GUIDANCE FOR LOCALLY COMMISSIONED NEUROLOGY SERVICES IN ENGLAND:

CLINICAL COMMISSIONING GROUPS (CCGs) DELIVERING BETTER CARE FOR PATIENTS WITH NEUROLOGICAL CONDITIONS

Developed by:

Services & Standards Committee, Association of British Neurologists

Approved by:

ABN Council
National Clinical Director for Neurological Conditions

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A. Executive Summary

From April 2015, outpatient neurology referrals made by General Practitioners to adult Neurosciences Centres and Neurology Centres (see Appendix 3) are no longer commissioned by NHS England and should be reflected in CCGs contracts (ref: Commissioning Intentions 2015/16 for Prescribed Specialised Services, published 30th September 2014 link). The arrangement for specialised neurology in-patient services will not be affected by this change and will continue to be funded by NHSE. At its meeting on 15 September 2015, the Specialised Commissioning Oversight Group (SCOG) endorsed the proposed methodology for determining the allocations for those services to be devolved to CCGs for 2015/16 so that recurrent allocation adjustments should be actioned on the basis of the agreed 2015/16 contract values for these services link. This commissioning toolkit provides guidance on the service specification that should be offered and, where not already provided by NICE, quality standards by which a neurology service should be measured.

Although this is a complex service to commission, and some uncertainty remains over which of the very rare and more expensive services will be commissioned by NHSE, this reorganisation provides an opportunity to improve the commissioning of out-patient and some in-patient general neurology care.

Prior to the new commissioning arrangements brought in under the Health and Social Care Act 2012, only non-specialised neurology scheduled care was commissioned by Primary Care Trusts (PCTs). Targets set for unscheduled new patient appointments, have unfortunately distorted neurology care by disadvantaging patients with acute neurological problems and the care of patients with long term conditions.

Despite their high frequency, patients presenting with acute neurological conditions rarely see a neurologist in the early days of admission, if at all. (ref: ABN Acute Neurology Survey link) Only a few patients with long term conditions - such as those with multiple sclerosis (MS) and Parkinson’s disease (PD) - have an identified integrated care pathway with access to a multidisciplinary team. People in the UK living with a LTNC make up 19% of hospital admissions (ref: RCP Long term neurological admissions 2008 link). Many of these admissions could be avoided.

Although acute neurology conditions are the third most common presenters (ref: Local adult Neurology Services for the Next Decade 2011 link) the failure to provide rapid access to a neurology opinion leads to delay in diagnosis, increased length of stay (LOS) and inappropriate use of investigations. The National Audit of Seizure Management in Hospital completed in 2011 (link) showed that 40% of District General Hospitals (DGH) had no policy for acute seizure care and 50% had no policy for further referral. Only 3.5% of patients with seizures were admitted onto a neurology ward (link).

By commissioning urgent liaison neurology care, there is the potential for 75% of patients admitted with seizures being seen by a neurologist within 24 hours, with a halving of LOS, a change in diagnosis in 30% and management change in 80% of epilepsy patients with cost savings of £500K in an average DGH, with significant improvements in outcomes (link)

There are 11,000 patients at least with a long term neurological condition in a 500K population (ref: Neuronumbers 2014 link). Every GP has 40 patients and...
every practice 120 such patients. Long term care is not properly integrated, which results in unnecessary admissions, re-admissions and poor care with increased costs. 25% of patients with Parkinson’s disease, for example, have never seen a Parkinson’s nurse; these posts free up an additional 50% of consultant time in clinic. Many patients with Parkinson's disease have difficulty accessing speech and other therapy for their patients including neuro-psychiatry and this often results in admissions which could have been avoided. Commissioning of “NeuroCare” multidisciplinary teams by clinical commissioning groups (CCGs) would radically improve this. (Ref: NICE, neurological conditions overview link)

The commissioning responsibilities of CCGs under the new arrangements present an opportunity for the first time for comprehensive local neurology services to be commissioned. Using this opportunity will enable radical improvements in care at lower cost. This document offers practical advice and guidance to support best practice to ensure CCGs able make the most of this opportunity for people with neurological conditions in their communities.

From April 2015, CCGs are responsible for commissioning all general neurology out-patient services for their population other than those highly specialised neurology services commissioned by NHS England. This locally commissioned service, will be provided in DGH’s and in community settings as well as in designated neurology and neurosciences centres, and covers the needs of patients with a neurological condition, whether this is an acute presentation or a life-long condition. It is important that pathways between specialised inpatient services and non-specialised outpatient services are collaboratively commissioned, ideally at regional level through the Collaborative Commissioning hubs.

Patients with neurological conditions may need to access care in a network of settings at different times in the lifetime of their condition and it is vital that CCGs and Local Authorities liaise with each other and with NHS England, Area Teams - including the 10 responsible for specialised services - and the strategic clinical network for mental health, dementia and neurological conditions to ensure smooth transition between services in the community, DGH and neuroscience centres.
B. Introduction
From 2015/16 CCGs are responsible for commissioning health services to meet all the reasonable requirements of their patients. Local authorities will be responsible for providing population health advice, and information and expertise to CCGs to support them in commissioning health services that improve population health and reduce inequalities.

