



NEUROLOGICAL REHABILITATION

A Briefing Paper for Commissioners of Clinical Neurosciences



British Society of Rehabilitation Medicine
C/o Royal College of Physicians, 11 St Andrews Place, London NW1 4LE
Tel: 01992 638865 www.bsrm.co.uk

July 2008

Briefing Paper on Neurological Rehabilitation for Commissioners of Clinical Neurosciences

1. Purposes of the paper

- To define and describe the specialist rehabilitation needs of people with both acute and chronic neurological conditions.
- To outline the role of Rehabilitation Medicine in neurological rehabilitation.
- To identify current commissioning issues.

2. Background

Rehabilitation is a goal-directed process which reduces the impact of long-term conditions on daily life. Rehabilitation is applicable both in acute injury and in progressive or static disability. The National Service Framework (NSF) for Long-term Neurological Conditions¹ requires rehabilitation resources to be available at all stages in a neurological condition, in both community and hospital settings. Relevant national clinical guidelines require **specialist** rehabilitation services, for example recent guidelines on brain injury² and NICE Guidelines on multiple sclerosis.³

All practitioners – neurologists and neurosurgeons as much as nurses and therapists - adopt a **rehabilitation approach** in their work with patients. The range of interventions, therapeutic modalities, equipment, etc available to them can be termed **rehabilitation technologies**. Rehabilitation services have developed over the last two decades, in a 3-tier structure:

1. Within each locality (Level 3):

Local general rehabilitation teams provide general multi-professional rehabilitation and therapy support for a range of conditions within the context of acute services (including stroke units), intermediate care or community services.

2. Local specialist rehabilitation services (Level 2) are typically planned over a district-level population of 250-500K, and are led or supported by a consultant trained and accredited in Rehabilitation medicine (RM), working both in hospital and the community setting. The specialist multidisciplinary rehabilitation team provides advice and support for local general rehabilitation teams.

3. 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 co-ordinated service networks planned over a regional population of 1-3 million through collaborative (specialised) commissioning arrangements.

Ref Specialised Services National definition Set No 7: Brain injury and Complex rehabilitation. Department of Health London 2009.

Rehabilitation Medicine (RM) consultants lead and co-ordinate neurological rehabilitation for people with complex needs. RM integrates neurological, musculoskeletal and other physical aspects with the psychological and social dimensions of rehabilitation, alongside the provision of assistive technology. The main focus is on people of working age.^{4,5} Supported by multi-disciplinary teams, most RM consultants are based in specialist inpatient neurological rehabilitation units, with strong community commitments including home visiting.

* Previously known as 'Complex specialised rehabilitation services' in the National Definition Set version 2.

Based on the WHO's International Classification of Functioning, Disability and Health,⁶ RM considers medical aspects of disability (pathology and impairment) in their social and psychological context. Thus, someone complaining of spinal pain is as likely to benefit from different seating arrangements as from drugs or other strictly medical treatments.

3. Major areas of need for specialist Neurological Rehabilitation

There is a severe shortage of epidemiological data on the prevalence of neurological **disabilities** as opposed to **disease incidence and prevalence**.

In **primary care**, key areas of need for neurological rehabilitation include:

- **Progressive neurological disorders** - these have a combined prevalence of around 400 per 100,000, i.e. about one quarter of the prevalence of stroke. Patients with progressive disorders, e.g. those with motor neurone disease or with late-stage multiple sclerosis - generate highly complex needs which absorb greatly disproportionate resources.
- **Long-term sequelae of trauma** – the NSF suggests that the prevalence per 100,000 of long-term sequelae is 1200 for traumatic brain injury and 50 for spinal cord injury.
- **Cognitive and behavioural disturbances** are an important and neglected source of rehabilitation needs. Multiple sclerosis is the most common cause of progressive dementia in adults of working age. Neurobehavioural problems are the most important source of disability in survivors of traumatic brain injury, and also in Huntington's disease.

