PE1179/B

Acquired Brain Injury – National Managed Clinical Network

NHS SCOTLAND

MCN Office
Administration Building
Astley Ainslie Hospital
133, Canaan Lane
Edinburgh
EH9 2HL
Tel: 0131 537 9092

Date: 18th November 2008

Dear Ms Tough,

Re: Petition PE1179.

Thank you for inviting a response to the above petition.

The specific issue raised is the proposal to establish a separate and distinct health and community client category of acquired brain injury (ABI).

As is explained in the petition, the key characteristic of acquired brain injury is the residue of physical and psychological impairments which result in people affected by their injury being a 'poor fit' with existing services.

The National Managed Clinical Network (NMCN) has focused initially on head injury in adults of working age (16-65yrs). Head injury is the most common cause of ABI. The mapping exercise has shown that while there are areas of good practice in some NHS Boards, in many the care pathway for head injury is poorly planned. A copy of the draft report will be forwarded as soon as possible (the final report will be available in early 2009).
In addition to the mapping exercise the NMCN has prepared clinical standards for head injury. The formal consultation on the draft version has just been completed and comments are being addressed. It is hoped that the provision of services to people with head injury and other forms of ABI will improve as a result. A copy of the draft standards is attached.

An objective for the NMCN for next year is to encourage and support the implementation of these standards.

The petition considers the issue of expanding the definition of acquired brain injury to include brain tumour and alcohol related brain damage. The definition they quote is from the Scottish Needs Assessment Programme report of 2000. This definition does not include tumour as malignant tumours represent progressive conditions often requiring palliative care services.

In relation to alcohol and drug-related brain damage, there is already significant recognition of their needs within the mental health service sector. Both these diagnostic groups could be considered forms of acquired brain injury.

At present it seems wise not to include these categories but to focus on single incident non-progressive conditions to help consistency in operational planning and service delivery.

Yours sincerely,

Dr Brian Pentland (NMCN Clinical Lead)

PE1179/B

NHS SCOTLAND

Traumatic Brain Injury in Adults Standards

ABI·NMCN

Acquired Brain Injury National Managed Clinical Network

Traumatic Brain Injury (TBI) in Adults – Standards

Contents

Page

1. Introduction: 5

2. Development of standards 7

3. Standards 11

Standard 1 Organisation of care for people with traumatic brain injury 13

Standard 2 Early/acute management of people with a potential traumatic brain injury 14

Standard 3 Rehabilitation 15
- 3a Rehabilitation referral process 15
- 3b In-patient rehabilitation facility 16
- 3c The rehabilitation team and process 17
- 3d Discharge to the community following in-patient rehabilitation 18

Standard 4 Challenging behaviour 20

Standard 5 People in vegetative & minimally conscious states 21

Standard 6 Information for patients, families and carers 22

4. Appendices

Appendix 1 Steering Group membership 24

Appendix 2 Standards & guidelines references 25

Appendix 3 Evidence base & references 28

Appendix 4 Glossary 31

1. Introduction

1.1 Background to the NMCN

As the human brain controls all our thoughts, feelings and actions, both voluntary and involuntary, when it is damaged the consequences are often complex and variable. Acquired brain injury (ABI) often leads to a mixture of physical, cognitive, communicative, emotional, and behavioural changes with profound consequences for the individual and their family. The person with such complex disabilities requires expertise traditionally based in medicine, mental health and learning disability services but does not fit neatly into any of these categories and so may be denied access to appropriate treatment. ABI rehabilitation is patient or family-centred and involves joint working with social work, educational, vocational and voluntary agencies as well as health professionals.

In 1991 temporary funding was made available to establish a national tertiary rehabilitation service at three units. Two of these were to provide early in-patient rehabilitation at Astley Ainslie Hospital, Edinburgh and Murdostoun Castle, Bonkle in Lanarkshire; the other at the Royal Edinburgh Hospital was to cater to those with severe challenging behaviour. During the ensuing decade a number of initiatives occurred, particularly the establishment of generic or specialist rehabilitation medicine services in a number of NHS boards with in-patient and out-patient components. There have also been a number of welcome developments outside the health service.

However, the Scottish Needs Assessment Programme (SNAP) report of 2000 indicated that the provision of services for brain injured people in Scotland continued to be inadequate and patchy. Amongst their recommendations related to health provision were the following:

- Agreed care pathways are needed by both professional and lay carers.
- Agreed standards of care are needed to complement care pathways
- Professionals and patients need access to better information (e.g. on care pathways, on patient and carer needs, on available services and on care standards)
- Patients and carers urgently need help with the choices and decisions involved in moving through a complex care system.
- Regional centres with expertise in the management of these conditions should be identified as sources of advice and training to extend the availability of their expertise.
- The data currently available to allow planning of services need to be improved

As part of the review of the SNAP report the National Services Division (NSD), a division of NHS National Services Scotland, agreed that the establishment of a National Managed Clinical Network (NMCN) approach would be appropriate to encourage development of services for this population of patients. The Steering Group of the NMCN is composed of stakeholders in the field of ABI management including professionals and patient representative (details available in appendix 1 and via our website www.sabin.scot.nhs.uk).

1.2 Initial focus

The Steering Group agreed that the aim would be to develop standards regarding Health Service provision for people aged 16-65 years with traumatic brain injury. More details on the rationale behind this decision are available via our website but in summary:

Head injury was chosen as it is the most common cause of ABI and the most practical starting point for a mapping exercise. ABI as a result of head injury is referred to as traumatic brain injury (TBI). The second most common cause is stroke and much work has already been done with regard to standards for this group.

The needs of children, particularly those less than 5 years of age, differ from adults and paediatric services for those with disabilities are longer established and usually greater than those for adults. Elderly people with head injury often have other pathologies that may have caused the injury and often complicate subsequent treatment. Thus the initial focus is on individuals **aged 16-65 years** but specific attention will be given to transitional ages of adolescence (where children with persisting problems move on to adult services) and 65 years (when care of the elderly services takes responsibility for some cases.)

For individuals suffering from moderate or severe TBI, the patient journey beyond accident and emergency, may include Intensive Care, Neurosurgery, and Rehabilitation on an in-patient basis. Rehabilitation is the transition from hospital to community care and often includes out-patient or community-based input from health professionals. Many community health resources are delivered from primary care and will be under the auspices of Community Health Partnerships. As the effects of TBI are often life-long, the journey does not end there, with many other agencies involved particularly social work, employment and education and the voluntary sector.

