational goals and he was able to return to employment in the police service in a different role.

This contrasts with another patient, a 35-year-old male teacher, who was injured in a road traffic accident and admitted to his local hospital. His spine was surgically stabilised but transfer to the SCIC was delayed and there was no local specialist rehabilitation service. On eventual arrival in the SCIC he had developed a deep, infected pressure sore, and he was unable to begin rehabilitation, requiring prolonged bed rest. He became depressed and withdrawn and this affected relationships with his family. On mobilising from bed five months later, he found it difficult to set goals and see a useful life after hospital. He was discharged from hospital ten months after his accident and did not return to work.

3.17 The SCICs vary in the contribution they make to the management of non-traumatic cord injury. Non-traumatic spinal cord pathologies, eg myelopathies due to spinal degenerative disease, neoplasms and demyelination, form an important part of the work of RM consultants whether they are based in specialist SCICs or neurological rehabilitation centres.

3.18 Similarly, traumatic cord injury occurring in people with significant comorbidities, eg renal failure, or with other complex injuries such as brain injury, are also managed in specialist RM services. Ideally, these patients should be able to access all of their acute health and rehabilitation needs in one location, but because of the rarity of these health problems this is not always possible.

Clinical scenario

A retired man with insulin-dependent diabetes and renal failure fell over, fractured his odontoid peg and became tetraplegic. He underwent surgical stabilisation of the cervical spine. The nearest SCIC could not meet his complex needs. These were met in his local specialist neurorehabilitation unit which was in the same acute hospital where he had his renal dialysis. He had a partial recovery which allowed him to use a joystick and drive a powered wheelchair. He had substantial care needs, but chose to return to live alone in his modified flat with a large care package and environmental controls. He was encouraged to learn how to use voice-activated software on his computer.

RECOMMENDATION

Standards have been devised to provide a framework for the development and monitoring of specialist spinal cord injury services which embrace the quality requirements of the NSF and NHS aspirations.^{1,6,7} These standards should be followed.

Sudden onset neuromuscular conditions

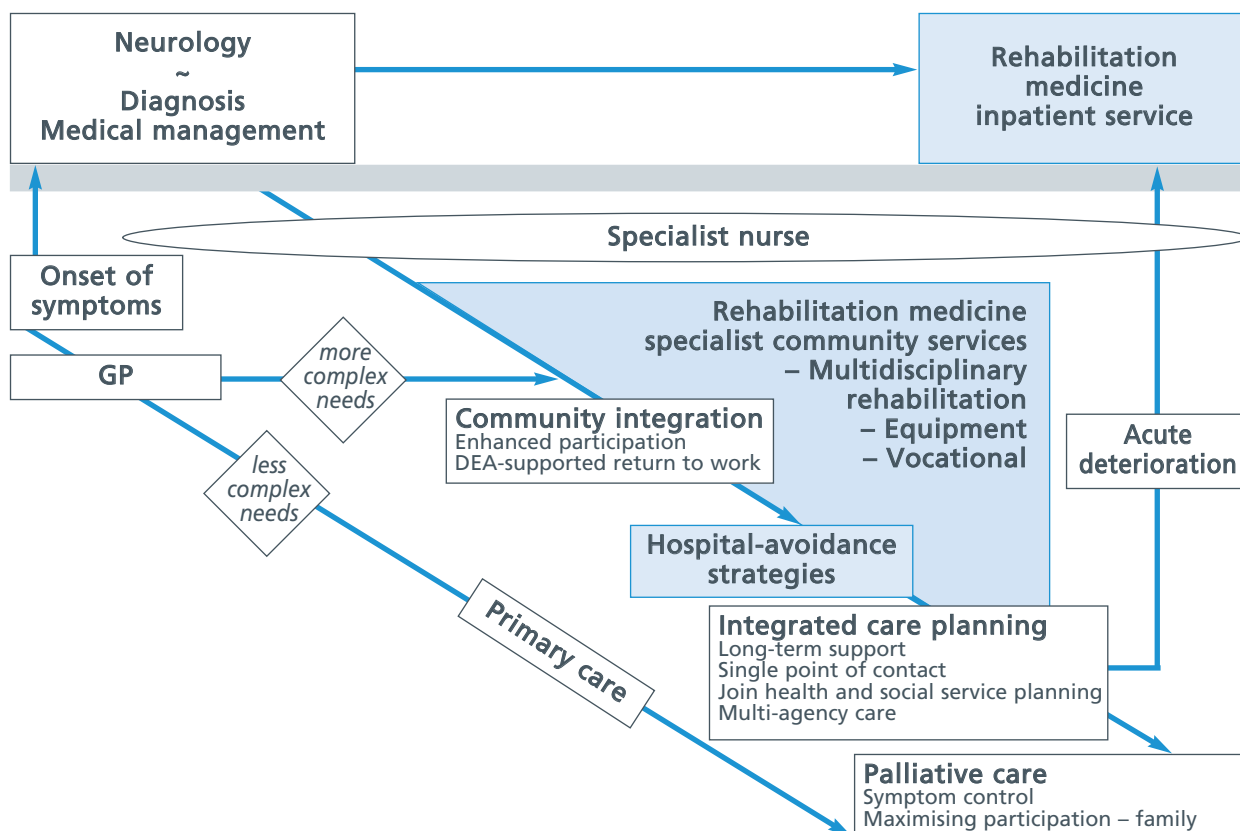


Fig 3.5 Clinical pathways for intermittent and progressive neurological conditions.

3.19 People with complex needs following acute onset neuromuscular conditions (eg Guillain-Barré syndrome and conditions such as inflammatory demyelinating polyneuropathy, critical care neuropathy and alcohol-related neuropathies) require specialist rehabilitation and the input of a RM consultant. Of these patients, 15% have a disability grade of ≥ 3 two years after onset.³¹ Although most people with Guillain-Barré syndrome make a rapid recovery, a significant minority (and particularly those who require admission to ITU for ventilation) will suffer long-term disability and require assistance from an RM consultant.

3.20 Fig 3.5 shows pathways for people with intermittent and progressive conditions such as multiple sclerosis. Needs tend to be unpredictable, changing and complex, posing challenges for primary care. For commissioners, a key question concerns the balance between the roles of primary and secondary care in supporting people with long-term conditions. RM typically becomes involved after the initial phase of diagnosis and early management, and thereafter has a coordinating role with other resources. There is a tendency for some patients to be discharged from neurological follow-up when neurological options are exhausted. Continuing contact through RM reduces the risk that needs, which could have been met, are neglected.³² For many

Box 3.2 Role of the RM consultant

The RM consultant may play a role at several points:

- ▶ as adviser when the patient is in an intensive care unit or the acute ward to initiate rehabilitation, avoid complications that will later impede rehabilitation, and to communicate with the patient and family about prognosis and rehabilitation
- ▶ to provide medical supervision of inpatient neurological rehabilitation and to continue after discharge with outpatient- or community-based follow-up
- ▶ to provide specialist rehabilitation interventions in outpatient and community settings for those people who have not required inpatient rehabilitation, but who still need assistance to participate in work, education and family life
- ▶ to give advice about work in the early stages of an acute neurological illness, encouraging the maintenance of contact with the employer and discouraging patients and their families from premature decisions about long-term prospects for (re)employment.

people, specialist RM follow-up is necessary in order to provide adequate disability management (see Chapter 2) throughout the course of a progressive condition, although the degree and frequency of contact will vary in relation to the speed and complexity of changing needs.

3.21 Compared with sudden onset conditions, RM services for progressive disorders require more community involvement and more provision of medical advice and support to other agencies. Key relationships include those with specialist nurses and with social services, and with employers through occupational health departments.

Clinical scenario

A social worker care manager writes to an RM consultant, describing a client with multiple sclerosis (MS) and housing problems. There is limited potential to adapt the house. The social worker asks for a likely prognosis on long-term mobility to guide social service decision making on whether to provide financial support for a stairlift and an adapted bathroom upstairs, or whether to support rehousing to more suitable ground floor accommodation with a wet room.

3.22 A second set of needs arises acutely. As Fig 3.5 shows, although rapid deteriorations or relapses in MS can call for acute neurological or medical management involving admission to a neurology ward, a neurological rehabilitation service is much more geared to the management and treatment of a changing disability. The benefits of inpatient rehabilitation in progressive conditions are short-lived,³³ and risks may outweigh benefits for some patients. RM expertise can alternatively be deployed through an intensive community-based rehabilitation programme, as part of the hospital avoidance strategy of the RM service.

3.23 A third set of needs arises towards the end of life, when, although the emphasis is on symptom control, there are still priorities for participation, for example in family life. Recognition of such needs has stimulated new approaches to joint working with palliative medicine.³⁴

3.24 In some areas, the RM consultant has full responsibility for a diagnostic group such as motor neurone disease, but, more often, neurologists initiate the diagnosis and early medical

management. Referrals to RM are then received from neurologists, GPs and other involved professionals. An analogous situation applies to services for Parkinson’s disease, Huntington’s disease and neuromuscular disorders, where an RM consultant may have either a lead or a supportive role.

Rapidly progressive conditions

Motor neurone disease

3.25 RM is a very useful coordinating resource in the care of patients with motor neurone disease and other rapidly progressive conditions, and may lead the entire service. Alternatively, it may be delivered jointly or consecutively by palliative medicine and RM, or else led by palliative medicine with involvement of RM for specialist issues such as enabling equipment. One of the challenges with conditions that progress rapidly is to ensure that the speed of service response matches the pace of changing needs. Remaining in work for as long as possible may be one person’s priority, whereas the next may want to achieve specific goals or dreams before it is too late. This often entails rapid, skilful and sensitive assessments of complex situations, leading to specialised interventions or the provision of specialised equipment. RM teams have the expertise to meet these challenges.

Other progressive conditions

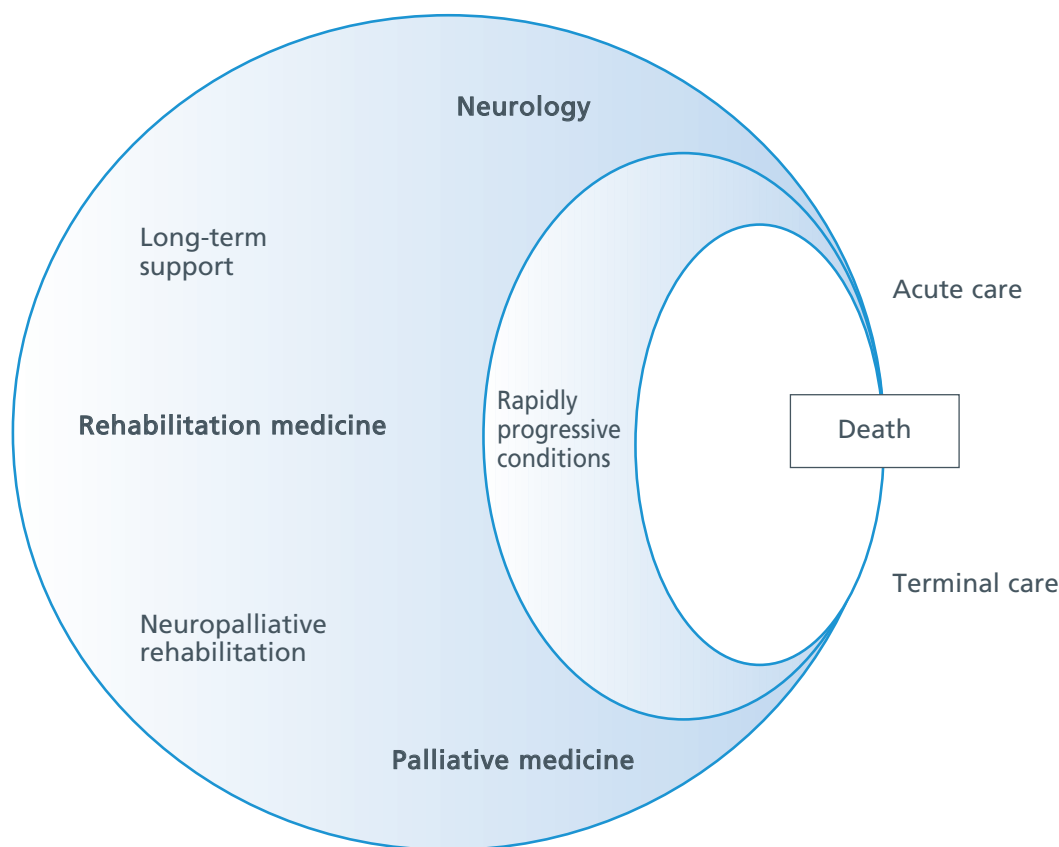


Fig 3.6 Life cycles. Adapted from Turner-Stokes *et al* 2008.³⁴

3.26 In some areas, RM consultants provide specialist services for Huntington’s disease (in conjunction with clinical genetics and psychiatry), for neuromuscular disorders, and for other progressive conditions. RM is also a resource for patients with Parkinson’s disease, usually

within a multidisciplinary framework that also involves geriatricians, neurologists, specialist nurses and the multidisciplinary team. Recommending equipment, such as electrically operated beds, specialised wheelchair seating, and relevant modifications to the home to maintain health and safety and avoid complications such as pressure sores, represent important contributions from RM services.³⁵

3.27 Among disabled adolescents and young adults, the needs of those with progressive conditions have much in common with those generated by both stable and progressive conditions, with generic problems such as declining mobility, changing seating needs and the challenge of providing access to life skills training, higher education and vocational resources set against the background of life-limiting problems which can include neuromuscular respiratory failure, intransigent epilepsy or specific tumour formation, associated with the diagnosis.

