ASSOCIATION OF BRITISH NEUROLOGISTS

STANDARDS OF CARE FOR PEOPLE WITH NEUROLOGICAL DISORDERS

SERVICES AND STANDARDS COMMITTEE

2004

These standards have been endorsed by the Neurological Alliance

These standards of care are for people with neurological disorders, some of whom will have long-term conditions. Some may seem outwith the practice of many neurologists but are set out to reflect the concerns of patients and carers and to give guidance to PCT commissioners and Trust Chief Executives and also to help clinical directors and lead clinicians in developing their services.

Whilst some areas may seem repetitious these standards represent different pathways for different disorders or stages of a single neurological disorder and each section should stand on its own. The standards themselves mirror the expectations set out in the Neurological Alliance document 'Levelling Up'[1].

Each section begins with an objective and is followed by one or more standards and a performance indicator. The final column gives an indication of the level of urgency of implementation of the standard.

A: Should be in place now
B: Should be in place by 2007
C: Should be in place by 2011.

Chapters

1 Organisation of the Provision of Neurological Care.

2 Services for people with long-term neurological conditions.

3 Prevention of Neurological Disorders.

4 Emergency care for people with neurological conditions.

5 Critical Care for people with neurological conditions.

6 Standards of care for people with neurological symptoms prior to diagnosis and treatment.

7 Continuing care for people after the diagnosis of a neurological disease has been made.

8 Longer-term management of people with a progressive disability or a stable condition with changing needs due to development or aging.

9 Palliative care for people with neurological conditions.

Chapter 1
Organisation of provision of neurological care

Concentration of facilities for provision of neurological care leads to improvements in patient management and outcome through increased levels of expertise and experience, including subspecialisation. The highly sophisticated, complex needs of neurological care require immediate access to specialised staff and facilities provided by cognate disciplines. The organisation of neurological services has been set out in previous ABN publications and some principles and definitions are re-stated in this document[2].

Clinical Network
The clinical network is an organisation that lies within at least one Strategic Health Authority but can cross the boundaries of NHS structures. It is an organisation, which enables the development of more than one provider of services in a co-ordinated manner and ensuring equitable access to care throughout the network boundaries. Networks are in place for most cancer services and are now starting to develop for cardiac and neuroscience services. The network should include an effective organisational structure directly responsible for commissioning services.

Multidisciplinary Network
A Multidisciplinary Network includes not only teams within the Neurology Neurosurgery Centre, but also teams providing specialised care from other agencies (eg post-acute neurorehabilitation) and staff in primary and secondary care who are involved in different stages and in different locations in the management of a patient receiving neurological care.

Neurology Neurosurgery Centre
As well as containing the neurological team, the Neurology Neurosurgery Centre is composed of identified and organisationally linked specialist teams in cognate disciplines. These include facilities and staff specialising in neuroradiology and neuroradiological intervention, neurosurgery and neurosurgical trauma, neuro-anaesthesia, euro-critical care neuro-pathology, neuro-physiology, neuro-psychology, neuro-ophthalmology and neuro-otology, neuro-oncology, neuro-rehabilitation, maxillofacial surgery, spinal surgery, endocrinology. Components are usually co-located together in one physical location but, where this is not feasible, explicit recognition and organisational coherence are essential.

Neurology centre
Facility in which are located the members of the neurological team plus nurses and other allied health professionals with specialised experience in neurology. The team should have on site access to neuroimaging supervised by neuroradiology staff, on site neurophysiology services and ward and critical care beds whose staff include those with neurological training and access to neurological rehabilitation.

Neurological Team
Consultant and other neurological staff, including trainees, nursing and other allied health professionals, working within a common location and grouped together in an organisational structure.

NEUROLOGY AND NEUROSURGERY CENTRES

Specialist neurological needs of the general population will be met by adequately resourced Neurology Neurosurgery Centres		
Standard	**Indicator**	**Urgency**
Neurological care of in-patients delivered in dedicated wards staffed by neurologically trained nurses	Designated Neurological Wards	A
Numbers of staffed Neurological beds in accord with national standards.	A minimum of 15 / 100,000 staffed beds with no greater than 85% occupancy[3].	C
Direct access to dedicated neurocritical care equipped and staffed to provide specialised neurointensive monitoring and therapy	Dedicated neurocritical care beds.	A
Related departments co-located with the Neurology Department.	Listed co-located services	A
Related departments functionally linked to constitute a Neurology Neurosurgery Centre	Formal linking arrangements e.g. joint meetings / clinics. Transfer of care protocols.	A