It was agreed that the initial focus of the managed clinical network should be on **health service provision** but with full consultation with and involvement of these other agencies. It is envisaged that the second stage of the network's work will include a shift of attention from the NHS component to the wider aspects and so evolve from a **Managed *Clinical* Network** to a **Managed *Care* Network.**

The NMCN decided to begin with four principal objectives:

- Develop standards of care
- Map out current services for people aged 16 - 65 with TBI
- Identify the educational needs of health care groups involved in the care of people with TBI
- Identify information requirements of patients and carers

This document deals with the first of these objectives - details of the others are available on request or via our website www.sabin.scot.nhs.uk

2. Standards development process

Under the direction of the NMCN Steering Group, the clinical standards for TBI were developed following NHS Quality Improvement Scotland (NHS QIS) methodology. These standards will inform part of the NMCN Quality Assurance Programme for which NHS QIS accreditation is being sought.

The Steering Group, a multi-disciplinary/multi-agency group with patient & carer representation, took on the role of the 'project group' and set up a working group to develop the standards.

In parallel with the development of standards, the NMCN undertook a mapping exercise to identify the pathway of patients with a head injury in each NHS board area. This involved face-to-face interviews with clinicians and others directly involved in the management of people with a head injury. As well as providing detailed scoping of the issues related to the pathway it enabled the NMCN to identify where all the providers of services were and generated early awareness of the development of the standards.

The Standards Group developed and agreed the areas for inclusion with the Steering Group then developed the draft standards and assessment framework (i.e. examples of evidence)

The approach used comprised four key elements

- Exploration of existing standards or guidelines
- Identification of the key stages in the patient pathway
- Involvement of patients and their carers
- Attention to NHS QIS guidance on developing standards

Throughout this document the text refers only to traumatic brain injury (TBI).
Some of the proposed standards will be appropriate and applicable to other types of ABI; to brain injury in children; and to non-health settings. It is anticipated, therefore, that where appropriate in future the text will be changed from TBI to acquired brain injury (ABI).

The terms *Standards* and *Guidelines* are sometimes confused and, indeed, in some regards overlap
Guidelines are recommendations on how to treat an individual with a particular disease or injury based on a detailed study of the scientific evidence on the best way to do so.
Standards are statements of the level of performance that people should expect from the NHS in Scotland. They too are based on evidence. Essential standards are obligatory whereas desirable standards are those each NHS Board should either provide or be progressing towards.

2.1 Existing Standards/Guidelines

The group reviewed existing U.K. and international standards and guidelines related to traumatic or acquired brain injury searching both published and internet accessible material. A wide range of documents were identified and these are listed in appendix 2. The following were considered most relevant:

Standards

- British Society of Rehabilitation Medicine. Standards for specialist inpatient and community rehabilitation services. 2002

- Scottish Head Injury Forum. The service standards for the rehabilitation of adults with acquired brain injury. 2001
- Commission on Accreditation of Rehabilitation Facilities (CARF) 2005
- NHS Quality Improvement Scotland. Physical Disability Quality Indicators. 2003
- NHS QIS Stroke services standard: Care of the patient in the acute setting. 2004
- South Thames Brain Injury Rehabilitation Association. Standards for post acute brain injury rehabilitation. 2003

Guidelines

- British Society of Rehabilitation Medicine. Rehabilitation following acquired brain injury: National clinical guidelines. 2003
- Scottish Intercollegiate Guidelines Network. Early management of patients with a head injury. 46 (2000)
- National Institute for Health and Clinical Excellence. Head injury: Triage, assessment, investigation and early management of head injury in infants, children and adults. (2007)
- New Zealand Guidelines Group. Traumatic Brain Injury Guideline. 2007
- Greater Manchester traumatic brain injury audit group. Head injury management in Greater Manchester. (2006)

All were a useful reference for the development of new standards but could not be adopted unchanged or without addition or modification.

2.2 Patient Pathway

Hypothetical case examples were used in the mapping exercise as a basis for discussion in relation to the standards along the various possible care pathways i.e.

Case A:
The individual who has no significant physical impairment and is sufficiently orientated to be allowed home, but has persisting cognitive impairments.

Case B:
A patient who is medically stable but has mixed physical and cognitive impairment without major behavioural issues. He requires physical assistance with transfers and all mobility activities and because of mixed cognitive and language difficulties needs supervision in activities of daily living.

Case C:
An acutely behaviourally disturbed person who, because of cognitive/language impairment, is unco-operative with ward staff, attempts to leave hospital and can be aggressive to staff.

Case D:
An individual in a vegetative state/minimally conscious state. Medically stable but requires nursing care for all needs and has been in this state for some weeks.

Case E:
Persisting challenging behaviour in a person who is aggressive to staff but lacks cognitive capacity to comply with the staff or go to the community.

Over 100 interviews were carried out across all 14 NHS boards between July 2007 and July 2008.This involved clinicians from areas such as A&E, neurosurgery, surgical, orthopaedics, rehabilitation and those involved in planning brain injury services. In addition, where the services existed, interviews took place with local authority or voluntary organisations that provided local brain injury services. A separate report from the mapping exercise is available.

2.3 Process and Involvement

Having prepared outline standards, focus groups were convened, which involved people with brain injury, together with their family members. Following discussion, suggested amendments were incorporated into further drafts, where appropriate.

We would like to thank Headway Scotland Development Group and the local Headway groups in Ayr, Dumfries & Galloway, East Lothian, Glasgow, Hamilton and Perth and the brain injury action group BrainIAC for their support in organising and contributing to these groups.

In May 2008 the NMCN hosted a conference with a representative audience of people identified through the mapping exercise. This included patients and their representatives. At this event the proposed draft standards were presented and workshops were held on each of the draft standards.

The revised draft standards were issued widely for a 3 month period of consultation. The analysis of this feedback has been used in the preparation of the standards.