Stable conditions

3.28 This group includes causes of disability acquired around birth and, viewed as a description of need, may also include people with conditions acquired early in childhood. Needs may change either because of a change in the medical condition or because of personal or environmental factors, so the medical stability of a condition will not preclude the potential to benefit from RM input. Achieving a stable state may take several years, and some, with conditions where there is a high complication rate, eg spinal cord injury or intellectual disability, may never have stable needs. Two critical periods of change are recognised. These are the period of transition from adolescence into adulthood, and the onset of degenerative changes and diminishing physical skills in later life.

RM for disabled young adults

3.29 Services for young adults are best provided by a young adult team serving people from around age 16 up to around age 25 or 30.³⁶ Transition from paediatric support may be facilitated by joint paediatric–RM clinics. The work includes:

- ▶ disability management
- ▶ coordination of medical and surgical interventions
- ▶ support for advanced forms of assistive technology
- ▶ attention to the individual's emotional and social adjustments
- ▶ encouraging self-management of the disabling condition
- ▶ encouraging habits that will optimise health through diet and exercise
- ▶ facilitation of participation through education and employment.

There is often a role to play in being an 'interpreter' of the medical world for the young person and his or her family, and their needs and potential to medical and surgical colleagues. Some young people will have conditions that can cause death in early adult life, such as Duchenne muscular dystrophy and leuko-encephalopathies, and there will also be a role here for the RM consultant assisting in advanced care planning and coordination with palliative care.

Disability management in adults with learning and physical disabilities

3.30 This group presents complex challenges with a combination of often unusual physical impairments and limitation of communication resulting in difficulties or barriers for successful intervention. The RM consultant will often play a consultative role to assist the local learning disability team to facilitate optimal functioning, but may need to supervise RM management for a period of time to address all the problems in a logical order. Careful timing of new ways of doing things can promote greater success than would otherwise be achieved. Sometimes an already disabled adult may lose walking ability simply as a result of an inappropriate period of time spent in bed with an infection such as flu. If they are in a weakened state, it becomes easier for carers to push them around in a chair, and the weakness is subsequently perpetuated. The unlucky get contractures or pressure sores. There is usually a window of opportunity to regain those lost physical skills, but someone needs to spot it and call for assistance, and an RM team needs to be available to respond. The primary care physician is in pole position to push for an RM colleague to come in, assess the situation and organise a trial of the appropriate rehabilitation process.

RM services for adults with other stable conditions requiring disability management (consequence of a disabling health condition in later life)

3.31 Many disabling conditions have further health consequences in later life, eg degenerative arthritis in cerebral palsy, respiratory failure in post-polio syndrome, or ischaemic heart disease affecting mobility. The RM consultant can use their specialist knowledge of complications to prevent or manage these occurrences. Follow-up and review are thus very important aspects of a rehabilitation service.

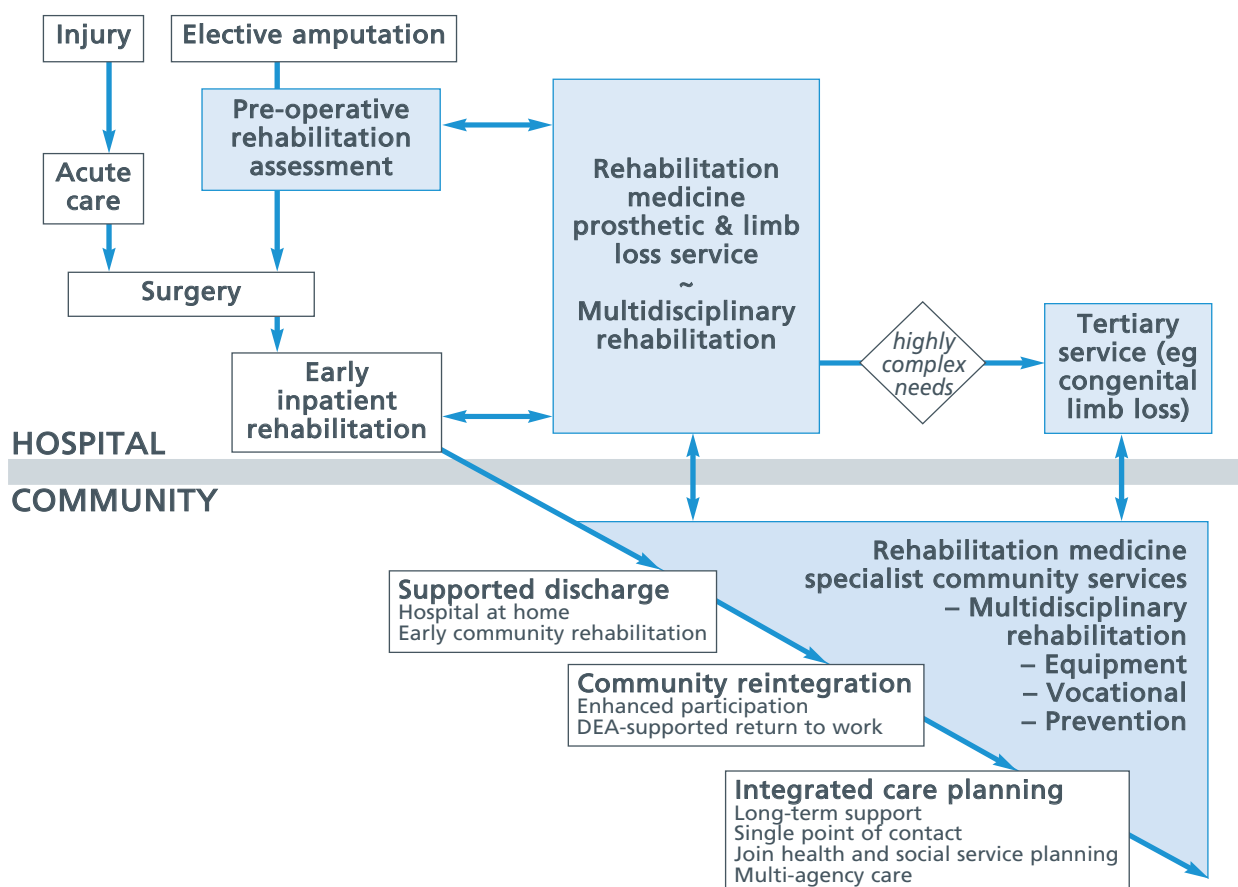


Fig 3.7 Clinical pathways for limb loss rehabilitation.

Rehabilitation in limb loss

Sudden onset conditions

3.32 The significant majority of major limb amputations in the UK are of lower limbs and are performed for ischaemia, often in the context of widespread complications of diabetes or heart and vascular disease. Other causes include infection and cancer. The cost of acute care for this group is high.³⁷ The incidence of traumatic and congenital limb deficiency is traditionally lower in our stable, western civilisation, but, because life expectancy and the ability to use prostheses (artificial limbs) are greater, these groups are disproportionately high users of limb loss rehabilitation services. Soldiers injured in the recent conflicts in Iraq and Afghanistan have changed the UK statistics; a number of young, previously fit, people now live with significant disability due to the loss of one or more limbs. Successful rapid retrieval of bomb blast victims from the field of conflict has led to increasing numbers with multiple limb loss. Unlike most of their older counterparts, these young people will have a normal life expectancy and have greater demands of their prosthetic limbs and their prosthetic services, requiring several artificial limbs for different levels of functioning and activities, eg running, climbing or swimming.

3.33 The value of rehabilitation is highlighted by the fact that 66% of working age amputees retain their employment.³⁸ However, statistics on the overall prognosis reflect the high prevalence of comorbidity in the non-traumatic, older population with comorbidities. Less than half of these are able to tolerate a prosthesis,³⁹ only one-third walk well six months after amputation,⁴⁰ and the rate for independent walking is only 11%.⁴¹ In this group, a quarter require a further amputation after one year, and the mortality at one year is 33% overall and 67% in those unable to use a limb.^{42,43}

3.34 Clinical pathways for limb loss rehabilitation are shown in Figure 3.7.

3.35 Following or just prior to amputation, patients are generally referred to one of the 43 NHS prosthetic and amputee rehabilitation centres by their GPs, surgeons or amputee physiotherapists. Each centre houses a multidisciplinary team, including a rehabilitation medicine consultant together with a prosthetist, specialist physiotherapist and nurse. Most centres run satellite clinics in district general hospitals (DGHs) where significant numbers of amputations are performed.

3.36 Preoperative consultation with the RM consultant is advisable to secure the best outcomes. Post-amputation rehabilitation involves the fitting of prostheses for some, but not all, patients. Other issues for rehabilitation include depression,^{44,45} sexual dysfunction⁴⁶ and pain. RM consultants contribute to the multidisciplinary team by diagnosing, investigating, and treating physical complications such as pain, skin disorders,⁴⁷ sweating,⁴⁸ infections and venous thromboses, as well as psychological complications such as depression and 'catastrophising'.⁴⁹ Secondary or tertiary prevention is also a key function with regard to skin and foot pathology, cardiovascular disease,⁵⁰ osteoporosis and drug complications. As in other fields of RM, the consultant also functions more broadly in the facilitation of specific aspects such as vocational rehabilitation, and the provision of wheelchairs, special seating, orthoses and assistive technologies.⁴²

3.37 Ongoing review is required because patients with prostheses may need socket adjustments, a different type of prosthesis to facilitate a new activity, or treatment for pain or other complications. Most children are reviewed three times a year in the school holidays, and established users should bring their limbs back for preventive maintenance at least once a year.

Stable conditions

Congenital limb loss

3.38 The incidence of congenital limb deficiency is much lower than the incidence of traumatic limb loss in adults, but as these people's life expectancy and ability to use their artificial limbs is potentially far greater, the cost implication for services is greater too, and this group makes up nearly half of the population attending artificial limb clinics.

Clinical scenarios

A young man complains of increasing phantom pain during urination since his below-knee amputation. The rehabilitation medicine consultant is able to reassure him that this is normal, and it does not mean that his spinal cord was injured by his epidural anaesthesia.⁵¹

An elderly man continues to be limited by stump claudication pain at the same distance as before his below-knee amputation. The RM doctor identifies unusual continuous muscle activity in the stump, which is reduced by botulinum toxin injections. Claudication distance increases to 300 yards.

A GP refers a man to the wheelchair clinic to replace his worn-out chair. He has avoided hospital contact for many years since his spinal cord injury, and has put on a lot of weight. He is finding it harder to get around. The wheelchair therapist refers him to the RM consultant who identifies obstructive sleep apnoea and hypertension, treats his limb spasticity and organises an ultrasound scan of bladders and kidneys as well as encouraging follow up attendance at the RM clinic. A rehabilitation engineer measures for a chair appropriate for his size and weight and sets the rear axle position to optimise balance and manoeuvrability.

