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# British Society of Rehabilitation Medicine Response to the Department of Health A New Ambition for Stroke – Consultation on a National Strategy

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## Summary

The BSRM welcome the stroke strategy and agree with many of the recommendations. The BSRM would specifically like to make the following points which summarize our position.

- The BSRM feel that Rehabilitation Medicine has a vital role to play in the immediate and long term needs of individuals who have suffered a stroke. We would emphasize the substantial role that RM specialists contribute to stroke services, and also the important role we play to identify, champion and maintain expertise within community teams, and the need for seamless rehabilitation through to vocational services

- Younger stroke survivors do have particular needs in addition to those of the older stroke population. Other people may be economically dependent on them, and they may have other social roles including parenting. Those of working age will suffer extreme financial disadvantage if they are not able to return to work and therefore return to work has to be a priority. The BSRM know that, in comparison to other European countries, the UK does badly in this, with an expectation that individuals will not return to work. **Expert vocational rehabilitation for those with stroke has to be a priority.**

- The BSRM are concerned that multi age stroke units will adopt a culture which is in keeping with some of the practices and values of the care of older people and therefore the needs of younger people will be overlooked. In addition, the level of ambition for younger stroke survivors will be forgotten. It is thus important to treat those who are young within a service, which has a specific remit to manage younger disabled people. Proper discharge planning should be practiced, so that social care is well aware of the potential needs of any individual several weeks prior to discharge.

- Improving discharge planning requires resources for adequate continued rehabilitation once they are home. All stroke patients (irrespective of age) should have access to outpatient specialist rehabilitation following discharge from

hospital, including spasticity management where necessary. The BSRM would stress the importance of a community rehabilitation team, which should have medical and psychological components. Ideally all community based stroke rehabilitation services should have consultant input.

- **It is essential that any government policy makes an appropriate distinction between the concepts of care and rehabilitation. The latter is a time limited, goal orientated, and multidisciplinary activity, based on expert evaluation and delivered in a timely and patient orientated fashion.**

- The BSRM do not think that the needs of carers are adequately considered. We would highlight the specific needs of families of younger stroke patients who may be still economically active, or be caring for children, or indeed elderly parents. A full analysis of the best way of meeting the needs of carers may be beyond the scope of the Department of Health alone. It will require joint working between Health and Social Care for the benefit of carers.

- Access to psychological support is vital. The BSRM believes that every patient admitted to a Stroke Unit should have access to the expert opinion of a Neuropsychologist if a cognitive impairment is suspected or a Clinical Psychologist if psychological factors are prominent. All professionals in the rehabilitation unit (often the nurses who are the closest to the patient) should be able to identify mood disturbances associated with stroke. All rehabilitation professionals need to be knowledgeable about services for psychological support in the community.

- More can be done to improve joint working across services. This includes closer working between neurological stroke services and rehabilitation services.

**Introduction**
The British Society of Rehabilitation Medicine welcomes the investment of the Department of Health in Stroke Services. Stroke is the most important cause of severe acquired disability within the adult population.

Stroke is an important condition which falls within the remit of The NSF for long term neurological conditions[1] which set standards for Rehabilitation Medicine. Although is has been said that the NSF does not cover stroke, because this is covered by the Older People's NSF, the Older people's NSF did not cover young strokes, so these were included in the NSF for LTnC under the heading of 'Acquired brain injury of all causes', which specifically includes cerebro-vascular accidents, trauma, inflammation, anoxia and a number of other aetiologies.)

Rehabilitation Medicine is a specialty that is concerned with the prevention, diagnosis and treatment and rehabilitation management of people with disabling medical conditions. It was developed primarily to meet the needs of Young Adults of working age but aspects of the specialty relate to disabled people of all ages.

Rehabilitation Medicine covers a large number of disabling conditions but the majority of rehabilitation services in the United Kingdom practice neurological rehabilitation and therefore have considerable experience of the rehabilitation of individuals with stroke. The BSRM covers a wide variety of neurological conditions. Besides stroke, these include Traumatic Brain Injury, Spinal Cord injuries, and chronic progressive conditions such as Multiple Sclerosis. There are a number of other less frequent neurological conditions including congenital conditions arising from childhood and other rarer conditions that require the specialist input of a Neurological Rehabilitation Service.

The BSRM agree with the premise that in the UK '*Wespend more money than most on stroke services -yet overall, we have worse outcomes*.' This may be related to the fact that the UK has the lowest number of Rehabilitation Medicine consultants in Europe and hence, possibly the most inadequate scope for specialist development of services for multidisciplinary rehabilitation of neurological conditions, such as stroke.