2.4 NHS QIS

The Standards Group are grateful to NHS QIS for their support and advice. In drafting the standards NHS QIS guidance as to the standards structure has been observed. Thus:

- All standards set by NHS QIS follow the same format.
- Each standard has a **title,** which summarises the area on which that standard focuses
- This is followed by the **standard statement,** which explains the level of performance to be achieved.
- The **rationale** section provides the reasons why the standard is considered to be important.
- The standard statement is expanded in the section headed **criteria,** which states exactly what must be achieved for the standard to be reached.
  Some criteria are **essential**, in that it is expected that they will be met wherever a service is provided.
  Other criteria are **desirable** in that they are being met in some parts of the service, and demonstrate levels of quality which other providers of a similar service should strive to achieve. Desirable is not the same as optional. Desirable criteria should be regarded as developmental and still have to be met – albeit in a longer timescale.

  The criteria are numbered for the sole reason of making the document easier to work with, particularly for the assessment process. The numbering of the criteria is not a reflection of priority.

3. Clinical standards for traumatic brain injury

Standard 1	**Organisation of care for people with traumatic brain injury**
Standard 2	**Early/acute management of people with a potential traumatic brain injury**
Standard 3	**Rehabilitation**
3a	**Rehabilitation referral process**
3b	**In-patient rehabilitation facility**
3 c	**The Rehabilitation Team and process**
3 d	**Discharge to the community following in-patient rehabilitation**
Standard 4	**Challenging behaviour**
Standard 5	**People in vegetative & minimally conscious states**
Standard 6	**Information for patients, families & carers**

Standard 1: Organisation of care for people with traumatic brain injury

Standard Statement 1
In each NHS Board the needs of adults with traumatic brain injury (TBI) have been clearly identified with planning and service provision in place.

Rationale:
Public involvement, inter-agency co-operation and joint working are required to plan, design and deliver high quality, integrated services.
References: 1,2,3,4,5,6,7

Essential criteria		**Examples of evidence**
1.1	There is a named lead clinician or senior manager with responsibility for the planning and review of traumatic brain injury services, who is a member of, or reports to the NHS Board	Recognised lead person for TBI. Remit in job description. Reporting arrangement.
1.2	The NHS Board should be able to demonstrate that there is a current, clear strategic plan for TBI across the continuum in partnership with Local Authority and Voluntary agencies.	Joint strategic plan for TBI which is current, documented, dated and has timescales.
1.3	The NHS Board should collect and collate data on activity at all points in the patient pathway and be able to demonstrate how this data has been used to plan and co-ordinate service provision.	Activity data available and referred to in the strategic or service plan.
1.4	There are formal partnerships established between NHS Boards, Local Authorities and other providers of services to people with TBI to determine strategy and commission services.	Interagency group • remit, • minutes, • implementation plan.
1.5	There is a of range of public & patient/carer involvement in the planning of TBI services.	Reports from public/patient involvement events, consultation.
1.6	All NHS boards will have a named lead consultant who is responsible for ensuring that patients are assessed for and, if appropriate, offered a rehabilitation programme.	Named consultant.
1.7	Education and training needs of staff providing services to people with TBI are identified and are included in their individual development plans	Training needs assessments, brain injury awareness and training programmes, induction programmes.

Standard 2: Early/acute management of people with a traumatic brain injury

<table>
<tr><td colspan="3">Standard Statement 2
All patients with a head injury require accurate assessment and management of possible brain injury</td></tr>
<tr><td colspan="3">Rationale
Accurate assessment is required to separate those with minor head injury from those who have brain damage. Patients with minor head injury should be reassured, to reduce the risk of subsequent disability.
Patients with suspected brain damage should be referred to appropriate services for further management

References: 8,9,10,11, 12,13,14</td></tr>
<tr><td colspan="2">Essential criteria</td><td>Examples of evidence</td></tr>
<tr><td>2.1</td><td>The early acute management of individuals with potential TBI is in accordance with SIGN guidance on head injury management.</td><td>Audit of A&E records</td></tr>
<tr><td>2.2</td><td>There is formal assessment by a trained clinician prior to discharge from hospital that the patient is out of Post Traumatic Amnesia (PTA). This should include brief 'bed-side' testing of anterograde memory and orientation using standardised reliable tests.</td><td>A&E PTA assessment protocol.
Assessment form including tests e.g. Abbreviated mental test, Westmead.</td></tr>
<tr><td>2.3</td><td>Patients with minor injury and the 'responsible adult' are given verbal and written advice on the likely presence of the following:
- Common early symptoms
- The expectations of recovery and lack of 'brain damage' in most cases
- High risk symptoms (indicating the need to return to the accident and emergency department)
- What to do if symptoms persist</td><td>Head injury advice leaflet
Documentation in patient records</td></tr>
<tr><td colspan="2">Desirable criteria</td><td></td></tr>
<tr><td>2.4</td><td>Patients who are concerned about persisting symptoms are reviewed by their GP or a dedicated service within 2 weeks.</td><td>Protocol or arrangements for ongoing care for those patients who fail to make satisfactory progress</td></tr>
<tr><td>2.5</td><td>A service, which is capable of conducting multifaceted assessment and offering treatments including the use of medication and psychological therapy, is available for early intervention with those patients who have failed to make satisfactory progress.</td><td>Service description, referral procedure.</td></tr>
</table>

Standard 3: Rehabilitation

Standard Statement 3a Rehabilitation referral process For all patients with TBI who require a structured rehabilitation programme, there is a clear referral pathway from acute admission to in-patient or community-based rehabilitation.		
Rationale: This allows timely patient assessment and contributes to planning and management of beds and other rehabilitation resources. **References**: 3, 15,16,17,18,19,20		
Essential criteria		**Examples of evidence**
3.a.1	All NHS boards will have a clear, documented referral system for rehabilitation. [c6]	Written procedure for referral for assessment
3.a.2	A clear description of the rehabilitation service is available which includes written access and exclusion criteria	Information leaflets for referrers including inclusion/access & exclusion criteria Information leaflets for patients
3.a.3	Assessment for rehabilitation occurs within 2 weeks of the patient being deemed stable, although he may still have acute care needs.	Procedure for assessment. Referral data, including time between referral and rehabilitation assessment