Musculoskeletal and pain rehabilitation

Development

3.39 In the UK, rheumatology and orthopaedic medicine clinicians in surgery and primary care have largely led the development of musculoskeletal rehabilitation (MSR). Many services for musculoskeletal treatments, for example for back and neck pain, are now placed in primary care. Without a specialised rehabilitation focus, the needs of these patients have typically been addressed at the level of impairment, without sufficient attention to many participation issues, such as employment. RM has a distinct role in managing people with complex problems, in order to promote these higher-order objectives through engagement with complex medical issues such as pain and deformity. The emphasis on getting people back to work highlights the need for specialist rehabilitation services, central to the philosophy of RM activity, and is embedded in the BSRM's report on musculoskeletal rehabilitation.⁵² Much has been done by the British Society for Rheumatology and Arthritis Research Council to develop services and information networks for people living in the community with musculoskeletal conditions. The benefits of continuing to work in spite of having a disabling disorder have been highlighted.⁵³

3.40 The natural history of the impairment and the consequent disabilities and disadvantages play a major role in rehabilitation outcomes; some conditions recover spontaneously and early intervention may give the false impression that therapy has been efficacious.^{54,55} On the other hand, early intervention may improve outcomes even without full recovery,⁵⁶ and independent functioning and good quality of life may be unattainable without rehabilitation.⁵⁷

Clinical pathways

3.41 There are currently only a few robust models of practice in the UK which cover the concepts of MSR. However, clinicians in Stoke-on-Trent have developed a clinical pathway for MSR involving orthopaedic surgeons, rheumatologists, RM physicians, physiotherapists and GPs with a special interest, covering spinal and shoulder pain and more complex regional pain syndromes. The service has created a triage facility, where people with 'red flag' signs indicating important underlying medical conditions are identified and fast-tracked, but those without are seen rapidly after triage. The overall aim has been to reduce orthopaedic waiting lists. Institutes of musculoskeletal medicine have been developed, for example in Leeds and Keele universities. Similar clinical pathways for MSR are being developed along the same lines elsewhere, with high levels of collaboration between orthopaedic, rheumatological and rehabilitation specialists leading to valuable results for patients.

3.42 Musculoskeletal problems are seen across the full range of disabling conditions, including neurological, limb loss and chronic pain, and can have a major impact on the outcomes of rehabilitation programmes. Physicians in RM have a key role in diagnosing and treating these; working with other medical and surgical disciplines, specialist nurses and professionals allied to medicine, they can contribute greatly to the overall benefit of patients through the combined efforts of a multidisciplinary team.

4 Evidence of the effectiveness of RM

Introduction

4.1 Rehabilitation for people with multiple needs due to disability requires complex interventions. It poses several major challenges for clinical research: relatively small numbers and marked heterogeneity with respect to the clinical presentation; the intervention and setting; and also the relevant clinical outcomes. In addition, there are ethical considerations where patients lack the mental capacity to consent for participation in research, and where the expanding body of evidence for effectiveness makes it increasingly unethical to randomise patients to ‘no treatment’ or even ‘standard’ care. The timescale over which rehabilitation may have its effects (often months or years) is usually longer than any funded research project, and hinders the use of ‘wait-list’ control groups.

4.2 The Cochrane reviews provide a robust summary of the random controlled trial (RCT)-based literature. Although these have provided a reasonably strong evidence base for the effectiveness of rehabilitation in several areas, it is increasingly recognised that this methodology cannot be applied to address all the questions that need to be answered.⁵⁸ Other review methods assimilate a broader range of ‘evidence’, including qualitative studies and mixed methods designs – for example the research typology that was developed to evaluate the evidence base for the NSF for long-term conditions.⁵⁹

4.3 The GRADE system offers an approach to formulating recommendations for clinical practice based on the balance between desirable and undesirable effects of an intervention. This system collates not only the quality of evidence, but also the balance between benefits and harms or risks, which may be judged both at the level of the individual, and at the level of society – for example, the balance between costs of the intervention and potential for cost savings to society as a whole.

4.4 It is not possible to summarise all the evidence for rehabilitation in each type of condition within this document. In this section we have provided a broad overview of the key research findings from both the trial-based literature and other research. We have used the GRADE approach to summarise the key evidence-based recommendations in each section.

Evidence in sudden onset neurological conditions

4.5 The evidence for effectiveness of rehabilitation in sudden onset conditions is summarised using acquired brain injury (ABI) – due to any cause, including stroke, trauma, anoxia, inflammation etc – and spinal cord injury (SCI) as exemplar conditions.

Acquired brain injury

4.6 The RCT-based evidence for the effectiveness of rehabilitation following acquired brain injury has been assimilated in a Cochrane Review.⁶⁰ To this, the authors have recently added evidence from a broader-based search and synthesis using the National Service Framework (NSF) typology.⁶¹ Both reviews focused on adults of working age, to reflect the principal caseload of specialist neurorehabilitation services in the UK. The key findings from a total of 16 RCTs and

31 non-RCT studies (mainly cohort analyses) which met the quality criteria for selection are summarised in Fig 4.1. The overall conclusion from this analysis is that there is evidence from both RCT- and non-RCT-based research to support the effectiveness of rehabilitation for adults with acquired brain injury. Patients who have survived major trauma or illness leading to brain injury should be fast-tracked out of acute medical, orthopaedic or neurosurgical beds into specialist rehabilitation units to make sure that they accrue the maximum benefit and avoid early and delaying complications.

Cost-effectiveness in ABI

4.7 The evidence for this has been addressed in a number of ways. There is moderate (grade B) evidence that savings can accrue to health service providers through reduction in length of stay due to early, intensive and coordinated rehabilitation.⁶²⁻⁶⁴

4.8 Taking evidence from specialist inpatient services and specialist inpatient behavioural units together, there is strong (grade A) evidence that rehabilitation can reduce the need for ongoing care with potential cost savings that offset the initial investment in rehabilitation,^{65,66} and this was particularly the case in the more dependent group of patients.^{67,68}

Vocational rehabilitation in ABI

4.9 With regards to return to work, the picture is somewhat mixed. No high-quality RCTs were identified, but within the non-RCT literature, three studies of specialist vocational or work support programmes (total n=433) provide strong (grade A) evidence for the effectiveness of supported employment.

4.10 There was also strong (grade A) evidence that comprehensive community programmes can achieve an improved productivity and return to paid employment, at least for a proportion of patients. However, the rates of employment remain disappointing overall (ranging from 27%⁶⁹ to 39%),⁷⁰ suggesting that careful patient selection is required.

4.11 In terms of cost-effectiveness, there was strong evidence for cost benefits of return to paid employment, in that the salaries from paid employment exceed the cost of intervention,⁶⁹ with overall gain to the taxpayer.⁷⁰

Spinal cord injury

4.12 The importance of appropriate acute management and rehabilitation programmes delivered by an expert interdisciplinary team in dedicated specialist centres has been demonstrated in previous studies,⁷¹ notably the Cochrane review in 2003, which concluded a benefit of immediate referral to spinal injuries units compared with delayed or no referral.⁷²

4.13 Reports from the UK spinal cord injury (SCI) centres have indicated an increase in the number of patients being referred and admitted to the service with complications secondary to SCI that may have been prevented by early specialist management.⁷³ Management of such problems delays progress within rehabilitation, prolongs lengths of hospital stay for rehabilitation patients, and results in unsatisfactory patient experiences. This led the Spinal Injuries Association to commission a national study which was published in 2009 in association with the Multi-disciplinary Association of Spinal Cord Injury Professionals (MASCIP) and the British Association of Spinal Cord Injury Specialists (BASCIS).⁷⁴ The results of the comprehensive one-year study on patients admitted to SCI centres confirms a significantly increased risk of complications where there was a delay from time of injury to admission to the specialist SCI centre,

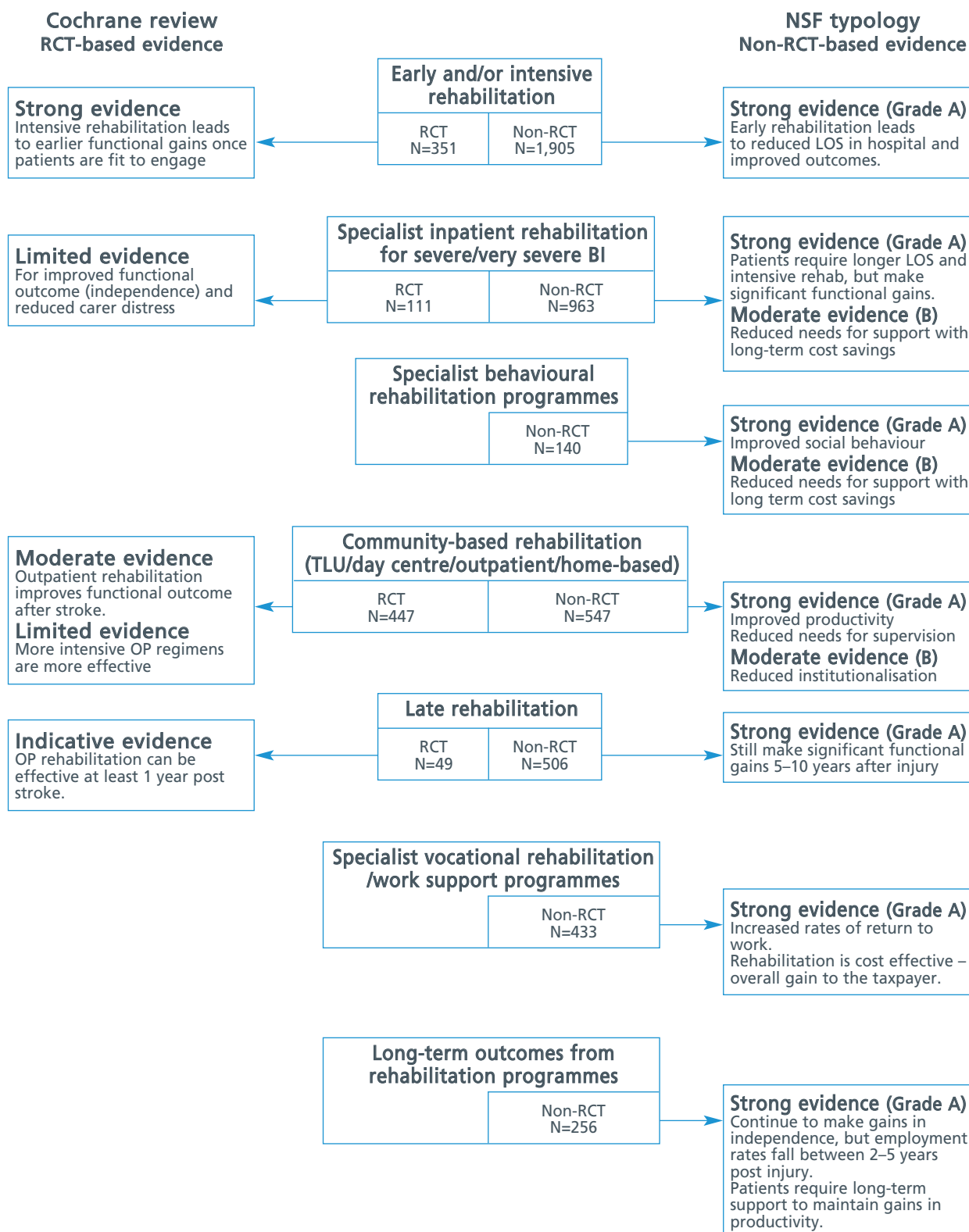


Fig 4.1 Synthesis of evidence for effectiveness of rehabilitation following ABI.⁶¹

and patients admitted with complications had a highly significant increase in length of stay. The same is true in survivors of complex trauma or critical illness, who are at very high risk of complications such as pressure sores and contractures if they wait in acute care beds for a place in a specialist rehabilitation unit.

4.14 Longer-term benefits of specialist centres have also been documented by Smith *et al.*⁷⁵ In their retrospective follow-up study of 800 subjects with SCI, 10% had not accessed specialist spinal services, despite having slightly more severe injuries. The spinal cord injury centre (SCIC) cohort achieved statistically significant better outcomes in health, activity and participation, including being more likely to have a partner, more likely to be in paid or voluntary employment, more likely to be driving if tetraplegic, and in the paraplegic group spending more hours out of house. No outcomes were worse in the SCIC group.

Putting together the evidence for sudden onset neurological conditions

4.15 On the basis of the research evidence available (from both the RCT- and non-RCT-based literature) and the demonstrated potential for cost-benefits, the strongest recommendations under the GRADE classification would be for:

- ▶ early intensive rehabilitation, starting as soon as possible after onset
- ▶ specialist programmes for all those with complex needs
- ▶ specialist vocational programmes for those with potential to return to work.

4.16 Although there is encouraging data from non-RCT studies to support the benefits of behavioural management programmes, community rehabilitation and longer-term interventions, the current evidence is not sufficiently robust to provide a basis for strong recommendations for management. More work is required, in particular with respect to demonstrating cost-effectiveness and to identifying those patients most likely to benefit. It is difficult to mount sufficiently well-planned RCTs to examine the effectiveness of downstream community-based services, and particularly hard to examine the work of neurobehavioural units, which are distributed between psychiatric units and the private sector. The former survivors are well enough to leave hospital and go home, and it is extremely hard to control for their wide range of home environments. The latter group are sufficiently disturbed to require secure confinement for an extended period, and although most achieve a community placement in the long term, the process can be very slow and costly.