Ensuring that specialist multidisciplinary teams are available to meet the needs of the population.		
Standard	**Indicator**	**Urgency**
1:40,000 accredited consultant neurologists available to deliver general neurology services.	Lists of Neurological Consultants and sessions worked	C
Appropriately trained and experienced consultant workforce capable of delivering subspecialty services including epilepsy, movement disorders, neuro-inflammatory diseases, neuromuscular diseases and stroke.	Accredited Neurologists with a range of complementary interests and substantial sessional commitments Evidence of internal referral of cases	C
Sufficient opportunities for consultant led neurological training in numbers appropriate to population and workload without cross cover by other specialties.	SAC accreditation for training posts Sufficient posts for neurological on-call rota	B
Sufficient consultant led training opportunities for general professional training in clinical neurosciences in numbers appropriate to population and workload.	Royal College accreditation for training posts Sufficient posts for on-call rota Compliance with European working time directive.	A A A
24hr, 7 day/week access to neurological advice/care with the person of first call having specialist neurological experience.	On call rota with defined contacts	C
Consultant on call accessible by phone for urgent advice and able to attend within an appropriate time	Category A in Consultant contract	A
Consultants not on call without intermediate grade cover	Appropriate intermediate grade rotas	A
Physiotherapists experienced in the critical care needs of neurology patients every day.	Lists of Physiotherapists and on call rota, details of cover	B
Adequate numbers of trained nurses of whom a majority will be involved in or have completed a course of study in neurology related care.	Lists of RGN/RSCN Nurses with higher qualification and/or successful performance in accredited course in Neurology/Neuroscience	B
Neurology patients will have access to allied health professionals experienced in caring for neurology patients[4].	List of staff required as per Working Group standards	B
Access to Neurology Nurse Specialists, Infection control nurses with experience in neurology, occupational therapy, Pain control services, pharmacist, Psychologist Psychotherapist or psychiatric advice, physiotherapy, speech and language therapy, social worker and dietetic advice	Posts identified and named individuals	B
Access to other Specialists meeting individual needs of patients.	Posts identified and named individuals	B

Adequate managerial and administrative support to deliver an effective service.		
Standard	**Indicator**	**Urgency**
Administrative support for clinical staff working in the wards, including full time personal secretaries for consultants in line with ABN recommendations[5].	Presence of posts.	A
Referring practitioners will receive comprehensive information on the patients discharge and follow up arrangements	GP informed by phone within 24 hrs of any in-patient death Interim discharge summary at time of discharge Formal discharge summary within 10 days	A
Trained clinical coders receiving input from consultant neurologists to improve the quality of data collected to serve clinical governance needs	Development of coding role to support clinical governance	B
Support from the Trust audit department to help design, collect and interpret results	Evidence of audit support, and central co-ordination of audit	B
Information systems to ensure regular production of clinically relevant reports to support clinical governance needs	Regular, clinically relevant, reports	B

NEUROLOGY only CENTRES

Meeting the neurological needs of the population at neurology only centres that do not have access to on site neurosurgery. All Neurology only centres should have on site neurophysiology and neuroradiology and at least one SpR who is part of a training rotation. Standards regarding multidisciplinary teams, administrative support and coordination between units, should apply as above.		
Standard	**Indicator**	**Urgency**
Neurological care of in-patients will be delivered in wards dedicated to Neurology and staffed by neurologically trained nurses	Designated Neurological Wards	B
Numbers of staffed Neurological beds in such wards will be in accord with national standards.	A minimum of 15/ 100,000 staffed beds with no greater than 85% occupancy.	B
There will be access to critical care facilities where staff has training in the management of the neurological disorders.	Designated trained staff	B
Related departments co-located with the Neurology Department.	List of cognate disciplines	B
Neurology centres will be linked to a designated Neurology Neurosurgery Centre	Evidence of function linking by formal arrangements, joint meetings/clinics Transfer of care protocols	A

Chapter 2
Services for people with long term neurological conditions

Many neurological conditions have a long lasting or life-long impact such there is a need for a coordinated, patient-centred service that ensures continuity of comprehensive care to meet people's on-going needs. People with neurological conditions are not necessarily heavy users of health services; many people will manage their own condition, with appropriate support from health and social services, for long periods of time.

People with long term neurological conditions should have access to co-ordinated specialist neurological care.		
Standard	**Indicator**	**Urgency**
Patients have access to specialist emergency care in the case of deterioration or acute neurological illness.	% patients reviewed within 24 hours of admission	A
An opinion is available on the same day during sudden clinical deterioration.	Time to review.	A
There is ongoing review and provision of information at other times from members of the care team.	Care plan for each patient.	A

People with long term neurological conditions should have care by individuals with appropriate skills at all points in the care pathway.		
Standard	**Indicator**	**Urgency**
Medical students receive adequate training in identifying common neurological disorders.	Neurology taught by neurologists in medical school curriculum.	B
Those entering primary care receive training in the referral, diagnosis and management of common neurological disorders	Defined competences within the VTS curriculum.	B
Basic specialist training is oriented to the neurosciences for those choosing this as a career.	Implementation of basic neurosciences training curriculum.	B
Each patient will have a named key worker responsible for co-ordinating their care	The patient and/or carer will be able to name their key worker	A

