

Rehabilitation Following Traumatic Brain Injury: Challenges and Opportunities

Background

The principles underlying the rehabilitation needs for patients with head injury have been recognised since the Second World War.¹ Since that time, numerous official reports have highlighted major deficiencies in service provision and make similar recommendations for an integrated service. However, recent national reports^{2,3,4,5} and a comprehensive survey in the Eastern Region⁶ have still found that whilst there are models of excellence, core service provision in the UK remains variable, inequitable and under-resourced. This is acknowledged and supported nationally by those with expertise in, and understanding of, the needs of brain injury survivors, their families and carers from across the spectrum of health and social services, and voluntary agencies.

Traumatic brain injury is the leading cause of disability in people under 40 years of age, and severely disables 150-200 people per million annually. It is now estimated that 200 - 300 per 100,000 of the population have a significant disability as a result of head injury. Survival rates following severe brain injury have improved dramatically in recent years due to advances in acute care, potentially increasing the requirement for rehabilitation.^{7,8,9} The majority of head injuries, however, are designated as minor and moderate and after initial management there is little or no follow up and support, yet recent studies show that a significant proportion of these may suffer persisting symptoms after what appears to be a minor injury.¹⁰ The need for comprehensive and effective rehabilitation programmes for these individuals is therefore ever increasing. Moreover, these patients can suffer considerably and there can be a significant economic impact in terms of delayed return to work and normal activities.

Rehabilitation medicine is a relatively new specialty, having been recognised as a separate discipline only in the past 20 years, and as yet there are relatively few trained rehabilitation specialists. Although it has traditionally been a low profile medical speciality, attitudes are changing and the importance of early rehabilitation interven-

tion to optimise the long term outcomes of head injury is now increasingly recognised. There have been a number of recommendations for neurorehabilitation, and the process of developing guidelines is ongoing, the most recent being the national guidelines for rehabilitation following acquired brain injury which seek to address the complex and three-dimensional nature of rehabilitation.¹¹

This review describes some of the challenges presented in planning and delivering effective rehabilitation services to head-injured patients and explores solutions and opportunities in the light of current development of the National Service Framework for Long-term Neurological Disabilities, which sets a national framework to enable local development, implementation and commissioning of services.¹²

Challenges

A number of challenging issues have been identified, defined and explored by the Eastern Head Injury Study in relation to neurorehabilitation, in particular the assessment of the organisation and clinical management of head injury in the Eastern Region. These are, however, common to neurorehabilitation services throughout the UK. Over time, a variety of rehabilitation models have developed across the NHS.

1. Complex needs of head-injured patients

Head-injured patients have complex and varied needs; the nature of disability following head injury is diverse resulting in a complex interplay of problems that can be physical, cognitive, behavioural, vocational or a combination of these, requiring multi-organisational involvement in the provision of rehabilitation. Consequently many specialties, professions and sectors may be involved in the process of rehabilitation, resulting in a lack of, or disjointed, untimely or inappropriate rehabilitation care and ongoing support for many patients. This has led to difficulties in co-ordination and integration of service provision (Figure 1).



Helen M Seeley BA, MSc(Econ), Dip.Lib. is a Clinical Auditor and Researcher in the Department of Academic Neurosurgery, University of Cambridge, at Addenbrooke's Hospital. For the past 5 years she has co-ordinated and carried out research for the Eastern Head Injury Group on developing a regional head injury service framework. Her qualification and expertise is in health information management and her particular interest is in systems analysis and service development. She is currently studying for her doctorate on head injury service planning.



Peter J Hutchinson BSc (hons), MBBS, PhD, FRCS (Surg Neurol) holds an Academy of Medical Sciences / Health Foundation Senior Surgical Scientist Fellowship within the Department of Clinical Neurosciences, University of Cambridge and Honorary Consultant Neurosurgeon post at Addenbrooke's Hospital. He has a general neurosurgical practice with a subspecialist interest in the management of trauma and brain tumours. He has a research interest in traumatic brain injury, multimodality monitoring in neuro-critical care and functional imaging. He is Director of Clinical Studies and a Fellow at Robinson College.