Evidence of effectiveness in rehabilitation of people with progressive or intermittent conditions

4.17 The largest body of evidence for rehabilitation in progressive and intermittent conditions comes from multiple sclerosis. Trial-based evidence for the effectiveness of multidisciplinary rehabilitation in multiple sclerosis has been assimilated in a Cochrane review,⁷⁶ which included 8 trials (747 participants and 73 caregivers), and also in a Cochrane review of vocational rehabilitation (VR).⁷⁷

Inpatient programmes

4.18 The Cochrane review concluded that there was 'strong evidence' that, despite no change in the level of impairment, inpatient multidisciplinary rehabilitation can produce short-term gains at the levels of activity (disability) and participation for patients with MS.

4.19 A number of cohort studies have followed people with progressive MS through goal-orientated multidisciplinary programmes in both the UK (n=79)⁷⁸ and Australia (n=1,124).⁷⁹ Both demonstrate that inpatient rehabilitation for patients with MS can lead to significant

functional gains in independence activities of daily living, and that this improvement can occur regardless of the starting level of disability.

4.20 The UK study went on to demonstrate a significant improvement in activity limitation and participation after a 20-day programme compared with waiting list controls.⁸⁰ The three-week inpatient programme was then compared with a three-week outpatient programme. Although there was an initial advantage of the inpatient programme, both groups were very similar at one year.³⁴ Importantly, however, both groups showed that, despite progression of their impairments, there was benefit to activity limitation and quality of life to at least 6 months later, and emotional benefit was sustained for up to 12 months. This suggests that patients had learnt valuable ways of managing their situation, which stood them in good stead for the future. Such rehabilitation approaches have also been shown to benefit MS patients requiring steroid treatment for disease relapse.⁸¹

Outpatient rehabilitation

4.21 Although studies have not been carried out on the specific impact of outpatient RM interventions in progressive neurological conditions, there is good evidence for the benefit of therapy treatments in this patient group.

4.22 The Cochrane review found some evidence that high-intensity outpatient and home-based MD rehabilitation programmes produced short-term improvements in symptoms and disability which translated into improvement in participation and quality of life. For low-intensity programmes conducted over a longer period, there was strong evidence for longer-term gains in quality of life, and also limited evidence for benefits to carers.

Vocational rehabilitation

4.23 There is evidence that early management of core clinical problems in people with MS (fatigue, spasticity, urinary urgency, memory issues, psychosocial aspects), and understanding of their complex interactions, can help a person with MS to manage home and work environments and facilitate continued employment.⁸² However, the Cochrane review of VR in people with MS found only two RCTs of poor methodological quality, and concluded that there is currently insufficient RCT evidence that VR programmes alter rates of job retention, changes in employment, or rates of re-entry into the labour force.

Putting together the evidence for progressive and intermittent neurological conditions

4.24 On the basis of the research evidence available, the strongest recommendations under the GRADE classification would be for:

- ▶ short-term intensive inpatient specialist rehabilitation programmes
- ▶ lower-intensity community-based programmes conducted over a longer period.

4.25 It is recognised that people with intermittent and progressive conditions experience work-related difficulties, and that specialist vocational support is necessary to help keep them in work wherever appropriate. However, more research is required to identify the particular interventions that are likely to help and the individuals most likely to benefit.

4.26 Effects on quality of life (QoL) are often difficult to quantify in relation to chronic conditions because of 'response shift' or the change in internal values, or conceptualisation of QoL,

so that people with MS may reassess their perceived limitations of daily living and reset goals and consider the impact of their MS less marked than they thought formerly.⁸³ More studies are needed to assess the impact of rehabilitation on QoL, and to understand the response shift phenomenon in the MS population.

Evidence of effectiveness in limb loss rehabilitation

4.27 The effectiveness of specialist inpatient rehabilitation, compared with generic rehabilitation or home care following amputation, has been reported in three large studies, although these used statistical methods to reduce selection bias rather than randomised allocation to different treatment arms.^{84–86} These describe consistent patterns of improved survival, function, use of prosthesis, discharge home, reduced redo or additional amputations, and a reduction in other hospital admissions. This evidence has not supported the current trend towards outpatient- and community-based services. More local audits have described higher rates of limb use and shorter hospital stays compared with older published work.⁸⁷ There is a need for further review of the outcomes of current outpatient-based services.

4.28 Chronological age is not a barrier to using a prosthesis, and even the very elderly may walk again, if their comorbidities permit.⁸⁸

4.29 This is an active field for research into both high-tech developments, for example femoral osseointegration for amputees who cannot manage with conventional sockets, and low-tech service changes, which will apply to many amputees.⁸⁹

Evidence of effectiveness in musculoskeletal rehabilitation

4.30 There is abundant evidence of the effectiveness of rehabilitation interventions in musculoskeletal conditions,⁵⁶ even though the specific contribution of RM requires further evaluation. The benefits of more specialist rehabilitation programmes also need evaluation.^{90–92}

4.31 A Cochrane review of RCT-based literature showed moderate evidence that early multidisciplinary rehabilitation following hip or knee joint replacement led to more rapid functional improvement with shorter hospital stay and reduced costs, and confirmed that home rehabilitation improves quality of life.⁹³ However, the optimal intensity, frequency and effects of rehabilitation over a longer period and the associated actual and social costs need further study. Exercise programmes can improve strength and mobility following hip fracture.⁹⁴

4.32 Several publications, including a Cochrane review⁹⁵ have shown the value of specialist rehabilitation in managing people with disabilities due to musculoskeletal impairments,⁵⁷ including lower back pain.⁹⁶ For instance, cognitive behavioural therapy is superior to other primary care treatments in managing patients with non-specific lower back and neck pain.^{97–98} Other evidence has confirmed that, by the end of a hospital admission, the introduction of intensive interdisciplinary rehabilitation with cognitive behavioural therapies has shown greater improvements in patients who were severely affected by pain, compared with a standard unenhanced rehabilitation programme.⁹⁹

Vocational rehabilitation in musculoskeletal conditions

4.33 A number of systematic reviews of back pain management have found strong, consistent evidence to guide prevention of back pain episodes in working-age adults.¹⁰⁰ In a large RCT in Spain, temporary work disability episodes were significantly shorter in the group receiving a specialist-run, protocol-based early intervention programme for most of the categories of

musculoskeletal disorder studied.¹⁰¹ The implementation of this type of early intervention programme would appear to be beneficial in the treatment of patients with work disability related to musculoskeletal disorders. However, other studies have found no difference between diagnosis-specific and non-specific programmes in reducing work disability associated with fibromyalgia¹⁰² or with hip fracture after osteoporosis.¹⁰³

4.34 In the non-RCT literature, a long-term prospective study of individuals on sick leave for neck and back pain 7 years after rehabilitation showed that a full-time multidisciplinary rehabilitation programme provided within 2 months reduced sickness absence as compared with a group receiving a less coordinated programme.¹⁰⁴

4.35 Not all studies have shown the benefit of specialist interventions,¹⁰⁵ but where musculoskeletal disorders are complex, an interdisciplinary approach has been found to be superior to pharmacological interventions.^{106,107}

Putting together the evidence for musculoskeletal conditions

4.36 On the basis of the research evidence available, the strongest recommendations under the GRADE classification would be as follows:

- ▶ General rehabilitation programmes provide effective rehabilitation for the majority of patients with non-complex problems, eg following hip and knee replacement.
- ▶ Specialist multidisciplinary rehabilitation programmes are likely to be required for patients with more complex needs, particularly where the interaction of physical, social and psychological factors requires an interdisciplinary cognitive behavioural approach.
- ▶ Early coordinated intervention is more likely to be successful in getting people back to work and keeping them in long-term employment.

5 Standards and training

BSRM standards for specialist rehabilitation services

5.1 The BSRM has published standards for specialist inpatient and community rehabilitation services.^{108,109} A project was undertaken to map them onto the National Service Framework (NSF), based on these standards and other key national guidelines and working party reports.^{110–112}

5.2 The standards in the mapped document give specific recommendations with regards to:

- ▶ response times for transfer to rehabilitation services from acute care settings
- ▶ minimum staffing provision for specialist rehabilitation services in inpatient and community settings
- ▶ key elements of the rehabilitation process, including goal-setting, discharge planning, follow-up and outcome evaluation within the different settings
- ▶ staff training, appraisal, audit and research.

5.3 The BSRM standards recommend that there should be a local specialist rehabilitation service, led by a consultant trained and accredited in RM, for every 160,000–200,000 population.¹² Key features of a specialist rehabilitation service are shown in the box below, and the resources required are given in Appendix 1.

Box 5.1 Key features of a specialist rehabilitation service

- ▶ It is led or supported by accredited consultants in rehabilitation medicine.
- ▶ It meets the national BSRM standards for specialist rehabilitation services.
- ▶ Its multidisciplinary team(s) has/have undergone recognised specialist training in rehabilitation, and its members work in a coordinated interdisciplinary way towards an agreed set of patient goals.
- ▶ It carries a caseload of patients with complex rehabilitation needs, and has specialist equipment, facilities and staffing levels to meet those needs.
- ▶ It provides support to local rehabilitation teams in hospital and the community, and has a recognised role in education and training in the field of rehabilitation.
- ▶ It routinely collects and reports clinical data for all patients as defined by the UK National Dataset for specialist rehabilitation services (including complexity and outcome data).

A national dataset for specialist rehabilitation

5.4 The BSRM and the NHS Information Centre have developed a programme of considerable work, funded by the DH, in creating a national dataset for specialist rehabilitation. In light of the coalition's white paper,² the details of this merit a description, which can be found in Appendix 2.

Current consultant and trainee numbers

Estimated requirement for consultants

5.5 There are 152 whole-time equivalent (WTE) consultants with RM as their main specialty, and a further 25 consultants with a different main specialty who also practise in RM.¹¹³ All but 8.6% are full-time consultants. This represents serious underprovision, and the BSRM recommends a minimum of 1.5 WTE consultants per 250,000 of the population, including 0.9 WTE for inpatient and standard outpatient services, and 0.6 WTE for community provision. To achieve this level, there would need to be 195 WTE consultants for England, and 233 for the UK as a whole – an increase of approximately 50% on current numbers. Additional consultants are required to serve patients with highly complex needs, meaning that current numbers are a little over half of what is required. There is a likelihood that if consultant posts are dispersed into the community there will be an even sharper increase in the need for greater numbers because of reduced productivity.

5.6 Viewed over a 10-year period, RM has shown the second highest expansion rate in consultant numbers at about 150%,¹¹⁴ but the current shortfall remains a matter of urgency. The development of new consultant posts is proving difficult at a time when there is pressure to meet restrictions in government spending, despite the NSF recommendations for suitable provision of specialist inpatient, community-based and vocational rehabilitation services (quality requirements 4, 5 and 6). Work-force calculations must take account of the parallel requirement for non-medical staff, as RM consultants practise more effectively as members of an interdisciplinary, multiprofessional team.

5.7 Further information on the disparity in provision of RM consultants across Europe is available in Chapter 6 (Table 6.1 and Fig 6.1). The arrangements for workforce establishment will change with GP commissioning, but as working practices change and there is more direct involvement in specialist community-based rehabilitation medicine, RM's current status makes a commitment to establish eight new consultant posts per annum over a ten year period necessary, in order to address in some way the increasing shortfall in expertise.

5.8 The current number of RM specialty registrars (StRs) in the UK is 65. In the last two years, there has been no increase in the number of national training numbers (NTNs). At the moment, the specialty is broadly in balance with regard to the trainee–consultant ratio, but if the planned increase in the number of consultants in the field is achieved, there will need to be a reciprocal rise in the numbers of specialist trainees.

RECOMMENDATION

Based on known population patterns of growth and changing practices, we recommend that there are 80 new RM consultants proposed and developed over a 10-year period.

6 Commissioning rehabilitation medicine services for people with complex disability, 2011–2020

Background to commissioning policy

6.1 The National Service Framework (NSF) and the Darzi report emphasise the need for local rehabilitation services as close as possible to the individual's home.⁴ All services caring for patients with disabling conditions have a responsibility to provide a rehabilitative approach. Basic rehabilitation skills should be a core competency of every health professional. This description assumes that the philosophy of commissioning policies for specialist rehabilitation will not change greatly following the implementation of the coalition's white paper.²

6.2 The NSF also recognises the need for specialist services for people with more complex needs, and therefore recommends that rehabilitation services are planned and delivered through coordinated networks in which specialist neurorehabilitation services work both in hospital and the community to support local rehabilitation and care support teams. A small number of patients have very complex needs, and require a higher level of specialist care. The NSF recognises the need for tertiary services to support people with profound and complex disabilities. It is neither feasible nor economic to duplicate high cost/low volume tertiary services in every locality.

6.3 The Carter Report on specialised commissioning recommends that these 'specialised services'* should be planned over a larger geographical area, and therefore require collaborative commissioning arrangements. In 2009, the Department of Health revised its national definitions sets for these specialised services to a third edition.¹¹⁵ Those particularly relevant to rehabilitation are:

- ▶ no 5: assessment and provision of equipment for people with complex physical disability
- ▶ no 6: specialised spinal services
- ▶ no 7: specialised rehabilitation services for brain injury and complex disability.