Care will be provided in an equitable fashion as close to home as is practicable and appropriate.		
Standard	**Indicator**	**Urgency**
Access to high quality services is independent of place or residence, ethnicity, gender or social class	Equal waiting times in each geographical area with common waiting lists.	A
Patients will only travel as far as it is necessary to reach the level of expertise and services required for their particular condition.	A network of services co-ordinated in such a way to ensure care is provided locally.	C
Secondary care facilities for the care of patients not needing complex investigation or treatment is available.	List of local, secondary care facilities	C
Patients are returned to local referring or rehabilitation facility as soon as is medically appropriate.	Admissions delayed because of over occupancy Delayed discharge to referring units or unplanned readmission	C
The Neurology team will be readily available for advice to other professionals on continuing care for patients	Communication channels identified	A

There should be clear protocols for the transfer of care between health professionals.		
Standard	**Indicator**	**Urgency**
Neurology units will have agreed policies for communication and referral criteria between primary, secondary and tertiary care and between different services.	Written Policies	B
Communication to referrers about the diagnosis and management of out-patients will take place within two weeks.	Evidence of response times following outpatient review.	A

High quality information, including a health records summary (with responsible clinician's name), a management or follow up plan when appropriate and radiological information/films will accompany patients transferring between healthcare facilities.	Audit of timeliness and completeness of information received about patient's diagnosis and management at transfer.	A
Preliminary discharge information will be made available to general practitioners at the time of discharge. Comprehensive discharge information will be sent to GPs within 10 days of discharge.	Audit of preliminary discharge notes. Evidence of compliance with 10 day final discharge summary.	A
Death of a patient will be notified to General Practitioner within 24 hours.	Audit of notification of death to GP.	A
Continued support and advice on neurological patients will be available from the unit to other hospitals and primary care.	Evidence of a system in place.	B

Patients and carers have access to regularly updated information about local services and voluntary organisations.		
Standard	**Indicator**	**Urgency**
Patients and carers have access to literature and multimedia information in an appropriate language and format.	Printed information Contact information for support groups	B
Each department has written information about locally available services.	Availability and date of information.	B
Health and social care professionals can provide contact details of appropriate organisations.	PC / Internet access in outpatients Web links on departmental website	B

People with neurological conditions, and their carers become experts in their condition to enable them to maximise their quality of life.		
Standard	**Indicator**	**Urgency**
Patients and carers get a comprehensive assessment of their rehabilitation, vocational and occupational needs.	Documented in care plan	A
There are seamless links between health and social services, education, housing, employment and benefit services for people with neurological conditions.	Care pathway	B

People with neurological conditions gain access to general health services that understand the impact of their neurological condition and treatment.		
Standard	**Indicator**	**Urgency**
Services are sensitive to the needs of people with a range of neurological conditions and disabilities.	Monitoring of complaints	A
Non specialist health professionals can understand the impact of neurological conditions and treatment.	Monitoring of complaints.	A

People with neurological conditions become involved in research that is likely to improve present and future quality of care.		
Standard	**Indicator**	**Urgency**
People with neurological conditions, their carers and the organisations that represent them are involved in setting priorities for research.	User involvement	B
People will be fully informed about relevant research and given the opportunity to participate.	User involvement	B

The use of electronic information technology should be maximised as a support to consultation & communication.		
Standard	**Indicator**	**Urgency**
Up to date patient records will be accessible to those involved in a patient's active medical care.	Case note audit.	A
Patients have access to their own records	System for review in place.	A
Rapid image linkage for image and data transfer is used between district hospitals and Neuroscience Centres	Presence of the system and its usage	A
Emergency results will be passed rapidly to secondary care.	Audit of response times	A

Chapter 3

Prevention of Neurological Disorders

Many neurological conditions cannot be foreseen or prevented. Where prevention or detection is possible, it is in the interests of patients, commissioners and providers to ensure that this is undertaken.

To reduce the impact of handicap resulting from traumatic and non-traumatic injury to the brain.		
Standard	**Indicator**	**Urgency**
Neurology departments can offer advice to bodies developing national and local strategies for accident prevention.	Individuals available to give advice.	A

To reduce the burden of neurological disease in those at risk.		
Standard	**Indicator**	**Urgency**
Health and social care professionals engaged in neurological practice are trained in appropriate disease e.g. stroke, prevention.	Curriculum	B
Each department will have written policies for disease prevention.	Availability of protocols	A

Provision of a full antenatal screening programme for neurological diseases.[6]		
Standard	**Indicator**	**Urgency**
Screening programmes for neurological disorders are available to all pregnant women and their partners.	List of programmes available.	B

A neuro-genetics service should be available in every neuroscience network.		
Standard	**Indicator**	**Urgency**
When a genetic condition is considered referral to a neuro-genetic clinic is offered,	Identified neuro-genetic clinic. Casemix of referred patients.	B
Information is available about screening tests for patients who may have genetically determined neurological conditions.	Up to date lists of available screening tests.	B
Specialised counselling and information is available to people with neurological disorders prior to and after genetic testing.	Named counsellors.	B
Adequate time for counselling and decision-making is available.	Clinic booking rules.	B

Chapter 4

Emergency care for people with neurological conditions.