A major concern of many consultants in Rehabilitation Medicine is that while many trusts are currently responding to the call for organised stroke care, this may result in diversion of resources away from services for individuals with other serious neurological conditions. Many of these have similar needs and people with neurological conditions other than stroke may be somewhat disadvantaged by the adoption of a single diagnosis type stroke strategy.

The BSRM are aware of a number of nationally recognised documents setting standards which are relevant to stroke rehabilitation. These include National Clinical Guidelines for Stroke[2], Acquired brain injury[3] and Vocational rehab[4]. The BSRM suggest that any stroke service should adhere to these guidelines.

To respond to the document as it stands, the BSRM is of the opinion that the recommendations around the emergency care of people with stroke are sound. The BSRM would support the use of urgent brain imaging and clearly there is a role for

thrombolysis in a minority of around 10% of individuals with acute stroke who would be suitable for thrombolysis.

**Stroke Units**

The BSRM agree that rehabilitation should start from day one. In particular The BSRM feels that certain issues should be addressed including the person's psychological and social needs. Their domestic environment and the presence of other pathology should all be documented and addressed at the beginning of the rehabilitation process. The BSRM would be reluctant to see the diversion of resources away from stroke rehabilitation care into acute care of stroke for a minority of people. The BSRM see one key role of the rehabilitation physician as providing an input in stroke units to educate staff on rehabilitation issues, prevent secondary disability and to be involved from the start the rehabilitation process.

About one third of people who have stroke will remain with significant disability and one third will die from the stroke. Therefore up to 50% of stroke survivors are going to have a degree of disability and these people should be entitled to high quality stroke rehabilitation care.

Stroke Unit care should be delivered by a specialist Multi Disciplinary Team, but the emphasis should be made on inter disciplinary working which is centred on patients' own goals and creates a goal orientated approach, which blurs the distinction between different professions. This allows generic rehabilitation workers such as rehabilitation assistants to work between different specialties in order to meet the patient's individual needs.

The BSRM call for high standards in stroke rehabilitation and would wish to draw attention to the BSRM standards for inpatient and outpatient rehabilitation[5, 6], which should apply to all units that describe themselves as offering rehabilitation. Rehabilitation must be intrinsic to the stroke pathway and never seen to be "added on" to acute stroke care. There is strong evidence for effectiveness of rehabilitation, which is summarized in a critical review published in Clinical Rehabilitation in 1999: [7], and subsequently a Cochrane review: of multidisciplinary rehabilitation for adults with ABI (mainly stroke)[8]. Although not inexpensive there is also good evidence for the cost-effectiveness of rehabilitation, including within a review of cost effectiveness literature[9], and also trial data of the cost efficiency of longer stay rehab in people with complex needs[10] [11].

A good team is characterised by strong leadership, which is prepared to understand the needs and skills of individual members of the multi disciplinary team and to respect and listen to their individual opinions. Therefore any Doctor who is taking charge of a stroke unit should have documented competencies in the specialist rehabilitation of individuals with stroke including certain specialist technical knowledge. It is insufficient for a doctor working on a stroke unit to simply have knowledge of the treatment of medical complications.

**Life after Stroke**

Turning to Chapter 2 and Life after Stroke the BSRM would support a culture where disability after stroke is not considered inevitable. The functional outcome should be regarded as dynamic and ameliorable by good clinical care and rehabilitation treatment.

It is true that currently only half of stroke patients receive sufficient rehabilitation in the first six months following discharge from hospital. This is one of our prime causes of concern. One area of great concern is the early discharge of patients from hospital to the community in the absence of well developed community based rehabilitation teams.

There is good evidence that generic community teams are less effective than specialist community based neurological teams or stroke teams. Patients should not be discharged early from hospital unless adequate community-based rehabilitation is there. The BSRM are concerned that, where community based early discharge support teams are in place they often lack medical leadership support and direction. Many of the medical complications such as post stroke pain, spasticity, long term mood disturbance, long term problems with continence are therefore not being addressed adequately in the community.

The BSRM are concerned that although a Stroke Unit will meet the needs of the majority of patients there will be some patients for whom it is not appropriate to be on a generic stroke unit. Examples of this include people with multiple pathologies which prevent their active participation, and those for whom palliative care is more appropriate. On the other hand The BSRM would suggest those that have specific cognitive problems (for instance as a result of a subarachnoid haemorrhage from an anterior communicating artery aneurysm) should be looked after alongside people with a traumatic brain injury, as their needs have much in common. In particular, adequate access to Neuropsychology should be mandatory for all people in this position.

There is a particular problem with strokes in the younger adult (under the age of 50). Although it may be appropriate for them to be in an acute stroke unit, adequate neurology input is essential. Many of these people would be best served on a Neurological Rehabilitation Unit where others are of a similar age. and there is specialist expertise related to support of people in this busy time of life. The implementation of stroke services should have seamless working relationships with local neurological rehabilitation services.