Correspondence to:
Academic Neurosurgery,
Box 167,
Addenbrooke's Hospital,
Hills Road,
Cambridge,
CB2 2QQ, UK.

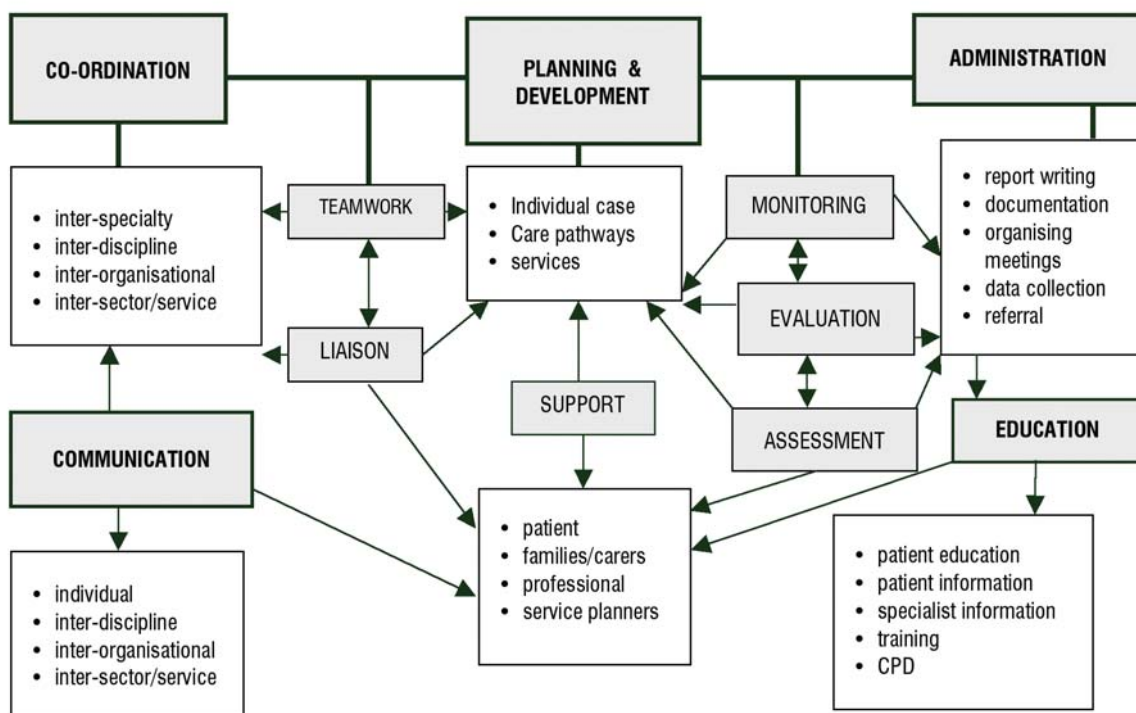


Figure 1: Multiple core skill requirements for co-ordination of Head Injury Services.

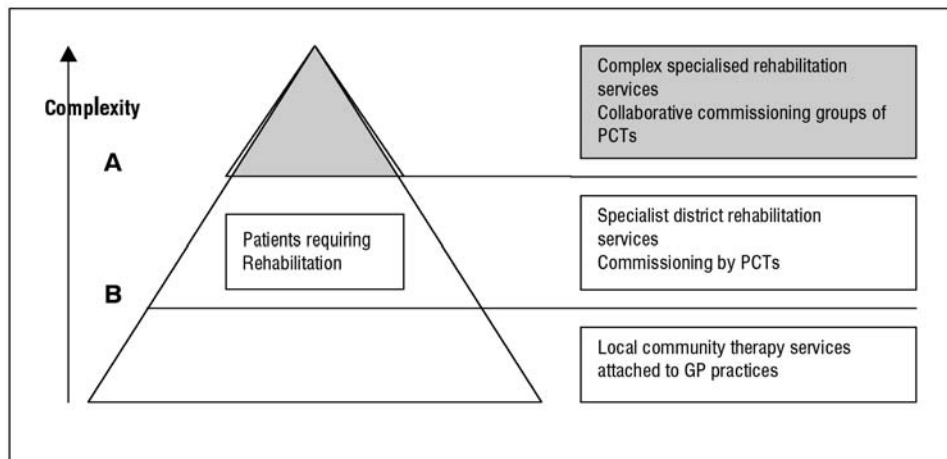


Figure 2: The different levels of rehabilitation service provision (the top tier above A denotes specialised service) From: DOH Specialised Services National Definitions Set (2nd ed.)