In **secondary care**, the main needs for inpatient neurological rehabilitation include:

- **Trauma/orthopaedics** - the dominant category is **brain injury**. Estimates of the incidence of injuries leading to significant disabilities has ranged from 75 to 175 per 100,000. Of these perhaps 1% require admission to a neurological rehabilitation unit but a larger number require support in view of physical, cognitive and behavioural sequelae. **Spinal cord injury** has an incidence of around 2 per 100,000.
- **Acute medicine - stroke** is the largest source of acute onset neurological disability; some 15% of incident cases are of working age. Other acquired brain injuries such as **subarachnoid haemorrhage** and **anoxic encephalopathy** often present with complex needs due to cognitive as well as physical impairments. Individuals with long-term neurological conditions, especially **progressive disorders**, frequently require hospital admission due to either deterioration in their condition or intercurrent illnesses such as infections.

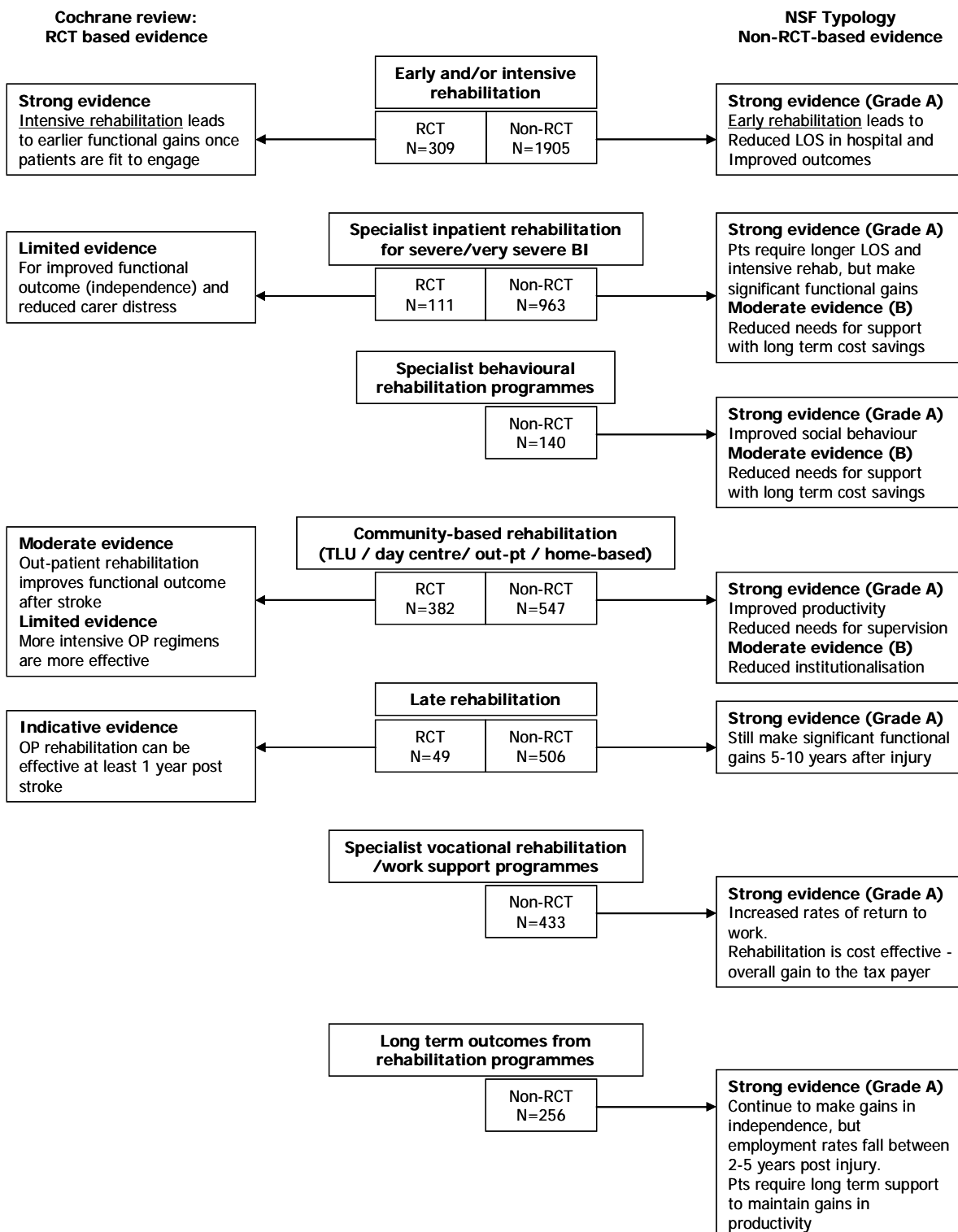
In **tertiary care**, Clinical Neurosciences Centres refer inpatients to neurological rehabilitation beds following acute management of conditions ranging from **acquired brain injuries** including subarachnoid haemorrhage to severe **peripheral neurological problems** such as Guillain-Barré syndrome.