Stroke care should be characterised by close working between individuals of different specialties, no present specialty has sufficient expertise to treat all stroke patients at all phases of their patient career. Even with the advent of specialist stroke physicians as a sole specialty there will always be patients who require expert analysis of their clinical condition in terms of their rehabilitation potential. The core skill of a rehabilitation physician is to diagnose the exact configuration of physical, medical, cognitive, psychological and social components which are determining a patient's condition, and to undertake correct medical management.

Finally there is a specific group of people who have brain stem strokes who have 'locked-in syndrome' who will require the services of a specialist neurological rehabilitation unit and specifically the use of assistive technology and specialist assessment methods for communication and again these people should be looked after in an appropriate setting.

**'Making sure that the newer technologies are used** '

Patients in the UK are seldom able to access new technologies such as Functional Electrical Stimulation, walking with a Space-trainer and constraint therapy to induce more activity in the arm (all are of proven value) for stroke patients of any age. It is immensely difficult to bring research findings into practice. Thus, it is known that the brain has great powers of plasticity, maximal shortly after the insult yet, almost without exception, patients with stroke or any other neurological disability do not get optimally intense therapy (even if the therapists give quality therapy).

**Vocational Rehabilitation**
The BSRM are pleased that Section 8 includes vocational rehabilitation, as services for people who have stroke in the UK in this area are poorly developed. The BSRM has a Vocational Rehabilitation Special Interest Group which educates individual clinicians and campaigns nationally for the implementation of Vocational Rehabilitation Services. The BSRM feel that as Vocational Rehabilitation is a specialist area of interest for Consultants in Rehabilitation Medicine, adults of working age should normally be referred to their local Rehabilitation Medicine service.

The BSRM supports the recommendations regarding driving and again assessments of suitability to drive is an area of expertise for the Rehabilitation Medicine specialist.

**Care in the Community**
The BSRM agree that health and social care services should work together to ensure there is a plan for individuals leaving hospital. The BSRM condemn the trend for individual patients who require a care package to be left in hospital for prolonged periods of time while care packages are awaited.
The BSRM would value a change in culture by which specialist stroke and rehabilitation services were seen to be a valuable resource on a par with intensive care units by both commissioners and social care providers.

Although early supported discharge is desirable, The BSRM are concerned about the lack of resource within the community, and the lack of specialist expert medical input for such teams. The BSRM therefore do not feel that this is a proposal which can reach its full potential until primary care trusts are forced to commission appropriate services. The BSRM respectfully point out that many people are being discharged prematurely into the community with a greater level of disability than if they received further inpatient rehabilitation and achieved a higher level of functioning. This is both wasteful of social care resource in the community and is of severely detrimental to the individual, (and indeed is extremely cost ineffective).

**There is confusion throughout the document between care and rehabilitation.**

Care is about support in an essentially static situation.

Rehabilitation is a dynamic process concerned with enabling the person to reach their goals by enhancing their function. It is usually considered to be time-limited and goal oriented but it is important to recognise that repeated episodes are usually necessary in a long-term condition, which may change over time.

**Getting home**

We get the goals right if we use the International Classification of Function with its recognition that disease leads to impairments such as spasticity, pain, poor range of movement at a joint, weakness .This leads to disability or loss of function (such as inability to manage activities of daily living, tasks associated with a job such as use of the computer, driving). Finally these lead to loss of participation and this is at various levels such as family commitments, local community, social networks and employment. Good interdisciplinary rehabilitation acts at all these levels

**Long Term Rehabilitation**

In terms of long term rehabilitation The BSRM point out that many consultants in Rehabilitation Medicine do provide outpatient services for those with established disability. Therefore, GPs should have ready access to consultants in neuro disability for individuals who have had stroke some time previously. They can help to alleviate stroke-related complications. The GP should have access to further reassessment of an individual's further rehabilitation potential. Specialist Review needs to be done by a person with knowledge of the disabilities associated with stroke and knowledge of what interventions work as opposed to only a general medical review. In addition to formal rehabilitation services, there is a wide range of community based opportunities. These include stroke clubs, aphasia groups and charitable organisations as well as the voluntary sector. These should be complementary to, not replacing statutory services.

The BSRM believes that a culture of social care provision should not just attend to personal activities of daily living but should look towards improving further participation in the community including the engagement of personal assistants.

It is important to acknowledge the wide age range of stroke patients. It should not be simply assumed that the majority of people who suffer stroke are above the age of statutory retirement. Not all stroke patients will have similar needs and expectations. It is our belief that certain resources should be ring fenced for the younger stroke patients who have quite legitimate expectations of both social participation and may have dependents who remain reliant on them.