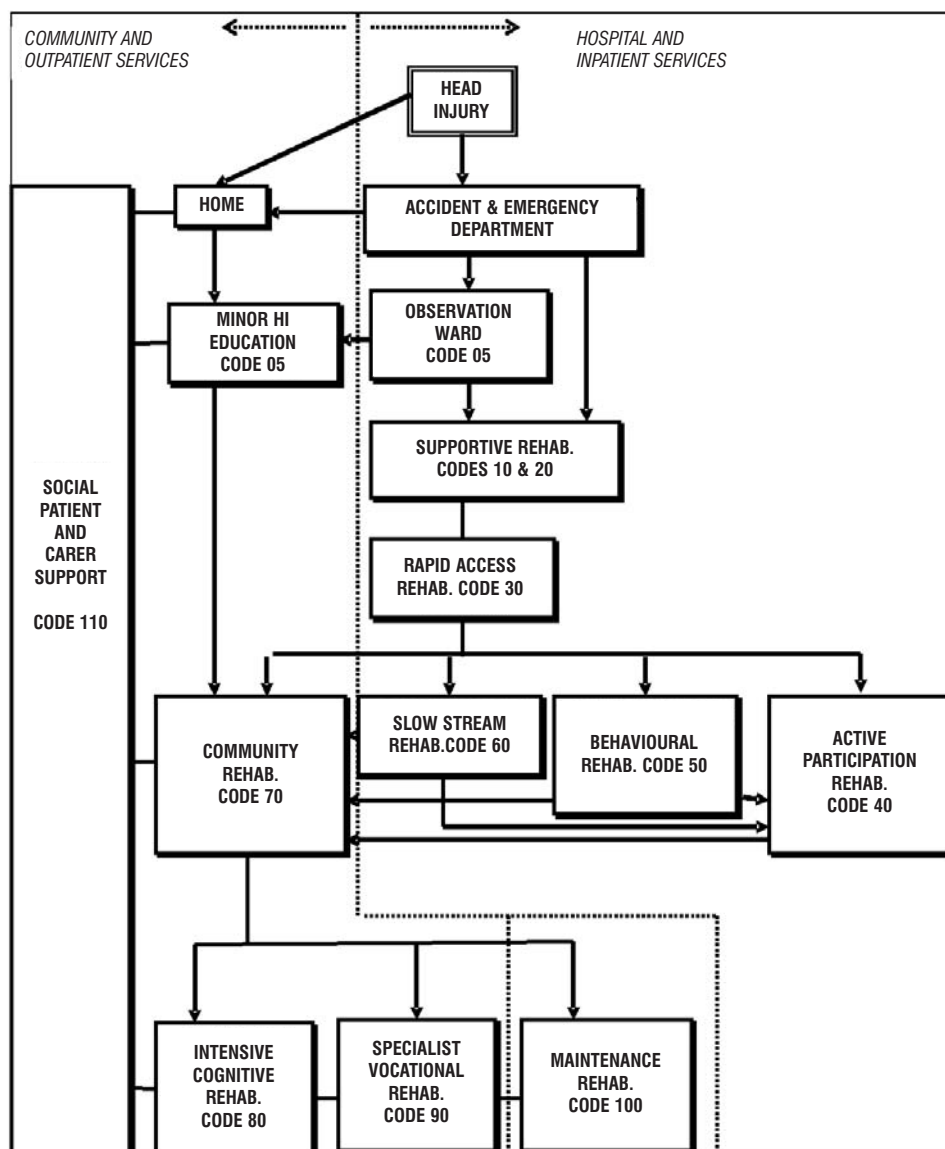


Figure 3: Flowchart of potential head injury rehabilitation services using the EHIG Rehabilitation Codes.