Rehabilitation service provision in the UK

6.4 Within the national definition set no 7, the Department of Health has defined three broad levels of rehabilitation service:

- ▶ Local non-specialist rehabilitation teams (level 3) provide general multiprofessional rehabilitation and therapy support for a range of conditions within the context of acute services (including stroke units), intermediate care or community services.
- ▶ District specialist rehabilitation services (level 2) are led or supported by a consultant trained and accredited in rehabilitation medicine working in both hospital and community settings. The specialist multidisciplinary rehabilitation team provides advice and support for local general rehabilitation teams.

*Terminology of the second Specialised Services National Definitions Set

- ▶ Tertiary ‘specialised’ rehabilitation services (Level 1) are high cost/low volume services, which provide for patients with highly complex rehabilitation needs that are beyond the scope of their local and district specialist services. These are normally provided in coordinated service networks through collaborative (specialised) commissioning arrangements over a population of 1–3 million.

6.5 Tertiary specialised rehabilitation services are thinly spread and, in some areas of the UK where access is poor, local specialist rehabilitation services have extended to support a supra-district catchment of 750,000 or more, and take a proportion of patients with very complex needs. These are currently defined as level 2a services.

6.6 In addition, local services which ‘specialise’ in certain conditions and include a significant component of rehabilitation (for example stroke, or care of the elderly) may act as a local source of expertise, even though they do not meet the full standards for a ‘specialist rehabilitation service’. These are level 3a services.

6.7 It should be noted that levels of service provision vary across the UK and, whilst the three-tier scheme works well in some of the more densely populated parts of the country, it does not easily map on to existing services in all areas. In many areas, level 2 services take on more specialised activities and act as a supra-district resource for parts of their programme, but do not serve the DH-required population base. It could undermine the funding of successful services in an unpredictable way. The model is most likely to succeed and be funded in the metropolitan areas, where it was first developed.

6.8 RM places increasing demands on commissioners of healthcare through the growth of rehabilitation and the increasing expectations of people receiving health services. Improved acute care is currently resulting in better survival for people with major disabilities. Trauma networks are intended to reduce mortality rates by over 20%. If this is achieved, then even greater pressure can be anticipated on already stretched services delivering both complex rehabilitation and long-term care, unless suitable further resources are available to appoint extra RM clinicians.

6.9 Effective service provision for people with complex needs requires effective commissioning of sound mainstream services at tertiary, district and community levels, backed up by the flexibility to meet the idiosyncratic requirements of a highly diverse and complex client group. A combination of block commissioning and case management currently exists. This has to fill a range of demands for people, from early specialist rehabilitation programmes to ongoing and longer-term post-acute rehabilitation programmes, to those placed in institutional care who require re-access or first access to RM, and lastly to those who are trying to establish personalised rehabilitation packages.

6.10 Responsibility for commissioning rehabilitation and ensuring the implementation of effective client care pathways rarely rests with one commissioner, presenting challenges for both commissioners and providers. This is complicated by the development of services, eg the ‘stroke care pathway’ and the trauma networks, which enhance mainstream delivery, but at the expense of clients whose needs or diagnoses fall outside the diagnostic related services or cannot be addressed within the 8- or 12-week timescales that pathways are seeking to achieve.

6.11 The continuing care of people with complex neurological needs is extremely expensive. Long-term care packages for such individuals can be expected to cost £1,500 a week or more. The NHS needs to find between £50,000 and £150,000 a year for each new client meeting the criteria for NHS continuing care, and over a clients’ lifetime of, say, 10 years, the costs rise to over £1.5m. Failure to invest in timely and effective rehabilitation therefore has profound consequences in both human and financial terms, because it has been shown that effective rehabilitation can reduce the overall cost of care.

6.12 As people with disabilities survive for longer, specialist commissioning arrangements are required to improve outcomes for people with disabilities through an appropriate investment in rehabilitation, at the same time as trying to minimise the exponential growth in continuing care. These arrangements need to ensure the full utilisation of all specialist rehabilitation facilities by working in partnership with health service providers for access to specialist inpatient services and with local authorities to facilitate rehabilitation and vocational programmes in the community. The key policies shaping NHS services and their impact on the development of RM are described in Chapter 4.

6.13 The priority for acute provider units is too focused on clearing beds, and they have little awareness of the financial implications of failing to support a full specialist rehabilitation service for those who need it. With many complex conditions, a length of stay in rehabilitation of 6 to 18 months is totally appropriate, but such a period of rehabilitation can cost up to £300,000. However, failure to access rehabilitation can cost the health and social care economy significantly more over a client's lifetime, and adequate provision must be made to meet the needs of the primary care trust (PCT) population. This requires not just capacity, but also competency, to assure the efficacy of rehabilitation services.

6.14 Commissioning of the rehabilitation medicine care pathway is frequently an adjunct to other commissioning roles and, within one PCT, is commonly divided between at least three commissioners covering acute, community and continuing care. This is compounded where complex neurorehabilitation may be commissioned by another lead PCT, resulting in little understanding or interest in the total care pathway.

6.15 Despite their differences, the core aims of World Class Commissioning are supportive of those of the NSF, in identifying the vested interest that commissioners should have in ensuring that patients make a smooth transition through all stages of the care continuum, from acute care, through rehabilitation and into continuing care or the community.⁴ This means that timely and appropriate rehabilitation is required in order to make best use of the resources available.

Case study

Jane was a bright, vivacious university student, who developed complex problems after a severe stroke. After four months of specialist rehabilitation, she made a reasonable physical recovery but had a range of cognitive and behavioural problems. Persistent severe disinhibition, irritability and poor social awareness made her very vulnerable and difficult to manage, and she required further treatment in a dedicated unit for young people with acquired brain injuries. Over the next 12 months, she made progress, so that she could manage weekends at home with her younger siblings and had accompanied trips into the community. Social Services agreed to fund an out-of-area placement at a supported living project for people with acquired brain injuries, where she was able to cope in her own bedsit, and she soon commenced voluntary work.

Her behavioural problems escalated three years later as a result of weight gain and changes to her medication. Help from a consultant in rehabilitation medicine was urgently required for Jane and for her support staff. A neuropsychologist was requested to manage the situation and to liaise with the RM consultant, if readmission was needed to avoid a serious incident and her placement breaking down. Her social worker had difficulties with Jane's PCT, where the commissioner stated that 'acquired brain injuries don't fall under mental health' (but did not identify where it did come) and was further caught between Jane's new PCT and her original PCT. Each claimed that the other was responsible under the 'responsible commissioner guidance' for providing services for Jane.

The above case study shows how:

- ▶ rehabilitation may need to be carried out in several settings, over a long period of time, as the focus and need for treatment changes
- ▶ episodes of rehabilitation may last just a few weeks or many months
- ▶ the cost of rehabilitation for Jane has been significant
- ▶ the improvement in Jane and her family's quality of life, however, has been substantial and the savings which will accrue from her reduced need for care from the NHS and social services, probably over the next sixty years, will be far in excess of the initial investment in her rehabilitation
- ▶ commissioners have a vital role in ensuring that decisions regarding care are timely, effective and well managed.

6.16 As people with increasingly complex disabilities are supported in the community, commissioners have a key role in ensuring the development of access to long-term support and further rehabilitation as an essential part of the care pathway.

6.17 Recent analysis showed that 25% of the lost bed days in one London acute hospital were due to delayed discharge while patients awaited rehabilitation placements. This places highly vulnerable patients at high risk of hospital-acquired infections and of missing the window of opportunity for effective rehabilitation. The commissioning of rehabilitation services through a London-wide consortium, which includes NHS and independent sector providers, has identified several issues.

6.18 In London, this has led to significant improvement in equity of access to specialist services, but has consequently caused capacity issues to arise from increased demand. Developing this pattern of service throughout the rest of the country, with lower population densities, is currently untried and uncosted, and the resulting impact on provision of and overall access to specialist services is unknown.

Case management

6.19 Case management models have existed for some time in the independent sector for clients with significant disabilities in receipt of sizeable compensation payments following accidents. The case manager's role is to optimise and organise access to (usually) private rehabilitation resources, and in addition, where appropriate, to organise care for clients making the best use of compensation payments to improve recovery and restore quality of life.

6.20 There are some examples of NHS case management teams. Such teams do acquire a better understanding of rehabilitation pathways and the effectiveness of different rehabilitation units in meeting the needs of patients, thereby bridging the gap between commissioning and service providers.

6.21 The recent work of the major trauma networks has identified the need for a 'navigator' role to steer clients through rehabilitation services, ensuring well-planned and timely transfer between services to ensure optimal use of limited resources. It emphasises the need for patients to move as soon as possible to specialist rehabilitation, preventing the complications so often seen when they remain in the acute sector.

6.22 In the context of the emphasis on outcome-monitored services, it is essential that an adequate flow of patients goes through rehabilitation units. Rehabilitation pathways must not be blocked by clients with unmet needs who are waiting on alternative services such as housing or who are unable to engage or benefit from rehabilitation.

RECOMMENDATIONS

- ▶ **Clear commissioning structures should be in place which facilitate the understanding, coordination, redesign and development of rehabilitation services.**
- ▶ **A commissioning framework should exist to support patients individually with regard to need, complexity and local circumstances.**
- ▶ **The benefits of supporting existing structures with consortium or collaborative commissioning arrangements need to be reviewed.**
- ▶ **The benefits of a case management arrangement to deal with gaps in service provision should be reviewed.**
- ▶ **Local specialists need to be supported through commissioning to reduce the long-term costs of disability.**
- ▶ **Medical leadership is required for commissioning complex issues rather than focusing on technological solutions.**

Examples of the range of services required

6.23 A number of services are required in the context of case management. Some examples are listed below.

- ▶ Mobile, disorientated, brain-injured patients need to be protected for their own safety and that of others in a secure unit, as they can have an impact on the care of other patients. One-to-one skilled nursing may be required to care for them for short periods, as they may be irritable or aggressive.
- ▶ Patients with mental health problems may also acquire physical disabilities, eg after a suicide attempt. This is not uncommon, and little integrated care is available for them. RM physicians are involved in deciding whether the priority of care should lie in mental health or in RM.
- ▶ Young people with acquired or congenital disabilities may need school or college education to be integrated into their rehabilitation programme. It is difficult to ensure a fair balance is achieved when two or more agencies are involved. An educational ‘statement’ may be required if this is likely to persist in the longer term.

Population and service needs 2011–2020

Incidence

6.24 As yet, there are no accurate figures on the number of patients requiring specialist rehabilitation in the UK. In this context, diagnosis is a poor indicator of ‘need’, and although work is underway to establish a dataset and register for people with complex needs arising from a long-term neurological condition, no data are as yet available. The NSF emphasises that, while each individual condition may be comparatively rare, neurological conditions as a whole are common.

6.25 Altogether approximately 10 million people across the UK have a neurological condition. These account for 10% of acute hospital admissions, and are the third most common reason for attending a family doctor. An estimated 350,000 people across the UK need help with daily living activities because of a neurological condition, and 850,000 people care for someone with a neurological condition.

6.26 RM service provision continues to be patchy, so the quantity of service provided does not always reflect the need. There is considerable unmet need. Commissioners should not assume that current provision of RM is sufficient. For example, a recent published audit demonstrated that 38% of patients occupying beds in a neurosurgical unit should have been transferred for specialist RM services. Addressing this unmet need would increase the availability of acute neurosurgery beds, without the need to build and staff more neurosurgery wards.¹¹⁶

6.27 Review of recent and current practice provides a perspective against which UKROC data can provide costing data. Review of local services, as follows in paragraphs 6.28 and 6.29, also informs future and developing trends and suggests capacity for given resources.

6.28 The North Staffordshire Rehabilitation Centre admits 225 inpatients and sees well over 1,000 new outpatients per year. In addition, special services are held for wheelchairs, special seating, amputee rehabilitation and a comprehensive range of spasticity services. There are also close links with the acute neuroscience, general medical and trauma services through the provision of a rehabilitation coordinator (a band 7 clinical nurse specialist) and a mild brain injury service, as well as community rehabilitation clinics and linkages with primary care teams.