The aim of emergency care is to prevent death and disability through immediate access to expert interventions immediately following an insult when it may be possible to arrest or limit major damage to the nervous system. Appropriate care should be provided to the patient with an acute neurological illness even in the absence of a locally based neurosciences service.[7]

Expert care should be available for people with an acute neurological illness wherever they are seen.		
Standard	**Indicator**	**Urgency**
National guidelines for the treatment of patients with neurological illnesses will be followed by staff involved in emergency care.	Guidelines available and followed Audit of compliance	B
Patients with acute neurological disorders who require emergency admission to neuro critical care or a general neurology bed are transferred within 24 hours of referral.	Record of emergency cases refused because of lack of beds Record of emergency cases refused elsewhere admitted for care.	B
When a neurological condition is suspected, a neurologist will review the patient within 24 hours of admission during the working week.	Audit of patients seen,	C

The needs of people with acute neurological illnesses should be met by staff with appropriate training who have access to appropriate facilities at the right time for their care and onward referral.		
Standard	**Indicator**	**Urgency**
Guidelines will be available to primary and secondary care staff and other sources of referral regarding the onward referral of patients	Availability of guidelines	B
Doctors responsible for the emergency management of neurological patients receive appropriate training within three months of their appointment.	Certificates of attendance at relevant courses.	B
Patients are only be treated at any time by staff trained and competent in the management of neurological emergencies.	Evidence of competence.	B

Emergency departments should know whom to refer and admit or transfer to specialist facilities.		
Standard	**Indicator**	**Urgency**
Guidelines for consultation and admission will be available to staff in referring hospitals and communities	List of guidelines	A
Patients with acute neurological disorders will be admitted or transferred within a nationally defined time interval	Analysis of reports of delayed or refused transfer	B
A regional bed bureau will provide continuous access to contemporary information about availability of in-patient beds including those for neurocritical care.	Bed state availability	C

Information about the disease and available services should be offered to patients and carers at an appropriate time.		
Standard	**Indicator**	**Urgency**
Staff are available to support families and make early referrals for further information and counselling.	Lists of named staff.	B
Patients & carers are given written information outlining any precautions they should take and with contact details of neurological services and support organisations.	Evidence of written information.	B

Chapter 5

Critical care for patients with neurological disorders

The outcome for patients with severe, acute neurological illness or injury is improved by treatment in a high quality Critical Care Unit with dedicated specialised facilities, staffed by a multidisciplinary team including Consultants with training in neurosciences critical care, supported by adequate facilities. Whilst not all neurologists will have active involvement in the care of such patients, Trusts offering critical care will be expected to have sufficient trained staff in other areas to meet these standards.

The neuro-critical care service should be designed and developed around the needs of the patient as an individual		
Standard	**Indicator**	**Urgency**
Each patient will have a named key worker responsible for co-ordinating their care	The patient and/or carer will be able to name their key worker	B
Patients and carers will have sufficient information to understand the effects of critical illness in an appropriate format.	Printed and other information sources Education and support programmes	B
Practical help for relatives including help with accommodation will be available.	Documentary evidence.	B
Patients or the family/carers will be involved in deciding how care is delivered.	Evidence of involvement in patient care plan	B
Patients/carers will have the opportunity to provide feedback on the quality of care received	Results of surveys	B
Patients and carers will involved in the design and development of neuro-critical care services.	Patient, carer, and primary care representation	B

Neuro-critical care should be properly coordinated by named individuals.		
Standard	**Indicator**	**Urgency**
Commissioners will co-ordinate and monitor the provision of neuro-critical care.	Identified commissioner with defined responsibilities.	B
Each Trust will have a named lead clinician who is responsible for establishing and co-ordinating the multi-disciplinary team providing neurocritical care.	Clinical lead identified and responsibilities defined Membership, roles and responsibilities of the multi-disciplinary team defined.	B