Divisions of service and the ensuing variety in responsibility of care have led to fragmentation of services and poor co-ordination. In addition, there are difficulties within statutory services relating to categorisation of head injury which have resulted in lack of knowledge of the nature and extent of the problems and

poorly defined care pathways for mild/minor, moderate and severe head injuries.

2. Poor resources

In the Eastern Region, the Eastern Head Injury Resource Study found that no area has easy access to the whole range of services that would

constitute a truly comprehensive neurorehabilitation service.⁶ The picture is similar throughout the UK.

While the need for early rehabilitation in an appropriate setting and adequate follow-up is recognised, the variability of facilities and resources often result in ‘bottlenecks’ with delayed and inappropriate referrals. Lack of adequate and appropriate rehabilitation facilities at all stages of rehabilitation can lead to blocked beds in District General Hospitals and inappropriately placed patients (acute admissions of moderate head injuries and repatriation of severe head injuries). Delays in transfer and discharge to each stage of rehabilitation may also be detrimental to the outcome of the head-injured patient. Another effect of blocked beds is the potential delay in elective surgery.¹³ Other resource deficiencies are lack of staff trained in the management of head injury and a national lack of neuropsychologists.

3. Commissioning issues

Bureaucratic and funding barriers may also prevent timely access to appropriate services. Long-term conditions like head injury make care particularly complex, and a small number of patients and diseases account for a disproportionate amount of healthcare use, both inpatient and community, making them high risk/low volume services (Figure 2).

Responses to rehabilitation need to coincide with increased awareness of economic efficiency of health care provision.¹⁴ This must be balanced with need and demand, equitability, efficiency and effectiveness. There are major cost implications in a comprehensive rehabilitation service for head injured patients. However, this should be balanced against the fact that effective rehabilitation may reduce dependence on carers and services over time, and implications for reducing the cost of overall care and impact on the health of carers. Measurable change and recovery may continue for several years post injury, so that rehabilitation services may be required for some considerable time for recovery to be maximised.

There is currently a lack of integration in commissioning services and many of the organisational problems in developing these services arise from this process. There are different levels of commissioning and different agencies are involved in the planning and development of services that require an integrated approach. Matching the level of care to the level of need calls for whole systems approaches to whole populations. The focus must be on service users as the pattern of the rehabilitation stages and process are dictated by the nature of disability. This poses a problem for commissioning head injury rehabilitation as social services commission independently from health.

4. Lack of evidence/research

The importance of evidence in support of demand, need and the effectiveness of rehabilitation for the head injured is emphasised as being particularly relevant with the increasing