Standard 3b: In-patient rehabilitation facility The NHS board has identified appropriate in-patient areas for patients with TBI throughout their journey of care. In some cases (e.g. those requiring in-patient rehabilitation) this may include utilisation of regional or national centres		
Rationale: Co-ordinated in-patient management in an appropriate setting has improved outcome **References:** 3, 15,16,17,18,19,20		
Essential criteria		**Examples of evidence**
3.b.1	The in-patient environment includes provisions to assess and manage the cognitive, behavioural and physical impairments that may occur in traumatic brain injury.	Accommodation including single rooms, adequate therapy/consultation space, quiet areas, clear signposting and accurate clocks, sufficient space for use of hoists. Access to equipment
3.b.2	Relevant risk assessments are carried out on individual patients and scenarios, including • wandering patients • falls (including falls from bed) • agitation and aggression • lone working by staff	Risk log, documentation for patients, service policies/procedures for wandering patients, falls, lone workers.
3.b.3	The in-patient facility meets appropriate Health and Safety requirements at both a clinical and non clinical level to treat the impairments and disability of this patient group	Health & safety audit
3.b.4	A named consultant with specialist registration and relevant clinical competencies will have lead clinical responsibility for the in-patient rehabilitation facility for TBI patients	Job plan GMC registration C.V.

Standard 3 c: The Rehabilitation Team and process

Standard Statement 3 c Rehabilitation team and process
There is a designated multi-disciplinary team responsible for the delivery of rehabilitation programmes for TBI patients on an in-patient or community basis.

Rationale:
Co-ordinated management for TBI improves outcome

References: 3,15,16,17,18,19

Essential criteria		Examples of evidence
3.c.1	The minimum composition of the multi-disciplinary team for TBI should include the following members with relevant knowledge & skills • clinical pharmacist • dietitian • medical practitioner • neuropsychologist or clinical psychologist • nurse • occupational therapist • physiotherapist • speech and language therapist • social worker • support – secretarial/administrative With access to a full range of clinical specialties and other identified agencies .	Service profile. Staff personal development plans. Training programme(s). Number of dedicated sessions. Job plans. Job descriptions
3.c.2	Rehabilitation programmes are: • goal-directed • tailored to the needs of the individual patient and their family/carers • involve the individual, families/carers	Evidence of goal setting including involvement of patient and carers. Clear evidence of discharge planning process. Evidence of outcome measures at admission and discharge.
3.c.3	The multidisciplinary team hold regular (e.g. weekly) meetings to discuss goals, review progress and discharge plans.	Documentation including MDT notes.
3.c.4	There is provision of or links to specialist services for disability management.	Evidence of wheelchair and seating, bioengineering, prosthetic & orthotic service provision.

Standard 3 d: Discharge to the community following in-patient rehabilitation

Standard Statement 3d

Effective discharge is facilitated by a comprehensive multidisciplinary approach.

Rationale:

Discharge is a process and not an isolated event and has to be started at the earliest opportunity across the primary, hospital and social care services.
Discharge from hospital following inpatient rehabilitation is based on a comprehensive assessment of the patient's present condition and future rehabilitation needs.
The engagement and active participation of individuals, families and carers is central to the planning of a successful discharge.

References: 3, 15,16,17,18,19,20,21,22

Essential criteria		Examples of evidence
3.d.1	There is a designated member of the MDT to co-ordinate the discharge process.	Key worker, named nurse. Discharge protocol.
3.d.2	Further risk assessment (see 3b2) including risk to others (especially children in the family) is carried out as part of discharge planning.	Risk assessments. Blank discharge planning form.
3.d.3	Individuals, families and carers' needs for post-discharge services are assessed and a mechanism is in place to refer to relevant services (e.g. social work day centres, vocational agencies).	Discharge plan audit. Carers' assessments. Referral pathway.
3.d.4	Individuals who have been identified as having on-going rehabilitation needs will have access to out-patient/day/home-based rehabilitation services. These may be provided directly by the NHS Board or in collaboration with Social Work and/or voluntary organisations.	Community service profile.
3.d.5	An immediate discharge summary is provided to the patient and GP, giving diagnosis and medication.	Audit.
3.d.6	Discharge/transition reports are sent to the patient's GP and other relevant health professionals and are available to the patient and, with their consent, their family and/or carer within ten working days of discharge. This report , which in most cases will be multidisciplinary, includes: • progress made • current needs (including recent assessments) • key contacts • responsible services/professionals, and • recommendations for future interventions.	90% target to be achieved within 10 working days. Report formats and circulation list. Support plans.

3.d.7	Arrangements will be made for patients admitted for brain injury rehabilitation to be reviewed by the rehabilitation service within 2 months of discharge.	Written policy and procedure on follow-up.
Desirable criteria		
3.d.8	There is a protocol in place to ensure the follow-up and monitoring of discharge plans to completion.	Protocol.
3.d.9	Feedback on the follow-up and monitoring of discharge plans is provided to relevant parties (statutory agencies, primary care providers, consultants and GP).	Survey results, audit.

Standard 4: Challenging behaviour

Standard Statement 4

There is clear care planning for patients who display challenging behaviour after brain injury, including consideration of the use of drug and non-drug interventions.

Rationale:
Patients who display challenging behaviour after brain injury require clear care planning with the aim of achieving better patient outcome; minimising possible harm from excessive use of sedative medication; and ensuring the safety of patients, staff and others.

References:
23,24

Essential criteria		Examples of evidence
4.1	All NHS Boards have an identified specialist(s) who can provide advice and clinical leadership on prescribing of psychotropic medication and non-drug interventions for the management of challenging behaviour in brain injured patients.	Named specialist(s) with role described in job plan(s) and dedicated time.
4.2	All clinical services who routinely admit head injured patients have a clinical strategy for risk management in patients who are disorientated or exhibit challenging behaviour after brain injury. This will include • referral pathway to identified specialist(s) [see 4.1] • a written observation policy – including the legal framework for compulsory care • safety measures e.g. - window locks; - door entry systems; - CCTV; - electronic tagging measures • prescribing guidelines for the use of medication in the management of challenging behaviour	Clinical risk management strategy detailing: - Referral pathway - legal framework - safety measures - Protocol for prescribing
4.3	All clinical services who routinely admit head injured patients have a staff training programme in the management of challenging behaviour including: • appropriate use of drug and non-drug interventions • application of mental health legislation - Mental Health (Care & Treatment) (Scotland) Act 2003 - Adults with Incapacity (Scotland) Act 2000 ; - Adult Support and Protection (Scotland) Act 2007	Training programme(s). Staff personal development plans.