There should be adequate critical care resources for assessment, admission, investigation and treatment to agreed standards at times when the patient will most benefit.		
Standard	**Indicator**	**Urgency**
There will be a dedicated unit or area for the intensive care of neurosciences patients.	Documentation of designated unit(s)	B
There will be 24-hour cover from imaging, anaesthesia, physiotherapy and other paramedical specialities.	Record of rotas for all specialities.	B
Referring hospitals will know the primary Neurocritical Care Unit for their locality.	Clear guidelines for the referral of patients Presence of Critical Care networks.	A
Neurocritical care will be available continuously to meet the needs of the catchment population	Record of compliance with required unit specification. Record of admissions and refusals	A
The Unit will be covered by consultants with appropriate training in Neurocritical Care.	Representation from professional bodies representing intensive care on appointment committees. Record of rota. Consultant job plans.	A
Nursing staff numbers will be in line with the recommendations of the Modernisation Agency report on Neuro Critical Care.	Record of nurse staffing	B
There will be critical care outreach, including Level 1 cover with designated consultant sessions.	Demonstrate response to Department of Health initiative of “Critical care without walls”.	B
The will be agreed protocols for the transfer of patients in whom intervention is required.	Protocols	B

Similar standards of care will apply where patients with acute neurological illness are cared for outwith the Neurology Centre.	Network arrangements Audit of outcome for delayed/denied admissions	A

Multiprofessional teams should work together across disciplines and locations to achieve the best outcomes for critically ill patients.		
Standard	**Indicator**	**Urgency**
Patients with a critical neurological illness will be cared for by multidisciplinary teams containing adequate numbers of specifically trained staff.	The name of each team member or staff position with their role agreed by the lead clinician.	A
Team members will meet regularly to review the patient's progress.	Entries in patient case-notes.	A
MDT members will take part in continuing education and professional development	CME / CPD programmes/attendance logs	A
Neurology SpR training programmes will include formal training in critical care	Local curriculum	B
Operational policies will be recorded annually.	Record at least one meeting per annum.	A

Neurocritical care should be provided in accordance with agreed national guidelines.		
Standard	**Indicator**	**Urgency**
There will agreed standards for admission to neurology critical care units.	Record of admission and discharge criteria.	A
Transfer to the neuro-critical care unit will be undertaken by trained personnel.	Guidelines for the transfer of head injured patients – Association of Anaesthetists, 1996.	A
Each patient will have a management plan agreed between intensivists and the neurological team.	Written record, including management options, unit protocols, and guidelines.	A
The Clinical lead will be responsible for the development and dissemination of guidelines/integrated care pathways together with arrangements for their regular review and revision	Evidence of dissemination of guidelines/care pathways to referring centres and to centres receiving patients after the completion of their acute intervention	B

There will be effective communication between all those responsible for the patient's care, and with the patient and carers.		
Standard	**Indicator**	**Urgency**
There will be regular communication with patients and their relatives.	Written records in notes.	A
There will be written information for patients and relatives including information about support networks, outreach services, liaison with other health and community services, self help groups, psychological, social and cultural support	Written or other type of material (audio/visual) in languages suitable to population served. Evidence of availability	A
Information about diagnosis and the care plan will be given to specialists who refer and receive patients and to general practitioners and to teams responsible for rehabilitation and community reintegration	Discharge summaries audit 'Core' information at the time or in advance of discharge The definitive summary dispatched within 10 days.	A
Patients or relatives will have access to a member of the Neurological Team to discuss the patients care.	Survey of patient's experiences and of the services offered by the Team, the results, action identified and implemented	A

There will be adequate facilities for ongoing care of patients after acute neurocritical care management.		
Standard	**Indicator**	**Urgency**
There will be adequate numbers of level 1 critical care facilities	Number of beds.	B
The MDT will be provide follow up and after-care for patients who have been in neurocritical care.	Evidence of regular follow up and review protocols	B
There will be consultant sessions for a follow up clinic to help review the outcome of patients and improve the service.	Recommendation of the Intensive Care Society	B
A neurological disability rehabilitation team will be available	Personnel in post	A

There will be links with social and community services eg social worker & domiciliary nursing	Named team members	B

Neurocritical care services should engage in regular audit and research.		
Standard	**Indicator**	**Urgency**
The Clinical lead will be responsible for developing an audit programme.	Evidence of an audit cycle, regular reporting of results and a timetable for review of guidelines	B
The unit participates in National Programmes for Audit.	Membership of ICNARC or equivalent.	B
Audit will take place against existing agreed standards.	Details of annual audit programme including outcomes, action plans and effects of changing practice At least one audit of clinical practice of demonstrable clinical significance will occur annually	B
Arrangements will be in place for formalised risk assessment, “near miss” and incident reporting, complaints and potential/actual litigation analysis.	Record of risks etc. Minutes of meetings, audits performed	A
Regular morbidity and mortality review meetings will take place within the audit programme. All clinical staff shall be provided with sufficient time to prepare for and to regularly attend such meetings.	Registry of attendance and lessons learned/practice changed	A
Information systems will be developed to ensure regular production of reports to support clinical governance and contract monitoring.	Regular, clinically relevant, reports	C
A research infrastructure will be in place to help improve the quality of service and patient outcomes.	Record of research project(s)	A

Chapter 6
Standards of care for people with neurological symptoms prior to a diagnosis and treatment

At the onset of symptoms most people will initiate the process of establishing a diagnosis through their GP. Not infrequently, problems arise because it may take some time before the GP recognises the symptoms as neurological and/or the GP is uncertain whether an individual's symptoms warrant a specialist referral - for example slight tremors, clumsiness or persistent eadaches. This can be a very anxious and frustrating time for the person and their family.