4. Efficacy of neurological rehabilitation

Trial evidence for the efficacy of neurological rehabilitation is accumulating. The strongest evidence base is for stroke⁷. A recent systematic review⁸ highlights evidence for the benefits of specialist rehabilitation following acquired brain injury in adults of working age. The review (summarised in Figure 1. below) used both Cochrane methodology and a new typology developed for the NSF for Long-term Neurological Conditions¹. Trial-based studies provide 'strong evidence' that more intensive programmes are associated with earlier functional gains, and 'moderate evidence' that continued outpatient therapy can help to sustain gains made in early post-acute rehabilitation. The non-trial-based studies provided strong evidence for the benefits of early or late rehabilitation, the effect of specialist programmes (e.g. vocational or neuro-behavioural rehabilitation), as well as evidence for the cost-benefits of rehabilitation.

Evidence is also emerging for the benefits of neurological rehabilitation in multiple sclerosis,⁹ as acknowledged in recent NICE guidelines,³ and more generally for community-based specialist services.¹⁰

Figure 1: Evaluation of evidence for the effectiveness of rehabilitation in acquired brain injury (from Turner-Stokes, submitted⁸)



RCT= randomised controlled trial; TLU=Transitional Living Unit

5. Cost-effectiveness

Some evidence is now available on the cost effectiveness of neurological rehabilitation.^{11,12,13} Delivered through a multidisciplinary team led by a consultant in Rehabilitation Medicine, rehabilitation helps to contain the costs of disablement for health and social services, for employers and also for disabled individuals and their families. The economic benefits of RM can be summarised under four main headings:

- **Preventing costly complications and avoidable hospital admissions** RM consultants implement strategies to prevent disastrous complications such as skin sores, joint contractures, fractures, malnutrition and infection which currently make a large contribution to the financial costs of long-term conditions. Predicting and preventing complications supports the work of Community Matrons and others involved in managing the most complex long-term conditions. Strategies to facilitate independence relieve pressures on acute services, thus helping to break the 'vicious circle' highlighted in the Audit Commission's report, *The Way to Go Home*.¹⁴
- **Reducing the duration of hospital admissions** As the NSF has recognised¹ long-term conditions have a highly disproportionate effect on hospital bed occupancy, because of delays in discharge. Delays are reduced where RM expertise is available to co-ordinate complex discharges. Recent suggestions for restructuring post-acute rehabilitation¹⁵ fit well with the proven ability of RM specialists to work across disciplines and between agencies.
- **Reducing costs of long-term care** Specialist RM expertise reduces the costs of long-term care by enabling more individuals to return home and by optimising care packages¹¹.
- **Helping disabled people return to the workforce** Many people with complex disabilities are frustrated by the barriers they face in retaining or regaining employment. The specialist expertise of RM consultants along with their teams helps such individuals to achieve their potential for economic participation.

6. Current service models

The standard (although not universally achieved) model is for each Health District to have an inpatient neurological unit including a specialist multidisciplinary team led by an RM consultant. The national network of supra regional spinal cord injury centres is also led by RM consultants. In many areas, RM is managed separately from neurosciences. However, in a recent BSRM survey consultants in 12% of Neurological Rehabilitation Units carried out weekly ward rounds on neurosurgical wards. In some areas the RM team is an integral part of a neuroscience directorate and an RM consultant may have lead responsibility for work which would previously have been undertaken by a neurologist, e.g. co-ordination of all services for motor neurone disease. Conversely, some neurology departments are providing certain interventions styled as rehabilitation (usually related to spasticity management) although sometimes not in the context of a multidisciplinary service. A recent study, commissioned by the NHS SDO programme,¹⁶ suggests that there is no consistent service model for neurological rehabilitation across the UK.