Standard 5: People in vegetative or minimally conscious states

Standard Statement 5 The NHS board has a policy for the provision of continuing care and reassessment for people in vegetative or minimally conscious states. **Rationale:** There is evidence that specialist assessment of patients with minimal consciousness/awareness leads to a reduction in misdiagnosis and inappropriate management. **References:** 25,26,27		
Essential criteria		**Examples of evidence**
5.1	The diagnosis of vegetative or minimally conscious state should be based on accepted clinical criteria. A person in a vegetative or minimally conscious state requires a period of skilled assessment of at least four weeks by an experienced medical specialist in collaboration with an multi-disciplinary team before being moved to continuing care.	 Anonymised assessment form
5.2	The diagnosis of persistent vegetative state should only be made in strict accordance with Royal College of Physicians guidelines	Anonymised assessment form
5.3	There is a policy for the provision of continuing care to people in a vegetative or minimally conscious state, and a named individual with responsibility for ensuring the delivery of that policy.	Written policy for the provision of continuing care. Job plan for the named individual. Longitudinal audit of the number of people in the vegetative or minimally conscious state. Staffed beds identified
5.4	The condition of a patient in a vegetative or minimally conscious state should be reviewed at least monthly by an experienced clinician for the first year after injury and agreed intervals thereafter.	Protocol. Anonymised assessment form
5.5	Planning the discharge and support arrangements for a patient in a vegetative or minimally conscious state should be individually tailored and be a joint responsibility of the NHS Board and the Local Authority, both of which have a statutory responsibility to provide care and services.	Discharge protocol.

Standard 6: Information for patients, families and carers

Standard Statement 6

Patients (with TBI) and families/carers are enabled and supported to take part in decision-making through access to information of high quality in easily accessible formats, taking account of communication abilities.

Rationale:

Good quality information is an integral part of good quality healthcare. It can

- Support the patient in making informed decisions
- Support and involve the family in the rehabilitation process
- Act as a reminder to the individual, family or carer of what they have been told

The provision of information to the patient/family/carer must allow for communication difficulties, cognitive impairment or emotional disturbance

References:

3,8, 28,29,30,31,32,33,34,35,36

Essential criteria		**Examples of evidence**
6.1	Information (both verbal & written) is offered and provided at various stages along the patient's journey.	A&E leaflet, Patient information folder (rehabilitation service)
6.2	Information is available in a variety of formats appropriate to the needs of the target population	Large print, translated leaflets. Dysphasia/aphasia friendly
6.3	Information about support networks, outreach services, self-help groups and community services is available	Information pack, leaflets, posters
6.4	An information pack is provided for patients and families/carers on, or prior to, discharge.(see 3d). This pack is tailored to the patient's individual need and communication abilities.	Information pack, Discharge process audit
6.5	All patients with TBI have access to an appropriately trained healthcare professional during the immediate period after discharge. This may vary depending on individual circumstances.	Patient info leaflet/information pack, Discharge process audit
Desirable criteria		
6.5	Feedback on information given to patients, families & carers should be sought on a regular basis, at least every 2 years.	Patient satisfaction survey, focus group report

Appendices

Appendix 1: Steering Group and Standards Group# membership

Name	Role	Organisation
Dr Brian Pentland #	Consultant Neurologist/ ABI NMCN Clinical Lead Scottish Brain Injury Rehabilitation Service	NHS Lothian
Mr. Bob Anderson	Non- executive Health Board Representative	NHS Lothian
Dr. Dallas Brodie	Representative Royal College of Psychiatrists	
Mr. William Bryden	Edinburgh Headway, Carer	
Dr Alan Carson #	Consultant Neuro psychiatrist Scottish Neurobehavioural Rehabilitation Service	NHS Lothian
Ms. Myra Duncan	Director of Regional Planning, South East & Tayside	SEAT
Mr. Laurence Dunn	Consultant Neurosurgeon Southern General Hospital	NHS Greater Glasgow & Clyde
Ms. Christine Flannery #	ABI NMCN Manager	
Ms. Shona Forsyth	Neuropaediatric Outreach Nurse Southern General Hospital	NHS Glasgow Glasgow & Clyde
Mr Douglas Gentleman #	Consultant in Brain Injury Rehabilitation Brain Injury Rehabilitation Unit	NHS Tayside
Dr. Jacques Kerr	Consultant in A&E Borders General Hospital	NHS Borders
Ms Bette Locke # Ms Shiona Hogg# (From July 2008)	Service Manager & Occupational Therapist Community Rehabilitation Service	NHS Forth Valley
Ms. Kitty Mason (Feb 2007 – June 2008)	Association of Directors of Social Work	Edinburgh
Ms Wendy Jack (From June 2008)	Association of Directors of Social Work	W. Dunbarton Local Authority
Mrs. Ailsa McMillan	Lecturer in Nursing Studies, Queen Margaret University	
Prof. Tom McMillan	Professor of Clinical Neuropsychology University of Glasgow	NHS Glasgow Glasgow & Clyde
Dr Phil Mackie (Feb 2007 – May 2008)	Specialist in Public Health Medicine	NHS Lothian
Mr Ken Rutherford (May 2007 – June 2008)	Patient Representative	Edinburgh
Ms. Helen Moran (From July 2008)	Patient Representative	Glasgow
Dr Lance Sloan #	Consultant in Rehabilitation Medicine George Sharp Unit	NHS Fife
Dr. Cameron Stark	Consultant in Public Health Medicine	NHS Highland

Appendix 2 Standards/guidelines reference list

American Academy of Physical Medicine & Rehabilitation. Standards for assessing medical appropriateness criteria for admission. 2006. Available from
http://www.aapmr.org/zdocs/hpl/MIRC0906.pdf

Australian Faculty of Rehabilitation Medicine. Adult rehabilitation medicine services in public & private hospitals. 2005. Available from
http://afrm.racp.edu.au/index.cfm?objectid=5F2AF08F-BD60-798C-F7801CEE5462760A

British Society of Rehabilitation Medicine. Rehabilitation following acquired brain injury: National clinical guidelines. 2003. Available from
www.bsrm.co.uk