Most people with neurological symptoms will only require a single consultation and out patient investigations, few will require long term care. For patients waiting to be seen the follow objectives should be achieved.

There should be a trained workforce available to manage the patient at the start of their illness.		
Standard	**Indicator**	**Urgency**
Those involved in the management of the onset and diagnosis of the patient with a suspected neurological disease will have had training in recognising, understanding and managing neurological problems and disability.	Evidence of training and competence.	A

Primary care physicians should be able to access specialist services for advice whilst waiting for diagnostic services for people with neurological symptoms.		
Standard	**Indicator**	**Urgency**
People will be referred for a specialist opinion when there is uncertainty about diagnosis or management.	Case mix of referrals against guidelines	B
Referral guidelines will be available for GPs	Guidelines available	A
Information will be available to GPs about subspecialty services.	Information available	A

Support and care should be available during the time between referral and appointment with specialist services.		
Standard	**Indicator**	**Urgency**
Patients will be reviewed by the GP whilst waiting for specialist services and appropriate action taken if there is any change in the patients condition.	Patient surveys	A
Trained community based care teams will be involved in the management of any neurological disability during this period.	Availability of community teams	B

Waiting times to see a neurologist should be appropriate for the initial symptoms.		
Standard	**Indicator**	**Urgency**
Patients who are acutely ill should be seen the same day.	Audit of waiting times	B
Urgent referrals should be seen within one week	Audit of waiting times	B
No patient should wait longer than 4 weeks.	Audit of waiting times	C
Inappropriate referrals should be redirected to another specialist and the GP informed.	Record of inappropriate referrals	A

The diagnosis and steps to confirm the diagnosis and information about the diagnosis should be shared as soon as possible with the patient and, with the patient's consent, their partner, family and other carers.		
Standard	**Indicator**	**Urgency**
A confirmed diagnosis will be discussed with the patient and, if they wish, a carer.	Patient satisfaction surveys	A
Patients will be informed about the nature of their investigations and likely waiting times.	Information about waiting times.	A
Neurology units will have access to comprehensive and comprehensible patient information about the common neurological conditions.	Evidence of available patient literature.	A
Patients know the purpose of a follow up visit.	Entry in medical notes.	A

Social and employment issues will be reviewed.	Entry in medical notes.	B
Information will be given about relevant voluntary organizations.	Entry in medical notes.	B
Information will be available in appropriate languages and formats.	Availability of information.	B

Adequate and timely diagnostic support should be available for people with neurological disorders.		
Standard	**Indicator**	**Urgency**
The technology and equipment required to ensure efficiency and effectiveness throughout the diagnostic process should be identified to commissioners.	Inclusion in local development plans	B
Patients should wait no longer than one month for routine CT imaging	Audit of waiting times	B
Patients should wait no longer than 1 month for routine MRI	Audit of waiting times	C
Patients should undergo neurophysiological tests within two months of their first appointment	Audit of waiting times	B
Neuropsychological testing should be available within three months of a request being made	Audit of waiting times	B

General practice should be involved early in the ongoing care of patients.		
Standard	**Indicator**	**Urgency**
Following an out-patient consultation, or in-patient episode written confirmation of the diagnosis and care plan, including reference to community services already involved, should be passed to the GP.	Audit of care plans	B
Patients should be encouraged to make a review appointment with their GP soon after hospital discharge or out-patient consultation	Case note review.	A

Chapter 7
Continuing care for people after the diagnosis of a neurological disease has been made.

By this time most people will have a diagnosis and even those in whom there is remaining uncertainty may require management of their symptoms. The implementation of appropriate medication, therapy and social support lays down the foundation on which long-term management and service input will be built. This phase of care is needed during any acute or unstable period. Continuity of care is important; when someone has a long-term condition their case should not be "closed", rather they should be able to speedily access this phase of care should they need it. Some people with neurological conditions will want to have complete control over their care and full knowledge about the services and treatment options available to them. It is acknowledged, however, that some people are not able, or do not want, to be fully involved in, and informed about, their care. The following standards, some of which may seem repetitive, may need some flexibility in their implementation.