In the community, effective models for joint working between RM and General Practitioners are constantly evolving, as recommended in a recent Joint Statement from the Royal Colleges of Physicians and General Practitioners.¹⁷ The connectivity between RM and community services, including social services, improves the ability to support people with long-term neurological conditions efficiently.¹⁸

7. Policy relevance

Neurological rehabilitation services meet the requirements of each domain of *Better Standards for Health*:

- **Safety** Prevention of unnecessary disability through early interventions.
- **Clinical and cost-effectiveness** Focus on self-management, avoidance of costly hospital admissions, facilitation of hospital discharges.

- **Governance** Led by consultants in RM working within a specified set of specialist competencies.^{19,20}
- **Patient focus** Involvement of service users in planning and delivery of services; self-management through education, advocacy of the NSF for Long-Term Neurological Conditions.
- **Accessible and responsive care** Community-orientated with provision of home visits where appropriate.
- **Care environment and amenities** Many services delivered locally or in the home, at point of need.
- **Public health** Implementation of strategies for tertiary prevention, working with other agencies such as employment services and education.

Community-orientated work is in line with the National Service Framework (NSF) for Long-term Neurological Conditions,¹ the White Paper *Choosing Health*²¹ and the Green Paper *Independence, Well-being and Choice*.²² Specialist rehabilitation helps people with long-term conditions to lead healthier lives, a key objective of the NHS Improvement Plan (2004)²³ and of the Health and Social Care White Paper, *Our Health, Our Care, Our Say*.²⁴ Using a community-orientated service model, RM contributes to this agenda for people with some of the most complex conditions. As highlighted in a recent BSRM report,²⁵ one of the core activities for RM consultants is helping people with complex disabilities retain or regain employment, and they are well positioned to make a major contribution to the new policies for employment as described in *A New Deal for Welfare: Empowering People to Work*²⁶ in the inter-departmental strategy *Health, Work and Well-being*²⁷ and in the NHS Next Stage Review²⁸.

8. Commissioning issues

Commissioning processes The pathways for commissioning low volume high-cost interventions for both in and out patient services are relatively complex and often slow. Commissioning difficulties have been reported in specialist out-patient services, vocational rehabilitation, and complex specialist in-patient services such as referral to specialist units.

Commissioning discussions, particularly at primary care level, are hampered by lack of clarity about distinctions between general and specialist rehabilitation (also between long-term neurological conditions and long-term conditions in general). In line with the recommendations of the NHS Next Stage Review²⁸, there is a need for consultants in RM to be linked more closely with their commissioning colleagues in order to clarify specialised clinical issues.

Bed availability The Royal College of Physicians recommends 60 RM beds per million population with a minimum size of 20 beds per unit.²⁹ Currently the average provision is about 40 RM beds per million population. A survey of the BSRM membership showed that units satisfied with their bed establishment had, on average, about 7 beds/100,000 population. Spinal injury units perceived a need for about 1 bed/100,000 population.

Over a third of units state that increased bed numbers would shorten the waiting lists. Because Neurological Rehabilitation beds are lacking, many patients are 'repatriated' from neuroscience centres to general medical wards in district hospitals while awaiting transfer for specialist rehabilitation. This frees up neurosurgical beds but leads to inappropriate management and lengthens total length of hospital admissions, typically by about 4 to 6 weeks, so that patients are exposed to the risks of hospitalisation without making progress.

Discharge pathways The BSRM survey found that arrangements for community discharge of people with brain injury are only considered to be 'good' for 42% of units, including 4% that provide their own outreach teams. Other units are finding discharge to the community difficult, mainly because of poor collaboration from social services or because services are disjointed. Delays in discharge inevitably result in delays for admission.

Access to complex specialised neurological rehabilitation The physical, cognitive and behavioural effects of brain injury pose highly complex challenges for rehabilitation. Two-thirds of units will accept patients with some behavioural problems though usually with limitations such as requirement for onward referral for severe cases (76%). Less than half of units are able to manage mobile cognitively impaired patients. Many specialist units lack resources to deal with challenging behaviour and complex cognitive difficulties, where mental-health trained nurses and high levels of psychology input are required. Only half of units have sufficient psychology input. Only one third of units accept patients in vegetative/minimally conscious states. The waits for many complex specialised services, e.g. specialist cognitive rehabilitation, specialist behavioural rehabilitation, rehabilitation for low awareness states and specialist vocational rehabilitation are long.