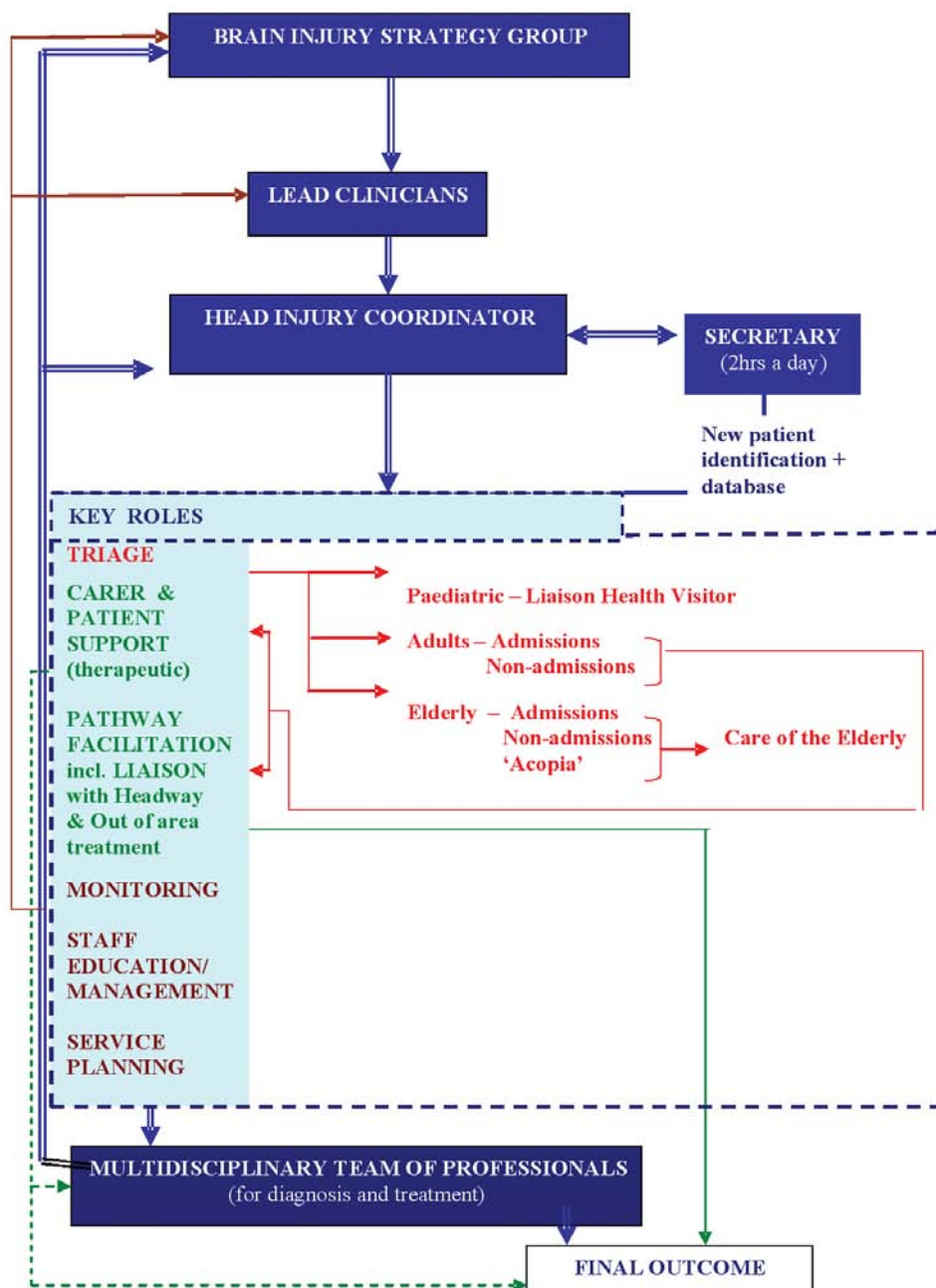


Figure 4: Template for co-ordination of Head Injury Services.

need to justify the use of limited resources within the NHS. However, the treatment of neurological disability is a major challenge for translational research. Complex interactions between the individual and their environment make accurate and reliable outcome measurement difficult. Rehabilitation aims to reduce the impact of head injury by restoration of damaged function or compensation for lost function within the limitations of resources and underlying disease to optimise physical, cognitive, psychological and social function. Measurement of the impact of rehabilitation is therefore difficult. Rehabilitation is a patient-based educational process towards optimum quality of life, yet clinically orientated outcome scales of disability and impairment are most often used and therefore only partially reflect the rehabilitation process.

The greatest burden is from the neuropsychiatric sequelae. However, the emphasis has been on physical rather than cognitive needs in early

assessment post injury. This may explain why unmet need is most evidenced in cognitive and psychological rehabilitation.¹⁵

Opportunities

While the challenges in providing quality neurorehabilitation services are many, the experiences of the Eastern Head Injury Group have shown that with a whole systems, collaborative and stepped approach, systematically working with and integrating new evidence and initiatives and improving co-ordination, there are opportunities for achievable, affordable solutions.