Plans for patient centred services should be established early on to ensure the individual's best quality of life both immediately and for the future. Local disability services should be available, involved, adequate and flexible and need to be integrated between key providers with good communication and liaison. There should be evidence of coordinated care for people with long term neurological conditions that includes the provision of continuity of care..		
Standard	**Indicator**	**Urgency**
Each patient will have a named key worker responsible for co-ordinating care.	The patient and/or carer will be able to name their key worker and give evidence of their involvement in their care plan	C
There will be evidence of good co-ordination, particularly between the different agencies and departments providing community care, that might include core[1] and non core[2] services.	Posts in place with named individuals Care plan audit.	C
Patients and families will have information on their condition in an appropriate language and format.	Evidence of information/support systems	C
Each patient will be assessed by appropriate professionals[3] as soon after admission as is practicable for their social and care requirements after discharge with the aim of coordinating community services and formalising discharge planning	Record of the referral to a Social Worker experienced in the requirements of patients requiring Neurological Care.	A
There will be appropriate staff for assessment and treatment	List of staff and names.	B
Patients and families will have the opportunity to provide feedback on the quality of care received.	Mechanism and results of feedback	B
Care pathways should be developed for commoner neurological diseases.	Presence of a care pathway	B
Social services should be involved in the design and implementation of integrated care pathways	Evidence of involvement	C

Rehabilitation services should be involved early on to reduce disability and improve long term outlook.		
Standard	**Indicator**	**Urgency**
Patients requiring specialist rehabilitation services will be referred early after diagnosis of a long term condition for assessment and treatment.	Care plan	B
Patients will be actively involved in setting their own goals.	Care plan	B
Secondary prevention advice on conditions such	Protocols in place	A

[1] Core services include those provided by Neurologist, Neurosurgeon, Neurophysiologist, Neuroradiologist, Neuropsychiatrist, Specialist nurse, Consultant in rehabilitation medicine, Neuropsychologist, Speech and language therapist, Physiotherapist with neurological expertise, Dietician, Social worker, Occupational therapist, Voluntary organisation as advocate or provider of service or information, GP, Orthotist, Prosethetist & Equipment providers

[2] Non core services are those provided by Counsellor, Genetic services, Education services, Leisure services, Housing services, Benefits agencies and Community nurses

[3] Including input from nursing staff, therapists, social worker, link nurses with involvement of secondary care local to patients home and GP.

as stroke will be an integral part of rehabilitation.		

The information needs of patients should be addressed during this phase of their illness.		
Standard	**Indicator**	**Urgency**
Patients and carers will have a single point of contact through which they can access appropriate information and advice.	Available of single point of access	B
Medical information and advice will be available to cover an explanation of the condition, options for the treatment and management, implications of the condition for life choices, advice on medication, secondary prevention and sexual health	Case note review	A
Information about services available from statutory and non statutory health and social service care providers will be available.	Information available	B
Information about what to do in a crisis and where to get emotional support including counselling services and self-help/support groups will be available.	Information available	B
Patients will know how to make suggestions for improvements or complaints about services.	Patients councils an place	B
Sources of information about other agencies[4] will be available.	Information available.	B

Care plans should be drawn up based on the principles of full involvement of the person affected, and their carers and family, emphasising real choice and optimising quality of life. Care plans should attempt to define the following.		
Standard	**Indicator**	**Urgency**
The diagnosis and the responsibilities of each member of the care team including the specialist, the GP and community services.	Shared care protocols	B
Arrangements for ongoing medical monitoring and easy re-entry to services.	Shared care protocols	B
How people will access or re-enter appropriate rehabilitation services will be stated.	Availability of services	B
A timetable for implementation of the care plan.	Care plan audit	B
Details of the levels of care and support services including day care and flexible respite/relief services required.	Care plan audit	B
How the person will access emotional and psychological support from appropriate professional and/or a voluntary organisation.	Involvement of appropriate persons	B
How the person will access equipment loan services	Care plan audit	B
Patients and carers will receive a copy of the care plan.	Record of information communicated	B

Appropriate aids and equipment should be provided in a timely fashion.		
Standard	**Indicator**	**Urgency**
Trained professionals will assess patients for equipment.	Names trained individual available	B
Reassessments of need will always include a reassessment of equipment needs.	Case notes review	A
Equipment will provided in a timely fashion.	Audit of provision of equipment.	A

[4] Other agencies should include information about respite care, housing, education, employment, recreation & leisure, transport & mobility, sources and funding for equipment, and where to gain information about financial and social security benefits

Chapter 8
Longer-term management of people with a progressive disability or a stable condition with changing needs due to development or aging.

Long-term management should be concerned with ensuring the highest quality of life, whatever the cause or severity of disability. In the intermediate phase, plans for treatment and services will have been initiated and put into practice, and in the majority of cases these will provide the basis for ongoing management. However, some conditions are unpredictable and can deteriorate due to their nature and care will need to be modified to take account of this. During a medical crisis or during a period of change in their lives however, people may need to access the kind of care described at the onset or intermediate management phase.