British Society of Rehabilitation Medicine. Standards for specialist inpatient and community rehabilitation services. 2002. Available from
http://www.bsrm.co.uk/ClinicalGuidance/standards.PDF

Commission on Accreditation of Rehabilitation Facilities (CARF). Available from
http://www.carf.org/

College of Occupational Therapy. Standards of practice: OTs working with people having traumatic brain injury. Available from
http://www.cot.org.uk/

Greater Manchester traumatic brain injury audit group. Head injury management in Greater Manchester. 2006. Available from
http://www.burypct.nhs.uk/fileadmin/user_upload/health_promotion/test_page_2/Paul/HI_Management.pdf

National Institute for Health & Clinical Excellence. Head Injury: Triage, assessment, investigation and early management of head injury in infants, children and adults. 2007 Available from
http://www.nice.org.uk/Guidance/CG56

Neurological Alliance Standards of care for people with neurological conditions. Available from
http://www.neural.org.uk/pages/online_ordering/LevellingUp.asp

New Zealand Guidelines Group. New Zealand Traumatic Brain Injury Guideline 2007. Available from
http://www.nzgg.org.nz/index.cfm?fuseaction=fuseaction_10&fusesubaction=docs&documentID=22#Injuries%20/%20Wounds

NHS Quality Improvement Scotland. Physical Disability Quality Indicators. 2003.

NHS Quality Improvement Scotland Stroke services standard: Care of the patient in the acute setting 2004. Available from
http://www.nhshealthquality.org/nhsqis/qis_display_findings.jsp?pContentID=1288&p_applic=CCC&p_service=Content.show&

NHS Quality Improvement Scotland Nutrition. Best practice statement 2002. Available from

http://www.nhshealthquality.org/nhsqis/files/BPSnutrition_assessment_May02.pdf

NHS Quality Improvement Scotland. Generic standards 2002. Available from
http://www.nhshealthquality.org/nhsqis/files/Generic%20standards.pdf

NHS Quality Improvement Scotland .Food, Fluid and nutritional care in hospital 2003.
Available from
http://www.nhshealthquality.org/nhsqis/controller?p_service=Content.show&p_applic=CCC&pContentID=1015

Royal College of Physicians. National Clinical Guidelines for stroke. 2004. Available from
http://www.rcplondon.ac.uk/pubs/books/stroke/stroke_conciseguide_2ed.pdf

Royal College of Speech & Language Therapists. Communicating quality 3. Available from
http://www.rcslt.org/resources/

Royal College of Surgeons. Report of the working party into the management of head injuries 1999. Available from
http://www.rcseng.ac.uk/publications/docs/report_head_injuries.html/view?searchterm=head%20injury

Royal College of Psychiatrists. Brain injury checklist for psychiatrists. Available from
http://www.rcpsych.ac.uk/college/specialinterestgroups/neuropsychiatry/braininjurygroup.aspx

Scottish Head Injury Forum. The service standards for the rehabilitation of adults with acquired brain injury. 2001. Available from
http://www.shif.org.uk/Docs/Rehab%20standards.doc

Scottish Intercollegiate Guidelines Network. 13 Management of patients with stroke (assessment) 1997. Available from
http://www.sign.ac.uk/pdf/sign13.pdf

Scottish Intercollegiate Guidelines Network 46 Early management of patients with a head injury 2000. Available from
http://www.sign.ac.uk/guidelines/fulltext/46/index.html

Scottish Intercollegiate Guidelines Network 64 Management of patients with stroke (rehabilitation) 2002. Available from
http://www.sign.ac.uk/pdf/sign64.pdf

Scottish Intercollegiate Guidelines Network 65 The Immediate discharge document. Available from
http://www.sign.ac.uk/guidelines/fulltext/65/index.html

Scottish Intercollegiate Guidelines Network. 78 Management of patients with stroke (dysphagia). 2004. Available from
http://www.sign.ac.uk/pdf/qrg78.pdf

Society of British Neurological Surgeons. Standards for Patients Requiring Neurosurgical Care .2002. Available from http://www.sehd.scot.nhs.uk/nationalframework/Documents/neuro/key%20docs/StandardsDoc.pdf

South Thames Brain Injury Rehabilitation Association. Standards for post-acute brain injury rehabilitation. 2003. Available from http://www.rhn.org.uk/institute/doc.asp?catid=1267&docid=1029

Systematic review of the rehabilitation of moderate to severe acquired brain injuries Brain Injury Vol. 21 number 2 Feb 2007

Appendix 3: Evidence base/References

1. NHS Quality Improvement Scotland: Standards for Clinical Governance & Risk Management 2005 http://www.nhshealthquality.org/nhsqis

2. Scottish Executive. Patient Focus, Public Involvement. 2001. http://www.scotland.gov.uk/Publications/2001/12/10431/File-1

3. British Society of Rehabilitation Medicine. Rehabilitation following Acquired Brain Injury – National clinical guidelines. 2003. http://www.bsrm.co.uk/Publications/Publications.htm

4. NHS Quality Improvement Scotland. Physical disability quality indicators. 2003. http://www.nhshealthquality.org/nhsqis

5. Scottish Executive. Co-ordinated, integrated and fit for purpose. 2007. http://www.scotland.gov.uk/Publications/2007/02/20154247/0

6. Scottish Executive. Fit for the future. 2005. http://www.scotland.gov.uk/Publications/2005/05/23141307/13135

7. Neurological Alliance. Levelling up. 2002. http://www.neural.org.uk/pages/online_ordering/LevellingUp.asp

8. Scottish Intercollegiate Guidelines Network. Early Management of Patients with a Head injury SIGN 46: 2000 http://www.sign.ac.uk/guidelines/fulltext/46/index.html

9. Carroll LJ, Cassidy JD, Peloso PM et al. Prognosis for mild traumatic brain injury: results of the WHO collaborating centre task force on mild traumatic brain injury. J Rehab Med 2004; Suppl. 43: 84-105.

10. WCB Evidence Based Practice Group - British Columbia. Mild Traumatic Brain Injury. Review of literature and British Columbia data. Dr CW Martin 2003.