1. Standards, templates and codes

As a result of addressing key issues of variability and gaps in the provision of rehabilitation of head injury, the Eastern Head Injury Group has developed a service framework from initial injury to reintegration into the community, together with a set of planning and evaluation tools collaboratively developed through an iter-

ative process. These consist of a set of Head Injury standards for Acute Hospitals, which complement the Society of British Neurological Surgeons, the National Institute for Health and Clinical Excellence and the National Service Framework,¹⁶ a set of Rehabilitation Definitions which clearly define and map the stages of the rehabilitation care pathway,¹⁷ (Figure 3 and Table 1) and a Head Injury Co-ordination Template (Figure 4), which details the various roles necessary for good service co-ordination, defining responsibilities and an accountability structure. Using these codes has identified a complete lack of rapid access rehabilitation (Code 30) in the Eastern Region.

These practical tools are designed to assist service planners and providers to develop and maintain optimum quality and responsive rehabilitation services and contribute to the growing evidence-base confirming the efficacy of a holistic and interdisciplinary approach to rehabilitation after TBI at the same time enabling services to be tailored to local needs and resources, complementing the evaluation of planning and thinking of the National Service Framework on long-term disabling conditions.

2. Resources

Resources will always be an issue, but the EHIG found that there are elements of services in most areas that could provide the basis for further development. Also mapping of current resources and the use of the rehabilitation codes and co-ordination template can identify gaps and variability to form the basis of business plans and care pathways.

Again, the whole systems and collaborative approach of the EHIG found that reallocation of resources can also be a solution, using the head injury co-ordination template. The development of networks and head injury coordinator-type posts assist co-ordination, develop communication systems and patient care pathways, by working across care settings and professions.

Conclusions

The management of the growing numbers of people with long-term conditions remains problematic. Developing a co-ordinated, personalised service across acute and community settings presents immense organisational and cultural challenges to the whole health and social care spectrum.

The National Service Framework for long-term conditions in the UK¹² describes how timely access to services can be achieved. The Quality Requirements (QRs) are particularly relevant to TBI and rehabilitation and set standards for specialised rehabilitation with markers of good, evidence-based practice. It provides guidance on establishing Neuroscience Networks to co-ordinate a collaborative, multi-agency approach to commissioning equitable services throughout the care pathway. Existing network models such as cancer, cardiac and renal, are good examples. The collaborative working required by networks and the now necessary multidisciplinary approach to the provision of head injury rehabilitation has the potential to facilitate implementation of complex changes and strengthen service co-ordination. This would be achieved

Table 1: Classification of head injury recovery and actual/ potential rehabilitation services for adults in the Eastern Region