Many people with long-term neurological conditions should be expected to become experts in their condition.		
Standard	**Indicator**	**Urgency**
People with long term conditions will be offered the opportunity to be fully involved in both assessing and in making decisions about meeting their needs.	Case note review	A
Regular needs based assessment will be offered to all people with long term neurological conditions.	Case note review	B
Care plans will include review of medical, therapy, social services, emotional support and equipment requirements.	Case note review	B
Medical review will include a review of the medical management and assessment for a range of interventions that might be of benefit.	Case note review	A
Rehabilitation review will include an assessment of the potential for the patient to benefit from intermittent (time limited) community rehabilitation, a comprehensive assessment of needs in relation to equipment and assistive devices and an reassessment of needs and abilities of the principal carer	Case note review	A
Individually tailored vocational rehabilitation will be available to assist people in getting back into work, provide a therapeutic earnings placement or provide purposeful activity.	Case note review	C
Appropriate services providing emotional and psychological support will be available to people with long-term neurological conditions, their carers and family members.	Case note review	B

The general health needs of people with long term neurological disabilities should be addressed		
Standard	**Indicator**	**Urgency**
General health services, such as dentistry, should be accessible and appropriate for people with neurological disabilities.	Evidence of availability Patient complaints	A
People should have access to a good incontinence service, including advice and provision of laundry facilities.	Evidence of incontinence services	A
Specialised care should be available to people when they are using mainstream services, such as maternity services.	Patient complaints and feedback	A

The needs of carers and family should be assessed and provided for.		
Standard	**Indicator**	**Urgency**
A separate assessment exercise will be undertaken to assess the care needs of carers and family.	Care plan review	B

Appropriately staffed residential care should be available when required.		
Standard	**Indicator**	**Urgency**
Where permanent residential or nursing home care	Availability of placements	A

is necessary, appropriate and adequate facilities will be available locally.		
Younger disabled people will not be placed in establishments generally intended for elderly people.	Availability of placements	A
Therapies and activities will be available as required.	Evidence of appropriate staffing	A
Professionals and care workers in residential and nursing homes and those in general and elderly care hospital wards will have training about the needs of people with neurological conditions.	Evidence of competence.	A

Chapter 9
Palliative care for people with neurological conditions

Some neurological conditions are life threatening. This section relates specifically to people who are in the last phase of a chronic and deteriorating condition, though it is recognised that for some neurological conditions, for example motor neurone disease, a palliative care approach might be initiated from the point of diagnosis.

Patients should be involved from an early stage in planning their own palliative care.		
Standard	**Indicator**	**Urgency**
At the appropriate time the affected person and the carer and family are as fully informed as possible as to the prognosis and the range of services available whether within a hospice, nursing home or for care in their own home.	Care plan audit	A
A care plan aiming to improve quality of life is to be agreed and frequently reviewed by the person affected, carer and family, GP and co-ordinator to include symptom and pain control, emotional and psychological care	Care plan audit	A
Support will focus as much on the family as on the patient.	Care plan audit	A
Advice and support is readily available about how to cope with practical issues after death including the availability of bereavement counselling.	Bereavement counselling available	A
Professional staff and volunteers participate in on-going training programmes and have access to support for their own emotional well-being.	Evidence of programmes in place.	A

Appropriate hospice and home care services should be available for people dying as a result of neurological disease.		
Standard	**Indicator**	**Level**
Those working in hospices and nursing homes have an awareness of the needs of people with neurological conditions.	Evidence of training and competence.	A
Service providers review the numbers of these facilities in order to ensure access for all those who might need them.	Commissioner review of requirements	B
Advance planning ensures that the person affected and their family are able to establish links with the hospice or nursing home to build up relationships with the staff whilst communication is still possible.	Care plan audit.	A

[1] 'Levelling up' The Neurological Alliance 2002. www.neurologicalalliance.org.uk/docs/levelling_up/level.pdf
[2] 'Neurology in the United Kingdom – Towards 2000 and Beyond'. ABN 1997 http://www.theabn.org/downloads/2000%20and%20beyond.pdf
[3] 'UK Neurology – the next ten years'. ABN 2003. http://www.theabn.org/downloads/Next%2010%20years-final.pdf
[4] 'Standards for Neurology'. Therapy Standards Working Group. March 2000. http://www.csp.org.uk
[5] ABN recommendations on secretarial support for consultants. http://www.theabn.org/downloads/private/ABNSEC.pdf
[6] 'Genetic Services for Neurological Disorders'. http://www.theabn.org/downloads/Genetic%20Services-final-Oct03.pdf
[7] Neuroscience Critical Care Report. Modernisation Agency 2004. http://www.modern.nhs.uk/scripts/default.asp?site_id=20&id=7117