Shortage of consultants in Rehabilitation Medicine The Royal College of Physicians recommends a minimum of 6 RM Consultants (WTE) per million population, including 3.6 WTE for inpatient and standard outpatient services, and 2.4 WTE for community provision. Additional consultants are required to serve patients with highly complex needs.²⁹ The present consultant level is about two RM consultants per million population. Two-thirds of consultants in rehabilitation units are in single-handed practice, posing problems from both clinical governance and training perspectives. The recommended number of consultants per 10 beds is about 1.4 for complex specialised and 1.1 for specialist services. As many as 8% of units, mainly run by part-time consultants, have no medical support staff.

Development of community services is currently hampered by the shortage of consultants. As a result, teams described as community neurological rehabilitation services may lack any specialist medical support. The negative effects of this situation for community rehabilitation services was highlighted in *The Way to Go Home*.¹⁴

UK provision of RM lags far behind that of Europe's largest economies.

	France	Germany	Sweden	Italy	UK
Number of RM specialists	1760	1571	160	2200	152
Number of RM trainees	125	65	20	350	57
Specialists (all types) per 100k	155	327	207	271	36
Specialists (RM) per 100k	2.9	2.0	1.9	3.7	0.2
RM as % of all specialists	1.87	0.61	0.92	1.36	0.55

Source: UEMS³⁰

Outcomes There is an urgent need to develop a framework of outcomes which validly reflect specialist rehabilitation activity. The BSRM has established a basket of outcome measures and will be developing these further for use in the outpatient and community settings as well as in hospital units. Outcome measures are required as commissioning benchmarks and will increase the potential for best practice to be spread through the regions, aided by initiatives such as the Commissioning for Quality and Innovation (CQUIN) scheme²⁸.

Costing If Payment by Results fails to identify the additional costs of **complex rehabilitation** (as opposed to **'general' rehabilitation** - see Section 2 above), the effects on neurological rehabilitation will be devastating nationwide. The following notes summarise the current position:

- The DoH is moving towards using HRGs v 4 for payment for core HRGs in 2009/10
- Rehabilitation HRGs are **'unbundled'** HRGs. The DoH currently lacks sufficient costing information to price these. They are not expected to go to tariff until 2011/12. HRGs v 4 specifically exclude **'complex specialised rehabilitation'** which will be subject to specialised commissioning, defined as **'Brain Injury and Complex Rehabilitation'**.
- A national research and development project has been funded by the DoH to develop case mix in neurological rehabilitation, supported by the BSRM and the Information Centre. A national database will collect case episodes from complex specialised and specialist

services. Data on needs, inputs and outcomes for rehabilitation services in England will be collated.

In the ongoing development of costing frameworks for long term conditions, it is essential that the complexities of outpatient and community neurological rehabilitation are taken into account. For example, consulting with people with impairments in speech, cognition, behaviour and mobility, along with their families and other agencies involved, is a much more time-consuming process than is accounted for in a standard medical outpatient service model.

Accounting for work across agency boundaries The effectiveness of neurological rehabilitation depends crucially on co-working with other agencies such as social services; conversely, cost-effectiveness of rehabilitation interventions is often registered outside the NHS, so that PCTs may lack the financial incentives for appropriate investment in services. The NHS Next Stage Review initiates a whole-systems approach through the establishment of Integrated Care Organisations (ICOs)²⁸. This development should bring large benefits to neurological rehabilitation services.