11. Ontario Neurotrauma Foundation. Evidence-based review of moderate to severe acquired brain injury. 2nd edition. 2006 http://www.abiebr.com/

12. Ponsford J et al. Use of the Westmead PTA scale to monitor recovery after mild head injury *Brain Injury* 2004*;* 18: 603-614

13. Hodkinson HM. "Evaluation of a mental test score for assessment of mental impairment in the elderly." *Age and Ageing* 1972;1:233-8.
14. Qureshi KN, Hodkinson HM "Evaluation of a ten-question mental test in the institutional elderly" *Age and Ageing* 1974;3:152-7.

15. Rice-Oxley M, Turner-Stokes L. Effectiveness of brain injury rehabilitation *Clinical Rehabilitation* 1999; 13 (suppl 1): 7-24

16. Turner-Stokes L, Nair A, Wade D, Disler P. *Multi-disciplinary Rehabilitation for Acquired Brain Injury in Adults of Working Age.* Oxford: Cochrane Library; 2003: issue 3.

17. Nyein K, Thu A , Turner-Stokes L Complex specialised rehabilitation following severe brain injury: a UK perspective *Journal of Head Trauma Rehabilitation* 2007; 22: 239-247

18. BSRM Standards for Specialist In-patient services. 2002 http://www.bsrm.co.uk/ClinicalGuidance/ClinicalGuidance.htm

19. Evidence from stroke units and reviews.

20. Department of Health. Discharge from hospital; pathway, process and practice. 2003. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications

21. Scottish Intercollegiate Guidelines Network. The Immediate discharge document. SIGN 65:2003
http://www.sign.ac.uk/guidelines/fulltext/65/index.html

22. British Medical Association. Improving communication, the exchange of information and patient care. Suggested guidelines for secondary care doctors and GPs. 2007

23. Fleminger S, Geenwood RJ, Oliver DL. *Pharmacological management of agitation and aggression in people with acquired brain injury.* Oxford: Cochrane Library http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD003299/pdf_fs.html

24. Royal College of Surgeons: Report of the working party into the management of head injuries. 1999
http://www.rcseng.ac.uk/publications/docs/report_head_injuries.html/view?searchterm=head%20injury

25. Andrews K, Murphy L, Munday R, Littlewood C. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. *Br Med J* 1996, 313: 13-16.
http://www.bmj.com/cgi/content/full/313/7048/13?view=full&pmid=8664760

26. The permanent vegetative state. *Journal of the Royal College of Physicians of London* 1996, 30: 119-121.

27. Royal College of Physicians. The Vegetative State: guidance on diagnosis and management, 2003.

28. Scottish Executive. Draft Guide to the production and provision of Information about health and healthcare interventions. 2003.

29. Department of Health. Toolkit for Producing Patient information. 2003.

30. NHS Quality Improvement Scotland. Generic Standards.2003

31. Junque C et al. Information needs of the traumatic brain injury patient's family members regarding the consequences of the injury and associated perception of physical, cognitive, emotional and quality of life changes *Brain Injury* 1997 ;11 (4):

32. Morris KC. Psychological distress in carers of head injured individuals: the provision of written information *Brain Injury*, 2001 ;15(3): 239-254

33. Headway – DoH Section 64-funded project. NSF Implementation: Delivering Quality Information. Report covering the period May 2006 – March 2007.

34. Sinnakaruppan I, Williams DM.Family carers and the adult head injured: a critical review of carers' needs *Brain Injury*, 2001; 15(8); 653-672

35. McPherson KM, McNaughton H, Pentland B. Information needs of families when one member has a severe brain injury *International Journal of Rehabilitation Research* 2000 ;23(4): 295-301

36. Bond AE et al Needs of family members of patients with severe traumatic brain injury *Critical Care Nurse* 2003 ;23(4):63-72

Appendix 4 Glossary

ABI	Acquired Brain Injury (ABI) implies damage to the brain that was sudden in onset and occurred after birth and the neonatal period. It is thus differentiated from birth injuries, congenital abnormalities and progressive and degenerative diseases affecting the central nervous system.
Aphasia/ dysphasia	An impairment of the ability to use and/or understand language.
Amnesia	Loss or impairment of memory. Associated with brain injury are: • *Anterograde amnesia*: amnesia of events occurring after the trauma or other cause of injury. • *Retrograde amnesia*: amnesia of events occurring before the trauma or other cause of injury. • *Post-traumatic amnesia (PTA):* the period between a head injury and the time the person knows where they are.
Carer	A person of any age who provides care on a regular and substantial basis, to an individual who could not manage without their help. In this document the term includes both paid and unpaid carers
GCS	Glasgow Coma Scale (See next page) A standardised method of recording a person's level of consciousness after head injury based on responses to stimuli. Total scores range from 3, when there is no response even to painful stimuli, to a maximum score of 15 indicating that the person can speak coherently, obey commands to move, and can spontaneously open their eyes.
MCS:	Minimally Conscious State (MCS). The terms "minimally conscious", "minimally responsive" or "low awareness state refer to the condition of patients who show minimal but definite evidence of awareness despite profound cognitive impairment. Patients emerging from the Vegetative State often enter the Minimally Conscious State.
MDT	Multidisciplinary team Several different health and related professionals working together and communicating with each other with the common purpose of assisting the person with TBI and their family to maximise recovery. However it does not imply that they adapt their skill or knowledge base or change their professional role to fit in with the roles and responsibilities of other team members in contrast to an Interdisciplinary team.
NMCN	National Managed Clinical Network
NHS QIS	NHS Quality Improvement Scotland: is a special health board whose purpose is to promote improvement in the quality of healthcare for the people of Scotland. [For further details see www.nhshealthquality.org]