One area of expertise which practitioners of Rehabilitation Medicine are involved in is the assessment of spasticity. The BSRM would like universal access to expert evaluation and treatment of spasticity, including the appropriate use of botulinum toxin therapy for focal spasticity. This should be provided at least on a regional basis, but ideally on a district basis.

The BSRM believes that all individuals should have access to expert provision of a wheelchair appropriate to their needs. This includes special seating and postural management solutions and those people should have access to an expert consultant opinion when required. Electric powered indoor/outdoor wheelchairs (EPIOCs) have been shown to increase quality of life of people of all ages and yet some London boroughs have not one single person who has had a stroke who is an EPIOC user (Frank AO - unpublished data).

The BSRM submits that individuals who have suffered a stroke should have adequate access to long term provision of orthotics (both for upper and lower limb). Again the provision of orthotics should not simply comprise the provision of equipment but should allow the individual to access expert services in terms of an adequate assessment of

their orthotic needs. This may include access to gait analysis and to other treatment modalities such as functional electrical stimulation for spastic foot drop, in those who require it.

The provision of appropriate upper limb splinting for those with spastic deformity in the upper limb and/or upper limb contracture should be a right of every individual who has long term disability as a result of stroke.

Individual Primary Care Teams including District Nurses should have an adequate care plan for prevention of contracture and deformity and should have adequate training to know when to refer for more expert assessment and advice.

Finally, The BSRM believes that individuals who reside in Nursing Homes as a result of their neuro disability from stroke should have equal access to medical care and further rehabilitation as those living in the community. The BSRM submits that unnecessary complications such as pressure sores and contractures should cause concern within care standards inspections. Stroke should be regarded as a condition which is an exemplar for assessing quality of care within nursing homes.

The BSRM would agree that rehabilitation is needed for months, even years and should be provided by Specialist multidisciplinary teams. Those with an acute stroke need an acute stroke unit. After the acute phase the literature shows that specialist multidisciplinary inpatient rehabilitation in either a stroke rehabilitation unit or a neurological rehabilitation unit is effective.

Whilst it is clear that the clinical network is a useful concept, it must be designed (like the cancer network) to provide for rarer conditions as well as common ones. The needs of those with rarer conditions such as Cerebral palsy and a variety of congenital and degenerative conditions needs to be considered and a generally provided for in Neurological rehabilitation units. These are part of a neurological network in many areas

The BSRM agree it would be ideal to have 7 day rehabilitation but therapy staffing is inadequate, and there are services within acute hospitals without an Occupational Therapist. This gives rise to problems for individuals who already have disability as a result of a stroke. For example, if someone with a stroke is admitted for urgent surgery he/she is likely to become more dependent as he/she remains in bed as a consequence of the acute but unrelated problem.

Post-stroke discharge can be managed most effectively if there is a combination of Intermediate care (for 6 weeks ), or a local stroke or neurological community team and a facility (Such as Leeds Community Rehabilitation unit ) for treating those with complex needs as an inpatient for a short period of goal–oriented rehabilitation (so called top up).

**Getting to stroke unit**

One of the outcomes which might be used is the effect on disability level at discharge, comparing the rates before introduction of thrombolysis and after. The BSRM are concerned about the diagram on p22; Rehabilitation is not synonymous with care. It comes first and should be separated from it. In evaluating services, change in

dependency levels before and after rehabilitation would be a good indicator of success and what the person with stroke wants.

The BSRM agree that a person with stroke can continue improving for at least a year and stopping rehabilitation at 3 or 6 months is often too early. If commissioners wish to reduce dependency costs they will need to support rehabilitation at all stages of the patient journey and not make a choice between them. Intensity of rehabilitation will reduce later dependency costs. The BSRM would argue that stroke can be regarded as a tracer condition for acquired brain injury. Service capacity is often insufficient for the need. It seems that for much neurological rehabilitation the capacity base has not increased with the recent increase in NHS funding, but has decreased as monies have gone to other areas.

**Conclusion**

Finally, the single most important point of this paper is the need for injection of new resources in order to manage the transition towards universal availability of proper stroke units. Existing resources are inadequate and The BSRM are concerned that existing specialist rehabilitation services will be undermined, as resources are channeled into stroke care to the detriment of the rehabilitation of other conditions.

The BSRM are concerned about the lack of training posts for newly qualified physiotherapists and feel that this will act to the detriment of future stroke care. This needs to be addressed on an urgent basis.

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**Footnote**

One of the authors of this response, (RK) is presently involved in the Royal College of Physicians Stroke Sub Specialty Training Committee in defining the competencies for stroke physicians.