6.29 In 2008, in Reading, which serves west Berkshire, but also accepts people from east Berkshire with more complex disabilities, an acute 16-bed neurorehabilitation service admitted and treated 89 patients out of 131 referrals. The median length of stay was 48 days; 89% were discharged to home, including 5% going through a step-down facility; 10% went to a nursing home; and 1% returned to an acute medical facility. The median age was 58, with a range of 17–85, and male:female ratio was 3:2. Between 2004 and 2008, the median length of stay fell from 63 to 48 days, because of the PCT pressures on the acute trust in which it was hosted, to reduce overall length of stay. It cannot fall any further without a substantial increase in dependency on other services elsewhere. Between 30 and 40 outpatients are seen every week, and there are specialist outpatient services for rapidly progressive conditions like motor neurone disease, and for spasticity management in addition to transitional and severe disability services. Specialist nurses are an integral part of the service. Community-based specialist rehabilitation services are being developed to support earlier discharge, but are not yet staffed adequately. There is close collaboration with the independent charitable sector for several groups of patients, with an MS therapy centre providing specialist outpatient services, Headway providing enabling day services for people with acquired brain injury, the Motor Neurone Disease Association providing equipment and social support, and the regional Huntington's Disease Society representative working closely with the specialist nurse.

Impact of trends in disability and changing patterns of practice

Increased numbers

6.30 From the point of view of patients and families, the criteria for high-quality rehabilitation medicine services must be matched against the changes in the health and social care environment which are planned for implementation by 2013. One of the persistent themes in the following suggestions about future trends is that RM services cannot be excellent without excellent management.

6.31 Current economic indicators suggest that public expenditure is likely to contract over the next five years. Historically, funding priorities have always been heavily influenced by political concerns about acute healthcare, and investment in specialist rehabilitation services has tended to be disproportionately limited when funding is restricted. Current inequalities in provision of rehabilitation medicine posts may therefore continue. The specialty will be under intense pressure to

make the case for the cost-effectiveness of RM services. It will be essential to present commissioners with evidence of effectiveness and evidence of when and how specialist rehabilitation medicine adds value to less specialist forms of medical or non-medical rehabilitation.

6.32 The current trend of increased autonomy of specialist nurses, therapists, and others will continue, for example with the extension of prescribing rights for nurses. Increased responsibility is a core aspect of increased autonomy. Similarly, there will be more precedents for the provision of invasive interventions such as botulinum toxin injections by professionals (eg physiotherapists). Rehabilitation medicine has the ability to respond creatively to these developments. One fundamental will be the functioning of multidisciplinary and inter-agency teams, which must be structured and managed to ensure that patients and families have equitable access to specialist advice. Good models already exist for effective relationships between RM consultants and other specialist professionals, both in hospitals and in the community, with appropriate sharing of roles and responsibilities.

6.33 Patients are benefiting from developments in other medical specialties. One example is the current expansion of palliative medicine services for people with non-malignant conditions. In some areas, there is a trend towards shared caseloads between neurologists and specialist nurses. These developments are to be welcomed, provided that management arrangements ensure that the overall pattern of services and referral pathways is coherent, with access to RM expertise ensured.

6.34 The trend towards a more primary care-led NHS will continue. This development is consistent with the service principles of RM to the extent that it enhances the focus on the impact of disabling conditions in the real-life environments of the home or workplace. RM consultants cannot remain tied to current models of service provision, and may also need to be positioned within different institutional settings such as independent agencies or community-based units. However, new challenges will arise with regard to maintaining the necessary functional relationships with secondary care, including facilities for investigation and treatment. Links with secondary care and also with centres outside localities, are essential to prevent isolation of consultants and to promote continuing professional development of specialists. If there is a significant diversification of employer, this in turn could have an impact on training facilities and trainee numbers.

6.35 The current trend towards stimulating competition in the healthcare market shows no signs of abating, and this will lead to an increasing proliferation of provider agencies, sometimes with contracts being reviewed over short time periods. This carries with it the potential risk of undermining continuity of care, which is highly prized by patients and families. The opportunity for the RM consultant to contribute to a coherent and cohesive community-based rehabilitation plan may also be undermined. This puts rehabilitation outcomes for potentially vulnerable people in community settings at risk. In the interests of their patients, RM consultants will need to be flexible, but will also need to strengthen management support if new models of RM practice are to be effective.

6.36 Telemedicine may be used in some situations to provide patients with specialist medical rehabilitation advice. In response to some of the other trends outlined above, RM consultants are likely to need to move away from the classic model of providing almost all their services through direct clinical contact, towards involvement in other forms of consultation. These may include telephone, or telemedicine, links supported by local professionals. These must be linked to RM effectively through the creation and management of teams, which, although they may be geographically distributed, are well led and managed, and capable of jointly maintaining and increasing their specialist expertise.

Spend on disabled person needs and comparisons with European practice

6.37 An example of a greater breadth of vision can be seen in the Netherlands. There, RM specialists follow up patients in nursing homes through a complement of nursing home physicians who have been trained in rehabilitation and can implement specialist rehabilitation programmes. These specialist physicians are considered competent in delivering rehabilitation management as part of a multidisciplinary team in the nursing home environment, and consequently nursing homes are viewed in a different light, with a greater potential for meeting rehabilitation health needs at different stages of illness and life.

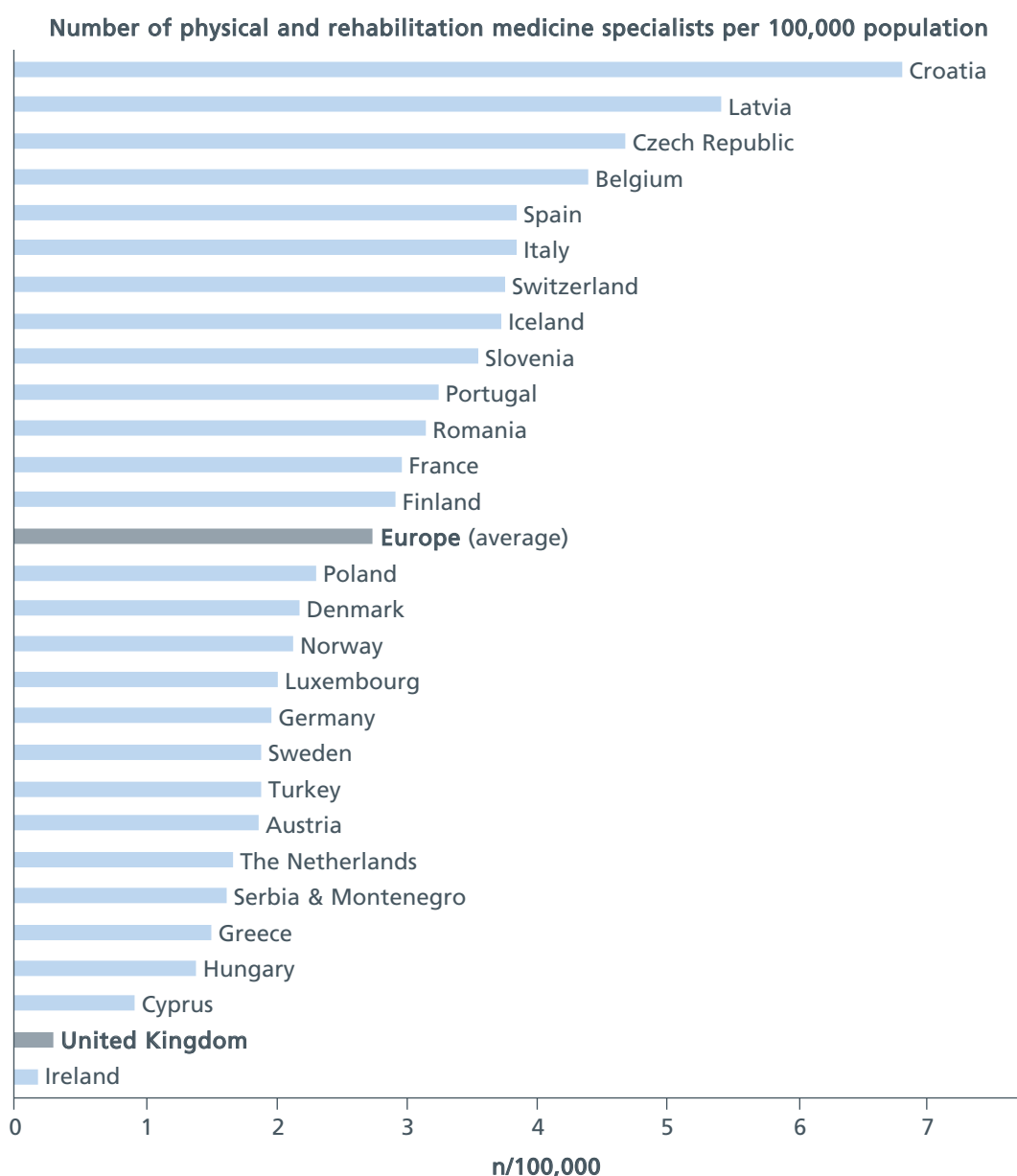


Fig 6.1 Comparison of the UK against other European Union of Medical Specialists (UEMS) states and the European average for PRM physicians.

6.38 The national position of RM in the UK is inferior to that of most countries in Europe. While there are differences in the range of physical and rehabilitation medicine activities in many EU states, the provision of UK RM specialists in the population is at the bottom of the European league table for both numbers and range of activity, as shown by the select data in Table 6.1 and Fig 6.1.¹¹⁷

Table 6.1 Comparison of rehabilitation medicine provision in the UK versus other countries

Country	Total number of doctors	Total number of specialists	Number of specialties	Practising RM specialists	Number of RM trainees	Number of RM doctors per 100,000 population	Population
France	183,700	95,000	38	1,760	125	2.87	61,300,000
Germany	394,432	261,437	43	1,571	65	1.96	80,000,000
Greece	60,700	15,200	37	164	33	1.49	11,000,000
Italy	307,600	160,000	45	2,200	350	3.73	59,000,000
Netherlands	39,800	16,500	27	248	78	1.65	15,000,000
Spain	157,900	70,000	51	1,500	292	3.85	39,000,000
Sweden	27,000	17,600	60	160	20	1.88	8,500,000
Switzerland	27,742	22,590	44	267	50	3.76	7,100,000
United Kingdom	150,000	21,000	58	152	65	0.26	58,000,000

Role of rehabilitation physicians in different settings

6.39 Rehabilitation medicine services cover a range of healthcare interventions in acute, post-acute and community settings. Table 6.2 describes the pros and cons of currently recognisable hospital- or residential-based rehabilitation settings, from the acute medical bed to the separate dedicated rehabilitation centre.

Acute settings

6.40 It has been observed that the simple act of transferring a brain-injured patient from a busy surgical, medical or neurosurgical ward to the calmer, quieter atmosphere of a rehabilitation ward usually has a therapeutic effect, consisting of improvement in attention and cognition and a reduction in agitation.¹¹⁸ The pressures of acute general wards make it difficult for multidisciplinary rehabilitation teams to treat patients with complex needs, exacerbating anxiety and restlessness which, if treated with sedative medication, reduce the potential for the individual to work on recovery.²⁵

Post-acute settings

6.41 Standards for post-acute inpatient rehabilitation have already been described in Chapter 2 and Chapter 5.¹¹⁹ In the post-acute setting, the RM consultant usually remains responsible for meeting the health needs of the individual, and working with team members to achieve a successful

discharge or move to a community setting. There may still be identifiable rehabilitation goals to meet in the next setting, and good liaison with the treating community-based rehabilitation team is essential to hand on the torch of first class rehabilitation practice.

Table 6.2 Issues for commissioners to consider various models of acute RM activities

Establishment	Activity	Clinical advantages	Logistical challenges on patient outcomes	Potential savings
RM beds in acute hospital	Transfer of patients to RM beds within acute hospital	<ul style="list-style-type: none"> – Rapid change to RM clinical activity – Early rehabilitation principles – Requires adequate number of dedicated staff 	<ul style="list-style-type: none"> – Limited numbers of beds and, therefore, of patients taken – Potential for bed-blocking – need to wait to transfer patients out to either home or rehabilitation facility – Need to protect against transfer of inappropriate patients – Difficulties if staff numbers inadequate 	<ul style="list-style-type: none"> – Enables rapid transfer to definitive rehabilitation services – Makes best use of inpatient facilities by concentrating rehab activities – Allows cooperative care between clinicians – Saves duplication of assessment and creation of rehabilitation plan – Starts rehabilitation earlier
Mobile/peripatetic RM team	An RM team working solely within an acute hospital visits patients under care of other consultants	<ul style="list-style-type: none"> – Possible to consult on larger numbers of patients with wider range of conditions – Good liaison between team and staff on acute wards 	<ul style="list-style-type: none"> – No clinical control – patients under care of other specialists – Treating nurses and therapists not within RM team – Least specialised format for acute RM – Does not often address participation issues 	<ul style="list-style-type: none"> – Provides rapid and comprehensive needs assessment – Carries uniform assessment into community settings – Prevents duplication of activity in other rehabilitation settings and responds to change in needs
RM consults to acute wards	An RM physician from a stand-alone RM centre visits patients under care of other specialists	<ul style="list-style-type: none"> – Possible to consult on larger numbers of patients with wider range of conditions – Closer links between RM consultants and acute specialists 	<ul style="list-style-type: none"> – No clinical control – patients under care of other specialists – Treating nurses and therapists not within RM team – Time and expense to be effective – Need to be on site 	Cheap to perform, but less detailed assessment than mobile team
Acute RM centre	Rapid transfer of patients to fast-track facility in stand alone RM centre	<ul style="list-style-type: none"> – Patient exposed to the total RM team and facilities at an early stage – RM physician competence in treating acute conditions 	<ul style="list-style-type: none"> – Patients must be medically stable – Patients may be transferred back in case of deterioration – Little contact between RM team and acute specialists – Little or no service for patients not transferred 	<ul style="list-style-type: none"> – Most effective option, if the facilities are in place – Effectively clears acute beds into less costly rehabilitation facilities

6.42 Specialised outpatient programmes have been described, mainly in the area of acquired brain injury, and the basis of practice remains multi- or inter-disciplinary, and a team approach continues.