NSD	National Services Division, a division of NHS National Services Scotland. It is funded by the Scottish Government and the 14 NHS boards to plan, support and fund services on behalf of NHS Scotland. [For further details see www.nsd.scot.nhs.uk]
Psychotropic	A chemical substance that acts primarily upon the central nervous system where it alters brain function, resulting in temporary changes in perception, mood, consciousness and behaviour
PTA	Post Traumatic Amnesia – see Amnesia
Persistent Vegetative State:	see Vegetative State
Rehabilitation	Rehabilitation implies the restoration of a person to their fullest physical, mental and social capability after an injury or episode of illness.
SIGN	Scottish Intercollegiate Guidelines Network (SIGN) was set up in 1993 with the objective of improving the healthcare for patients in Scotland by reducing variation in practice and outcome, through the development of national evidence-based guidelines. Since 2005 SIGN has been part of NHS QIS. [For further details see www.sign.ac.uk] .
SNAP	Scottish Need Assessment Programme(SNAP) was set up in 1992 across all Scottish NHS Boards to assist them in carrying out their required task of health needs assessment. With the establishment of the Public Health Institute of Scotland (PHIS) in 2001 the work of SNAP was incorporated in the work programme of the Institute. In 2003 PHIS merged with the Health Education Board for Scotland to become NHS Health Scotland.
Steering Group	The group of people responsible for directing and ensuring effective completion of the aims of the NMCN including overseeing the activities of the working groups.
Standards Group	The working group responsible for developing draft standards for the management of adults with traumatic brain injury.
TBI	Traumatic Brain Injury: damage to the brain resulting from an injury to the head.
Vegetative state	A patient in the vegetative state appears at time to be wakeful, with cycles of eye closure and eye opening resembling those of sleep and waking. However, close observation reveals no sign of awareness or of a "functioning

mind", specifically, there is no evidence that the patient can perceive the environment or his own body, communicate with others, or form intentions. As a rule, the patient can breathe spontaneously and has a stable circulation.

Persistent vegetative state refers arbitrarily to a vegetative state which has continued for four weeks or more.
Permanent vegetative state refers to patients in a persistent vegetative state that continues for 12 months after traumatic brain injury and 6 months after other causes.

SEVERITY OF INJURY

The conventional manner of categorising severity of injury is by the Glasgow Coma Scale score after initial resuscitation; duration of unconsciousness; and duration of post-traumatic amnesia (PTA) as summarised below

	Duration of unconsciousness	GCS score	PTA
Mild	<15 minutes	13-15	< 60 minutes
Moderate	15mins.-6 hours	9-12	1-24 hours
Severe	>6 hours	3-8	> 24 hours

Estimates for each category attending Accident & Emergency are

- mild 90%
- moderate 5%
- severe 5%.

Definitions of minor head injury and mild traumatic brain injury vary. For the purposes of this document an injury with GCS 13-15, PTA less than 1 hour, duration of loss of consciousness of less than 15 minutes is highly unlikely to be associated with any lasting brain damage or long-term effects. Although some patients will complain of poor concentration and 'fuzzy' thinking for some months afterwards they can be appropriately reassured that they are highly likely to recover.

GLASGOW COMA SCALE (GCS)

The Glasgow Coma scale is used to measure levels of responsiveness. It thus provides a measure of severity of brain injury. It also allows the patient to be monitored, as any decline in level of responsiveness would raise the question of whether there were developing intracranial complications

Responsiveness is measured in three domains

EYE OPENING		BEST MOTOR RESPONSE		VERBAL RESPONSE	
Spontaneous	4	Obeys	6	Oriented	5
To speech	3	Localises pain	5	Confused conversation	4
To pain	2	Withdraws from pain	4	Inappropriate words	3
Nil	1	Abnormal flexion	3	Incomprehensible sounds	2
		Extensor response	2	Nil	1
		Nil	1		

The total score is Eye Opening + Best Motor Response + Verbal Response, giving a worst score of 3 and a best of 15. (Sometimes points 3 and 4 on the Motor scale are collapsed reducing the total range to 3-14.)

It has become common to describe a total GSC score after resuscitation of 3-5 as indicating "very severe" head injury, a total of 6-8 as indicating "severe" head injury, a total of 9-12 as indicating "moderate" head injury, and a total of 13-15 as indicating "minor" head injury. However, this classification is not universally accepted.

POST TRAUMATIC AMNESIA (PTA)
Duration of Post Traumatic Amnesia (PTA) is a yardstick of the severity of injury.
PTA is the period between the injury and regaining day to day memory so that the patient knows where he is, what happened to him, etc. It includes the period of coma.

In some cases there is long PTA (suggesting severe injury) while the Glasgow Coma Scale score was never particularly low (suggesting the injury was not severe). In these circumstances, PTA is generally the preferred index as there is a group of head injured patients with severe injury and poor outcome who have long PTA but whose GSC is never low.

The significance of PTA duration may be gauged by the following summary:

MILD	1 hour or less
MODERATE	1 to 24 hours
SEVERE	1 to 7 days
VERY SEVERE	1-4 weeks
EXTREMELY SEVERE	More than 4 weeks

GLASGOW OUTCOME SCALE
This scale is widely used to describe outcome in large groups/populations of patients. It is less useful for describing individual patients.

1 Death	
2 Vegetative State	There is no behavioural evidence of cerebral cortical function. Patients may open their eyes, may make reflex postural adjustments. However, they never speak nor make any response that is “psychologically meaningful”: they therefore do not obey even simple commands and do not utter even simple words.
3 Severe Disability	Conscious but dependant Dependant on another person for some activity during every 24 hours. The worst are physically disabled, or marked dysphasia may be the major handicap. Marked handicaps in such cases are associated with severely restricted mental activity; however some patients are physically well but are so affected mentally that they require permanent supervision.
4 Moderate Disability	Independent but disabled Can look after themselves, can travel by public transport, and some may be capable of work which may be sheltered work. Most “moderately disabled” after head injury have memory deficits and/or personality changes and/or hemiparesis /ataxia/ dysphasia/ epilepsy etc.
5 Good Recovery	The definition notes that this “need not imply the restoration of all normal functions”. However, “the patient is able to participate in normal social life” and “could” return to work (but may not have done so). However, in practice ‘Good Recovery’ is often used simply to denote a better state of affairs than ‘Moderate Disability’ – studies have found considerable deficit in such patients including an inability to resume work on the open market.

You can read and download this document from our website.

You can also request this information

- by email
- in large print
- in audio tape or CD
- in Braille, and
- community languages

The National Managed Clinical Network for Acquired Brain Injury
MCN Office
Administration Building
Astley Ainslie Hospital
133, Grange Loan
Edinburgh
EH9 2HI
Tel. 0131 537 9092

Email: Cflannery@nhs.net

Website: www.sabin.scot.nhs.uk

First published: January 2009