Code	Title	Patient description	Sites	Examples	Description of rehabilitation input
05	Minor HI education	Medically stable, requiring 24-48hrs observation prior to community rehabilitation, (as necessary in a small minority) with low probability of acute neurological deterioration requiring neurosurgical advice/transfer	Acute A&E observation ward	Addenbrooke's, Peterborough Bedford	Assessment and observation - education, emotional and social support. Planned discharge home or moves to code 30 at 48 hours
10	Supportive rehab	Medically unstable, requiring neurosurgical or critical care	Acute hospital	Neurosurgical unit	Identifying and addressing early rehab goals before medically stable and transfer of care to rehab team
20	Supportive rehab	Medically unstable, not requiring neurosurgical or critical care	Acute hospital	Acute hospital ward	ditto 10
30	Rapid access rehab	Medically stable, not (necessarily) able to actively participate due to, post traumatic amnesia (PTA), confusion, rejection, low response or awareness.	Acute hospital	National Hospital for, Neurology and Neurosurgery, London, Brain injury services (Current practice: DGH - GSUR, ORTH,NLGY)	Needs inpatient care due to physical dependency & requires continuous clinical assessment (nursing, medical, therapy) in order to facilitate optimal timing for rehab input and detect deterioration in clinical condition (in minority of patients). Immediate early rehab delivered, and judgement made on timing/appropriateness of referral to next rehab sector.
40	Active participation in-patient rehab	Medically stable, able to actively participate with and benefit from therapy.	Acute or community hospital	In-patient rehabilitation unit (Lewin / Colman)	Needs in-patient care due to physical dependency, or need for specialist therapy equipment, safe environment, supervision or intensity of therapy which can not be provided in community
50	Behavioural rehab	Medically stable, but prolonged confusion or behavioural difficulties, amnesia requiring specialist behavioural management, intensive supervision and secure environment	Specialist in-patient unit	Brain Injury Services, Kelmsley Unit, Northampton BI Rehabilitation Trust, M.Keynes, Colman	Specialist behavioural management, including high staffing:patient ratio to ensure intensive supervision and secure environment. Access to neuropsychology and neuropsychiatry
60	Slow stream rehab	Medically stable, but low awareness or response persists beyond eg. 3 weeks after sedation withdrawn and ICP corrected. Able to benefit from medical and physical therapy to prevent complications and support recovery.	Community hospital or specialist in-patient unit	Putney, Wayland, Lincoln	Assessment/active rehabilitation phase which needs to be distinguished from long term care, although planning care increasingly important aim after some (eg. 6) months. Patients may go to active participation unit if they improve sufficiently.
70	Community rehab	Medically stable, able to actively participate with and benefit from therapy. Will include spectrum of initial severity of injury with a small minority derived from Code 05 category	Domiciliary or day hospital	Community rehab team (Icanho, Pboro)	Interdisciplinary co-ordinated management therapy aimed at community re-integration /inclusion by enhancing independence, wellbeing, & assist return to work/education. In collaboration with Social Services, voluntary and statutory services. Includes treatment of patients in residential care or with live-in carers
80	Intensive cognitive rehab	Medically stable, independently mobile, primarily cognitive impairments likely to benefit from intensive neuropsychological therapy	Domiciliary or day hospital	Oliver Zangwill	Aiming to return to work, studies or independent community life.
90	Specialist vocational rehab	Medically stable, living in community, aiming to enter/return to employment	Domiciliary or residential	Papworth Rehabilitation, Rehab UK	Aiming for return to work where this is influenced by physical or cognitive problems or needs residential placement
100	Maintenance	Medically stable, but permanent disability	Domiciliary, residential or nursing home, respite unit	Community therapists, Sue Ryder	Prevent deterioration of physical, emotional and behavioural condition, and long term management of seating, pressure, spasticity etc.
110	Social, patient and carer support	Carer support from initial injury, patient support when able to communicate	All sites	Headway	Developing social skills, stamina, confidence, attention & leisure pursuits, sorting out benefits, day supervision & respite care. Specific attention paid to: Community involvement & integration (further education etc) Personal social development and empowerment Structured daytime activity with the individual's competency framework Information and guidance over a continuum Family support and outreach; Advocacy

by identifying and strengthening existing communication systems, and improving information systems such as the development of clear patient care pathways across care settings and professions.

Recent advances in neuroscience treatments and rehabilitation research has also made considerable strides in the last two decades in developing robust measures at different levels due to advances in neuroscience. The advent of a range of brain imaging techniques such as MRI and PET scanning and advances in cognitive neuroscience have enabled greater understanding of brain damage and neurological recovery. This is revolutionising the measurement of outcome in neurological patients, and new multi-dimensional measurement tools are being collaboratively developed.¹⁸ Also, the research and audit programme carried out in the Eastern Region over the past 12 years demonstrates that the problems of transforming a complex service are not intractable or necessarily costly and the service planning tools developed give opportunities for significant improvements across the UK. Whether the NSF and other strategies provide the necessary resource to deliver these opportunities remains to be seen.

Acknowledgements

The Eastern Head Injury Group members: JD Pickard, Neurosciences Department, Addenbrooke's Hospital Cambridge, UK. P Hutchinson, Neurosciences Department, Addenbrooke's Hospital Cambridge, UK*. H Seeley, Neurosciences Department, Addenbrooke's Hospital Cambridge, UK.