References

1. Department of Health. *National Service Framework For Long-Term Neurological Conditions* 2005 www.dh.gov.uk/longtermnsf
2. Royal College of Physicians and British Society of Rehabilitation Medicine. *Rehabilitation following acquired brain injury: national clinical guidelines* (Turner-Stokes, L ed). London: RCP/BSRM 2003
3. NICE. *Guideline on the Management of Multiple Sclerosis in Primary and Secondary Care*, 2004
4. Royal College of Physicians *Medical Rehabilitation for people with complex disabilities*. London 2000
5. Royal College of Physicians *Physical Disability in 1986 and beyond*. London, 1986
6. World Health Organisation *International Classification of Functioning, Disability and Health*. 2001 <http://www.who.int/classifications/icf/site/>
7. Langhorn P, Williams BO Gilchrist W, Howie K. Do stroke units save lives? *Lancet* 1993;**342**:395–398
8. Turner-Stokes L Evidence for the effectiveness of rehabilitation following acquired brain injury: a synthesis of two systematic approaches' (*accepted for publication, J Rehab Medicine*)
9. Freeman JA, Langdon DW, Hobart JC, Thompson AJ. The impact of rehabilitation on disability and handicap in progressive multiple sclerosis: Randomised controlled trial. *Ann Neurol* 1997;**42**:236–244
10. Barnes MP, Radermacher H. *Community rehabilitation in neurology: a summary of the evidence of the efficacy of community rehabilitation*. Cambridge: Cambridge University Press, 2003.
11. Turner-Stokes L, Paul, S, Williams H (2006). Efficiency of specialist rehabilitation in reducing dependency and costs of continuing care for adults with complex acquired brain injuries *J Neurol, Neurosurg and Psychiatry* 2006; **77**: 634-639
12. Turner-Stokes L. Cost-efficiency of longer-stay rehabilitation programmes: Can they provide value for money? *Brain Injury* 2007 **21**:1015-21.
13. Turner-Stokes L. The evidence for cost-effectiveness of rehabilitation following acquired brain injury. *Clinical Medicine* 2004 **4**: 10-12
14. Audit Commission. *The Way to Go Home* 1999 <http://www.audit-commission.gov.uk/reports/>
15. Black A. *The Future of Acute Care*. NHS Confederation 2006 (ISBN 1 85947 121 8)
16. Gladman J et al. *Specialist Rehabilitation For Neurological Conditions: Literature Review And Mapping Study* Research Report for NHS Service Delivery and Organisation Programme **2007**
17. Royal Colleges of Physicians and Royal College of General Practitioners. *Making the Best Use of Doctors' Skills - A Balanced Partnership*. London 2006
18. Ward CD, Phillips M, Smith A and Moran M. *Multidisciplinary approaches in progressive neurological disease: can we do better?* *Journal of Neurology Neurosurgery and Psychiatry* 2003 **74**:iv8
19. Rehabilitation Medicine Training Curriculum <http://www.jrcptb.org.uk/Specialty/Pages/default.aspx>
20. Turner-Stokes L. Clinical governance in rehabilitation medicine. The state of the art in 2002. *Clin Rehabil* 2002;**16**(Suppl 1):13–20
21. Department of Health. *Choosing Health: Making Healthy Choices Easier* 2004 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4094550
22. Department of Health. *Independence, well-being and choice: our vision for the future of social care for adults in England* 2005 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4106477
23. Department of Health. *The NHS Improvement Plan : Putting people at the heart of public services* 2004 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4084476
24. Department of Health. *Our health, our care, our say: a new direction for community services* white paper 2006 <http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Modernisation/Ourhealthourcareoursay/index.htm>
25. British Society of Rehabilitation Medicine. *Vocational Rehabilitation – The Way Forward (2nd Edition): Report of a Working Party* (Chair: Frank AO). London 2003
26. Department for Work and Pensions *A New Deal for Welfare: Empowering People to Work* 2006 http://www.dwp.gov.uk/welfare-reform/empowering_people_to_work.asp
27. Department of Health, Department for Work and Pensions and Health & Safety Executive *Health, Work and Well-being: caring for our future* 2006 http://www.dwp.gov.uk/publications/dwp/2005/health_and_wellbeing.pdf
28. Department of Health. *High Quality Care for All: NHS Next Stage Review Final Report* 2008 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825
29. Royal College of Physicians. *Rehabilitation Medicine in: Consultant Physicians Working With Patients*. 2008 in press Edition 4.
30. Gutenbrunner C, Ward AB, Chamberlain M.A. (Eds) *The White Book of Physical & Rehabilitation Medicine in Europe*. *J Rehab Med* 2007 **41** (Suppl. 1)