6.43 Against this backdrop, there is still a highly professional, generally hospital-based RM specialist outpatient practice. The emphasis is on holistic disability assessment and initiation of a management plan. This may seem to follow a traditional ‘physicianly’ model, where, after an investigation and functional assessment, patients are treated through a number of medical interventions, or may be referred to therapy (physiotherapy, occupational therapy, or others). However, it remains an integrated part of providing expert specialist RM input in a timely and convenient fashion.

6.44 RM consultants assess the patient with their family, and outpatient consultations are often detailed and lengthy, reflecting the complexity of the condition. Cognitive and communication difficulties place higher demands on the consultation process. It takes significant experience, expertise and good communication skills to ensure that patients, their families/carers and team members all understand and agree with the aims, treatment, and expectations of outcome. There may be a need to involve other medical and surgical specialists, and the commissioning process must support this.

6.45 Specialised clinics may be established to streamline some aspects of services. Below is a list of some examples that currently exist.

Box 6.1 Examples of specialised RM clinics

Neurological disability

- ▶ Mild acquired brain injury
- ▶ Spasticity management
- ▶ Rapidly progressive neurological disability, eg motor neurone disease
- ▶ Progressive neurological disability, eg Huntington’s disease, multiple sclerosis
- ▶ Post-stroke assessment

Musculoskeletal

- ▶ Early referral pathways
- ▶ Localised and complex musculoskeletal pain, eg back pain
- ▶ Joint clinics with other specialists, eg hand

Community settings

6.46 The role of the RM consultant varies according to skills and circumstances. Consultants in RM recognise the trend towards a greater community presence, although the evidence to support this trend is lacking. They can make a huge input into the development of specialised community rehabilitation teams. The community team can draw on the consultant’s expertise, and together they can develop strategies not only for improving activity and participation, but also for preventing deterioration.¹²⁰

6.47 RM specialists and multidisciplinary team members often have a role in both the community team and the rehabilitation centre. This can facilitate the individual receiving targeted treatments in the most appropriate location. Commissioners will realise that the input of a consultant

in RM can enhance the effectiveness of a community team and help with communication across service boundaries and between health, social and vocational settings

6.48 There is currently little formal specialist input for many people with disabilities living in the community, particularly for those in institutional care. People in the latter category have an array of preventable problems, which are currently not addressed. There are funding barriers in institutions that can prevent access to necessary equipment or therapies that could enhance ability and well-being. Medical complications and disabilities due to physical and cognitive impairments are both major causes of entry into nursing home,^{121–124} and re-entry into acute hospital beds.¹²⁵ The concept of nursing home medicine as a sub-division of rehabilitation medicine exists in the Netherlands, but, while the reasons for and benefits of its activities are plain, cost-effectiveness has not been demonstrated.

7 Future perspectives for the specialty

7.1 In an era of economic austerity which will affect all public services, clinical pressures will arise, because achieving a good rehabilitation outcome is often costly. Rehabilitation medicine will be a key resource at times when the need to minimise acute hospital admissions is urgent, and when community and family resources must be optimised. RM will have a role in preventing admissions and avoiding complications in people with long-term conditions. This is in line with the strong emphasis on health maintenance and prevention in the Department of Health's command document *NHS 2010–2015: from good to great. Preventative, people-centred, productive*.¹²⁶ The Audit Commission has highlighted rehabilitation as part of a strategy to contain the growing costs of an ageing population.¹²⁷

7.2 Rehabilitation medicine will consolidate its future in terms of clinical standards, research and education. A wider number of methodologies are likely to be required to show the benefits of rehabilitation across healthcare. Practice-based evidence is likely to grow in importance. Current cost-effectiveness studies are likely to provide more evidence of the benefits of rehabilitation input. Achieving funding for collaborative clinical and research networks among RM specialists in the developed world is an achievable goal. Establishing best practice and supporting development of novel treatments will depend on further support for academic RM collaborative research.

7.3 Although healthcare is an ever-changing field, several policy strands can be expected to influence the future delivery of specialist rehabilitation services, irrespective of the political context. The trend towards a more community-orientated NHS, enshrined in the Department of Health's policy initiative 'Transforming community services', can be expected to continue.¹²⁸ A parallel strand is the agenda of personalisation in both healthcare and social care.¹²⁹ Whether this turns out to be a cost-effective approach to provision cannot be predicted.

7.4 Current initiatives on acute stroke care, critical illness rehabilitation and trauma care networks all highlight the early need for specialist rehabilitation intervention, but do not go far enough in describing the downstream situation of people left with complex long-term disability who need ongoing and recurring access to specialist services in RM.

7.5 Practice-based commissioning has the potential to support high-quality community services in line with the integrated model of care advocated jointly by the Royal College of Physicians, Royal College of General Practitioners, and Royal College of Paediatrics and Child Health,¹³⁰ and also by the Department of Health.¹⁵

7.6 These policies fit well with the practice of rehabilitation medicine, which has always entailed multidisciplinary working and close liaison with primary care and with other community health and social services. However, as the medical royal colleges' document acknowledges, there is a risk of fragmentation and loss of medical leadership unless commissioners ensure that specialist clinical interventions and support for people with long-term conditions are available at the point of need. Models of integrated care are being developed, including schemes for joint health and social care delivery of services for people with long-term conditions.¹³¹ GPs play an important part in the clinical care of people with physical disabilities. RM specialists can work with GPs to raise the expectations and expertise of primary care teams on disability management. This

collaboration could be a powerful force in minimising unnecessary referrals to secondary care and reducing preventable complications.

7.7 There should be no barriers to adults of any age accessing specialist RM services. Greater numbers of people are surviving disabling illness and trauma, and more infants are surviving into adulthood, with ever more complex disability. These increasing needs suggest that the UK needs an expansion of consultant and trainee numbers, by at least 7% in the next two years, simply to stay at the current level of provision.

7.8 Exciting new technology provides greater opportunities for people with disabilities. Teletherapy could supplant telemedicine and provide individuals with the opportunity to continue rehabilitation in their own homes with therapeutic telemonitoring of their applications and progress. Current availability of enabling technology is described well in Chapter 2, but considerable progress might be achieved with robotics and implantable devices that allow the control of computers with brainwaves. This has been demonstrated in academic and research fields, but is not yet clinically available.

7.9 Neuroprotective drugs and systems to reduce brain or spinal cord damage are in their infancy, but are developing. Methods of promoting brain and spinal cord recovery after injury are being trialled and tested. Drugs and treatments to enhance new learning are considered applicable for people with neurological disability, but are also likely to be viewed with great interest by educationalists, and will stimulate serious ethical debates on availability, use and access. A current major clinical problem lies in finding the funding to bring new research developments and findings into clinical practice where further evaluation of efficacy and safety can take place.

7.10 Vocational rehabilitation has now acquired a higher profile. RM specialists have a role in promoting the employment of disabled people. The agenda here concerns the well-being of individuals, as well as fiscal pressures.^{15,132} Such developments provide the rationales for further development within the scope of RM of vocational rehabilitation, and also of musculoskeletal rehabilitation. There is a recognition of the cost to the nation in loss of working days, and a huge national shortfall in the clinical expertise required to manage the many people with complex problems due to fibromyalgia and chronic disabling pain. RM teams have the clinical expertise to work with primary care teams and others in this field.¹⁰¹ This includes careful assessment and application of principles of pain control and self-management, and development of the expert patient model.

7.11 One of the platforms of the National Service Framework (NSF) has been to advocate coordinated networks in England and Wales. There is now a need to update the NSF by agreeing a UK rehabilitation strategy, similar to that achieved in the devolved healthcare environment in Scotland, and to that achieved for mental health.¹³³

7.12 The consultation associated with the development of this report has produced some very positive feedback from a wide range of professional colleagues. There is a real will expressed by our colleagues in neurosciences, psychiatry, psychology, rheumatology, primary care, trauma care and RM therapist groups, to develop a higher level of interdisciplinary integrated practice with RM doctors. Together, they can ensure the development of better services for people with brain injury with superadded cognitive and behavioural problems, for people with complex musculoskeletal problems, and for people with disabilities who want to explore their vocational potential.

7.13 The NHS is constantly changing, and this report may require updating once the effects of new commissioning arrangements are known. These are currently planned for full implementation by 2013, after which time consideration for a review will be appropriate.

Appendix 1 Resources required for a high quality service

Inpatient unit

The BSRM recommends that between 45 and 65 beds should be available per million population for specialist rehabilitation medicine (RM). Variance reflects the extent to which other services are locally available for stroke and for the rehabilitation of older people. This equates to around 15 beds per 250,000 population, but the BSRM recommends that the minimum size of a viable inpatient unit should be 20 beds for critical mass. The beds must be located together, in order to provide an appropriate environment for rehabilitation, and to make best use of the rehabilitation nursing complement.

- ▶ Some single room accommodation is needed, and sufficient space must be available for therapy, recreation and social activities, team meetings, and case conferences.
- ▶ The inpatient unit must have immediate access to medical and surgical services listed in Chapter 4, and also to dietetics and enteral feeding services, together with imaging and pathology services.
- ▶ The unit must have a supply of wheelchairs (including electric powered chairs) immediately available for patients on the unit and have access to specialist orthotics, special seating and wheelchair clinics.

Outpatient facilities

Whilst conventional outpatient facilities may meet the needs of some patients undergoing rehabilitation, the majority need access to the multidisciplinary team. Therefore, day assessments, case conferences or outreach visits are often more appropriate.

Whatever the pattern of outpatient services, the consultant will need access to:

- ▶ physiotherapy, gymnasium and hydrotherapy resources
- ▶ occupational therapy facilities including a domestic environment and workshops
- ▶ IT equipment and software for patient use
- ▶ orthotics and prosthetics
- ▶ specialist wheelchairs and seating
- ▶ electronic assistive technology
- ▶ driving assessment and training services
- ▶ local education and employment training services
- ▶ vocational rehabilitation services
- ▶ social services
- ▶ counselling services

- ▶ psychology services
- ▶ sexual and genetic counselling services.

The role of the RM consultant

Inpatient work

There is considerable variation in job plans, but a typical consultant's working week will include:

- ▶ **Ward round** – A conventional weekly medical ward round for 20 beds takes around three hours.
- ▶ **Inpatient multidisciplinary team meeting** – In addition to the ward round, a rehabilitation unit holds at least one weekly multidisciplinary team meeting to discuss the progress of patients. This meeting is complex and takes a minimum of three hours.
- ▶ **Referral work** – Between five and ten referrals may be seen per week, including reviews of existing referrals, requiring one to two programmed activities (PAs), or more if they necessitate travelling off site to see the patients.
- ▶ **Interdisciplinary liaison** – Liaison between members of the multidisciplinary team and between the numerous medical and surgical specialties involved in inpatient rehabilitation requires around two PAs per week.
- ▶ **Case conferences** – There are two to three per week, lasting one to two hours (one PA).

Outpatient work

- ▶ **Conventional (unidisciplinary) medical outpatient clinics** – Between two and six new patients or between four and eight follow-up patients may be seen in a session of one PA.
- ▶ **Special clinics** – These are conducted either on the specialised unit or by outreach. Examples include:
 - spasticity clinic (botulinum toxin and intrathecal baclofen treatments)
 - young adults clinic (in conjunction with paediatrics)
 - prosthetic amputee rehabilitation (specialised unit)
 - specialised wheelchair seating (specialised unit or outreach)
 - electric indoor/outdoor powered chairs (specialised unit or outreach)
 - environmental control assessment (outreach)
 - continence clinic
 - diagnosis-specific clinics, eg multiple sclerosis
 - specialist investigative and therapeutic procedure clinics – these include spasticity clinics where botulinum toxin and phenol blockade services are provided (other clinics in this category include those for specialist seating assessments and for gait analysis).