K Haynes, Neurosciences Department, Addenbrooke's Hospital Cambridge, UK.
 K Quinn, Neurosciences Department, Addenbrooke's Hospital Cambridge, UK.
 C Maimaris, Emergency Department, Addenbrooke's Hospital Cambridge, UK.
 S Kirker, Lewin Stroke & Rehabilitation Unit, Addenbrooke's Hospital Cambridge, UK.
 R Tasker, Department of Paediatrics, Addenbrooke's Hospital Cambridge, UK.
 * Peter Hutchinson is supported by an Academy of Medical Sciences/Health Foundation Senior Surgical Scientist Fellowship.

Competing interests: none

References

- Russell W. *Rehabilitation after gunshot wounds of the brain*. Br J Surg War Surg 1947;(War Surg Suppl No1):252-5.
- British Society of Rehabilitation Medicine. *Rehabilitation after Traumatic Brain Injury*. London: Royal College of Physicians, 1998:8.
- Royal College of Surgeons of England. *Report of the Working Party on the Management of Patients with Head Injuries*. London: RCS, 1999.
- Society of British Neurosurgeons. *Safe Neurosurgery 2000*. London: SBNS, 2000.
- House of Commons Select Committee on Health. *Third Report: Head Injury Rehabilitation, 2001*. London: Stationery Office, 2001.
- Seeley H, Maimaris C, Carroll G, Kellerman J, Pickard J. *Implementing the Galasko Report on the management of head injuries: the Eastern Region approach*. Emerg Med J 2001;18:358-65.
- National Institute of Clinical Excellence. *Head injury. Triage, assessment, investigation and early management of head injury in infants, children and adults*. London: NICE, Jun 2003.

- Boyle A, Santarius L, Maimaris C. *Evaluation of the impact of the Canadian CT head rule on British practice*. Emerg Med J 2004;21(4):426-8.
- Patel H, Bouamra O, Woodford M, King A, Yates D, Lecky F, on behalf of the Trauma and Research Network. *Trends in head injury outcome from 1989 to 2003 and the effect of neurosurgical care: an observational study*. Lancet 2005;336:1538-43.
- King N, Crawford S, Wenden F, Moss N, Wade D. *Interventions and service need following mild and moderate head injury: the Oxford Head Injury Service*. Clin Rehab 1997;11(1):13-27.
- Turner-Stokes L (ed). *Rehabilitation following Acquired Brain Injury. National Clinical Guidelines*. London: Royal College of Physicians & British Society of Rehabilitation Medicine, 2003.
- Department of Health. *National Service Framework for Long-term Conditions*. London: Department of Health, 2005.
- Bradley L, Kirker S, Corteen e, Seeley H, Pickard J, Hutchinson P. *Inappropriate acute neurosurgical bed occupancy and shortfalls in rehabilitation: implications for the National Service Framework*. Br J Neurosurg 2006;20(1):36-9.
- McGregor K, Pentland S. *Head injury rehabilitation in the UK: an economic perspective*. Soc Med 45(2):295-303.
- Wade D, de Jong B. *Recent advances in rehabilitation*. BMJ 2000;320:1385-8.
- Seeley H, Maimaris C, Hutchinson P, Carroll G, White B, Kirker S, Tasker R, Steward C, Haynes K, Hardy D, Pickard J. *Standards for head injury management in acute hospitals: evidence from the six million population of the Eastern region*. Emerg Med J 2006;23:128-132.
- Pickard J, Seeley H, Kirker S, Maimaris C et al. *Mapping rehabilitation resources for head injury*. JRSM 2004;97:384-9.
- Academy of Medical Sciences. *Restoring Neurological Function: putting the neurosciences to work in neurorehabilitation*. A report from the AMS: London, March 2004.

The European Association for NeuroOncology

7th Meeting 2006




See you in

Vienna

September 14-17
Hofburg Congress
Centre, Austria

For further information please contact the EANO 2006 Conference Secretariat:

Vienna Medical Academy
 Alser Strasse 4
 1090 Vienna, Austria
 Tel: +43 1 40513830
 Fax: +43 1 4078274
 Email: eano2006@medacad.org
 or visit the webpage:
www.medacad.org/eano2006