Community work

Where a consultant undertakes a substantial community commitment, activities will include:

- ▶ **Multidisciplinary team meetings** – often include an element of inter-agency liaison
- ▶ **Outreach clinics** – may be sited in a local hospital
- ▶ **Home visits** – require around one PA for three or four visits
- ▶ **Scheduled visits to specialist nursing homes** – entail both clinical assessments of individual patients and liaison with staff
- ▶ **Home-based inter-agency review meetings** – frequently required for severely disabled people
- ▶ **Outreach or network-based activity** – increasingly undertaken by RM consultants, supporting local and specialist teams in the community or other centres.

Specialist on call

Job plans for consultants running specialist inpatient facilities include PAs for on-call duties. With a unit of 20 beds, consultants may be on call one in two or one in three, but are usually on a 'non-onerous' band.

Other specialist activity including activities beyond the local service

RM consultants regularly undertake a number of other additional specialist activities. Assessments for disabled drivers, for example, are largely linked to RM services. Patients with neurological disabilities, who require specialised urodynamic and fertility advice, will be seen in conjunction with appropriate specialties, as will those requiring other interventions such as enteral feeding or respiratory support.

Clinically related administration

Clinic-related correspondence is especially complex in RM, both because the assessments are complex and because referral letters to numerous services and agencies are often required. Dictation following a typical clinic requires at least half as much time as the clinic itself, and at least one PA per week should be allocated for administration.

Additional administrative demands arise from the need for consultants to be involved in negotiating agreements on funding of individual care packages for complex patients. This involves liaison with primary care trusts, social services and others.

There is also a frequent requirement for assessments of physical and mental capacities, for the purposes of employment, benefits, insurance etc, as well as for medicolegal and forensic correspondence in connection with patients who have suffered trauma.

Appendix 2 The national dataset for specialist rehabilitation

Specialist rehabilitation

The national dataset for specialist rehabilitation is a critical tool to provide proper service evaluation and benchmarking for specialist rehabilitation, and to collate activity data and for benchmarking outcomes. This is part of a collaborative venture between the BSRM and the NHS Information Centre, in a programme funded by the Department of Health to inform casemix development in rehabilitation services.

The dataset will provide systematic data that will be analysed at national level to describe:

- ▶ the types of patient admitted to each service, their needs for rehabilitation, and rehabilitation interventions received
- ▶ the differential costs of providing the different levels of rehabilitation service
- ▶ outcomes from rehabilitation, in terms of what patients want (personal goals, quality of life etc) and what commissioners want (cost of ongoing care etc).

It will ultimately provide information on the patient characteristics that define the need for specialist services. It will examine the balance between inputs and outcomes to identify service models providing best quality and value for money at different levels of rehabilitation need.

These data will be collated under the relevant casemix classification codes – eg Healthcare Resource Groups (HRGs) – in order to provide ongoing costing information which will be used to inform tariff costs for the Department of Health’s ‘Payment by results’ programme after 2012.

Defining rehabilitation needs and case complexity

The key factors that determine complexity of rehabilitation needs are the patient’s needs for:

- ▶ basic care and safety
- ▶ skilled rehabilitation nursing care
- ▶ therapy input – a number of disciplines involved, intensity of treatment and need for specialised equipment and facilities
- ▶ medical care and intervention.

If a service is to handle patients with complex needs, it must be able to demonstrate that it provides a level of rehabilitation inputs and facilities commensurate with addressing those needs.

If the commissioners are to fund these higher level services, there must be measurable outcomes to demonstrate that a useful gain has been made. This will not necessarily be improvement in recovery status, but may be achievement of a defined and structured successful care programme that allows an individual with highly complex needs to have a future living in the community.

A hierarchical series of tools has been developed to capture needs, inputs and outcomes, with more detailed tools being used to define higher levels of complexity in low volume/high cost services, as shown in Fig A1. The data, which form part of the national dataset for specialist rehabilitation, are collated through the UKROC database.

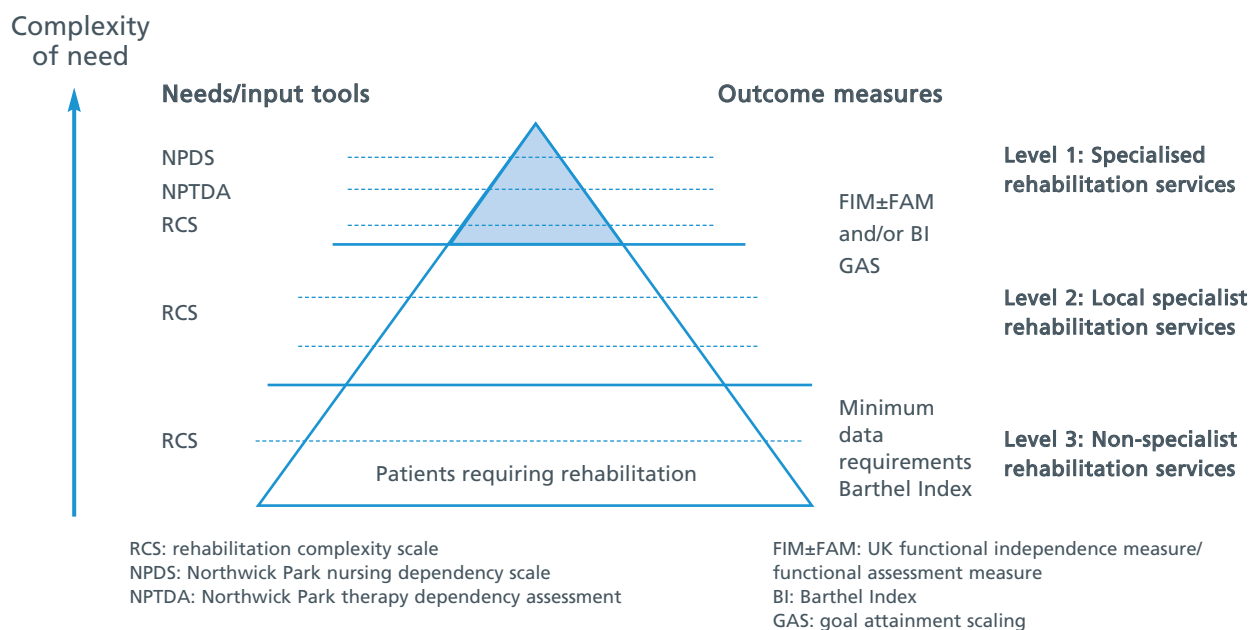


Fig A1 Hierarchical series of tools to capture needs, inputs and outcomes within the different levels of service.

Outcome measures and person-centred goals

The domains of the ICF, described in Chapter 2, paragraph 2.7, are classified from body, individual and societal perspectives by means of two principal lists: a list of impairments (ie body functions and structure), and a list of domains of ‘activity and participation’.³ This forms a useful framework for thinking about outcomes and grouping them across different goal domains.¹³⁴

Patients have diverse goals for rehabilitation, and no single measure will adequately capture this diversity. The BSRM has published a ‘basket of measures’, from which rehabilitation providers are encouraged to select the instruments which are most applicable for their client group.¹³⁵ However, many of the widely-used outcome measures have similar core content, which may yet have the potential to provide a ‘common language’ in outcome between centres that use different instruments.¹³⁶

The UKROC dataset is not designed to be restrictive. Units are still encouraged to collect any outcomes that they consider to be most relevant to their caseload. However, for the purpose of comparative description, all units are asked to collect a minimum of standardised outcome data, which includes one of those already routinely collected by 95% of specialist rehabilitation units in the UK.

Improved independence in basic activities of daily living is an important goal for rehabilitation, and a number of standardised instruments exist to measure it:

- ▶ At the simplest level, the Barthel index^{137,138} (10 items) is a widely used measure of physical disability, and is robust and reliable, but lacks sensitivity.

- ▶ The functional independence measure (FIM)¹³⁹ (18 items) adds in a communication and cognitive rating. For spinal cord injuries (SCIs), the FIM is replaced by the spinal cord independence measure (SCIM).
- ▶ The functional assessment measure (FAM)¹⁴⁰ (30 items) adds 12 further items addressing cognitive and psychosocial issues. There is no equivalent measure in SCI.

In other areas of rehabilitation, however, the goals for intervention may be targeted at areas other than functional independence – for example symptom management, societal participation, or quality of life. Here, the wide diversity of individual goals makes the application of standardised measures more problematic, and confounds comparison. Goal attainment scaling (GAS) offers a potentially useful option for capturing individualised person-centred outcomes, or putting together the outcomes from a range of different measures, where the standardised measures of physical disability fail to capture the intended purpose of the programme.¹⁴¹

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Glossary of terms and abbreviations

ABI	acquired brain injury – <i>due to trauma, ischaemia eg stroke, hypoxia</i>
activities	nature and extent of performance in functional activities at the level of the person, eg walking
ADL	activities of daily living
ASU	acute stroke unit
BASCIS	British Association of Spinal Cord Injury Specialists
BI	Barthel Index – <i>a measure of independence in personal care</i>
BSRM	British Society of Rehabilitation Medicine
BSR	British Society for Rheumatology
DGH	district general hospital
Disability management	aspect of clinical practice using a collaborative rehabilitation approach in conditions characterised by, and which produce, changing/unpredictable health needs
EAT	enabling assistive technology
FAM	functional assessment measure
FIM	functional independence measure – <i>measures independence, cognition and communication in personal care</i>
FES	functional electrical stimulation – <i>a way of producing a muscle contraction</i>
GAS	goal attainment scaling – <i>a statistical transformation of goal attainment scoring</i>
GBS	Guillain-Barré syndrome
GRADE	grading of recommendations assessment, development and evaluation – <i>a method of evaluating evidence which includes looking at benefits and harms</i>
HRG	health-related group
ICF	International Classification of Functioning, Disability and Health – <i>has superseded ICIDH</i>
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ICU	intensive care unit
impairment	a loss or abnormality of body structure, psychological or physiological function, eg paralysis
inpatient behavioural unit	a residential unit that can provide a therapeutic and safe environment for people with challenging behaviour, usually licensed under Mental Health Act

ITU	intensive therapy unit
limb loss rehabilitation	rehabilitation services for people with congenital or acquired limb deficiencies
LOS	length of stay
LTC	long-term condition
LTNC	long-term neurological condition
MD	multidisciplinary
MDT	multidisciplinary team – <i>In rehabilitation, this usually includes a specialist RM doctor, physiotherapist, occupational therapist, psychologist, speech and language therapist, dietician, and rehabilitation nurse. Therapists often have specialist training, eg in neurological disorders.</i>
MASCIP	Multidisciplinary Association of Spinal Cord Injury Professionals
MND	motor neurone disease
MNDA	Motor Neurone Disease Association
MS	multiple sclerosis
MSK	musculoskeletal
NA	Neurological Alliance – <i>umbrella charity for neurological charities</i>
NSF	National Service Framework
neurological rehabilitation	rehabilitation services for those with all forms of complex neurological disability, whether sudden-onset, progressive, intermittent or stable
NRU	neurological rehabilitation unit
NIV	non-invasive ventilatory (support)
NTN	national training number
neuro-palliative care	Later-stage care of people with progressive neurological conditions. Clinical pathways are shared by palliative care, neurorehabilitation and neurology services.
palliative care	care of the dying; focus on hospice-based services
participation	involvement in life situations, performing ones chosen roles in life, occupation, social integration
PBC	practice-based commissioning
PbR	payment by results
PCT	primary care trust
progressive conditions	impairments and disability which gradually increase over a timescale varying from a few months to many years
prosthesis	artificial structure that replaces a missing body part, eg artificial limb
QoL	quality of life

Quality Outcomes Framework (QOF)	targets for GPs which, if achieved, trigger additional payments
rehabilitation	active, time-limited collaboration of a person with disabilities and professionals
RM	rehabilitation medicine
RCT	randomised controlled trial
SCI	spinal cord injury
SCIC	spinal cord injury centre
specialised commissioning	<i>see tertiary services</i>
SpR	specialist registrar – <i>doctor in higher medical training</i>
stable conditions	the condition is static, but additional effects of degenerative and other changes may be superimposed over time, producing new disability
sudden onset	a catastrophic onset which is followed by a variable degree of recovery
TBI	traumatic brain injury
tertiary services	Department of Health-defined specialised service which serves a population over 1,000,000 and is purchased through specialised commissioning and has a specialised definitions set
UKROC	United Kingdom Rehabilitation Outcomes Collaboration
VR	vocational rehabilitation
WCC	world class commissioning
WTE	whole-time equivalent