Neurologists and all other healthcare professionals specialising in neurology are keen to and must be involved with CCGs in planning of local neurological services, and to play a strategic role in developing safe, high quality and efficient services for the local population. A local neurologist and lead general practitioner need to be identified and be accountable for this.

Over the past 30 years we have seen a slow evolution in the delivery of neurological services from provision by a few Neurosciences Centres to fully comprehensive local services in some areas. Hopefully with the creation of the commissioning bodies under the Health and Social Care Act 2012, services will now radically improve, so that people with a neurological condition, their carers and families can see for themselves that care is improving, as are outcomes and quality of life.

Initially we saw the development of the “hub and spoke” model; this was limited at the time by the small number of neurologists, who would visit a DGH once a week with dependence on general physicians to manage neurological cases on a day to day basis. Although the number of neurologists has grown steadily (current UK average is one consultant per 100,000), the total number in each of the Home Nations is still well below what is needed to provide a comprehensive service of one consultant per 70,000 population (ref: Local adult Neurology Services for the Next Decade 2011 link). Bringing the neurology service provided in many busy hospitals with acute medical services up to an appropriate standard, must be a key priority for CCGs across the country.

A variety of factors have contributed to the significant increase seen in general neurology workload over the last decade, and include:

- A significant year on year increase in out-patient referrals from primary care, where neurological problems account for 17% of consultations. (ref: National Intellegence Network for neurology link)


- a reduction in the numbers of neurology beds in DGHs and neurology/neurosciences centers.

- introduction of acute stroke units and trauma centres, that require immediate neurology input into patient management

Properly informed commissioning will ensure a sustainable future for the care of neurological patients (Table 1)
Table 1: Key points for CCGs to consider when commissioning neurology services

- There should be strong clinical representation and patient and public involvement should be established to develop a comprehensive local neurology service over a 10-year period, working closely with regional neurosciences services;

- Resources should be provided to increase neurology sessions to improve acute (unscheduled) care of patients with a neurological condition in district general hospitals, neurology centres and regional neurosciences centres;

- The importance of the partnership between the DGH/NC and RNC must be recognised;

- Commissioning of health care and social care for neurological patients should be linked;

- Alternative community settings for elements of neurological long-term care should be considered – for example, neurologists linking with community hospitals and GP surgeries;

- There is a shortage of neurology provision and this needs to expand to provide an acceptable quality of service with planned further expansion to take account of demographic changes;

- Local geographical, population and manpower variations mean that different models of service delivery must be used (see p.9);

- There is currently no mandatory tariff for neurology outpatient consultations. There is a wide range of indicative tariffs used, which require rationalisation (planned for 2017) Payment by results tariffs for outpatient and inpatient work require careful research and should be calculated to allow high-quality services to be maintained and developed;

- Improved resources for neurological rehabilitation are urgently needed.
C. What should a local neurology service offer?

A CCG commissioned neurology service should consider the fact that patients with neurological conditions may access the healthcare system in various settings. The scale of the current demand is outlined in Table 2.

### Table 2: Current neurology demand

Neurological Alliance Neuro Numbers 2014 ([link](#))

- 12.5 million patients in UK with a significant neurological disorder (rising as we all live longer)
- More than 4.8 million are permanently disabled by their condition
- 700,000 neurological admissions per year
- 17% of GP consultations are for a neurological problem
- 10% of A/E visits
- 19% of all hospital admissions
- 33% of people living in residential care

Neurologists see a wide range of patients. There are 11 common groups of neurological conditions (Table 3), which account for about 70% of new neurological referrals, but additionally there are hundreds of different neurological diseases, syndromes and symptoms.

### Table 3: Common neurological conditions

- Stroke and transient ischaemic attacks (TIA)
- Headache including migraine
- Epilepsy
- Dementia
- Congenital neurological problems including cerebral palsy
- Parkinsonism and other basal ganglia disorders
- Inflammatory disorders of the central nervous system including multiple sclerosis
- Polyneuropathies
- Mononeuropathies
- Traumatic brain injury
- Functional symptoms

Patients need a rapid and accurate diagnosis, with information and advice from diagnosis onwards, including support to self manage where relevant, and appropriate treatment where possible. If patients have a chronic condition, they may also also require appropriate continuing follow-up and support from a sympathetic team, all members of which will possess the required clinical neurological expertise. Services should be available as close as practicable to the patient’s home.
There are only a few possible venues and types of direct interaction between patients and neurologists, and for convenience it is possible to divide the service into those delivered from a hospital setting and those from a community setting.

1. Hospital Services

CCGs will be responsible for commissioning neurology services provided in DGHs that will meet all the reasonable requirements of their population, and will include:

a. Unscheduled care:

Patients enter this pathway as an unplanned emergency admission with new or existing neurological problems or with a neurological condition which has undergone routine or emergency surgery requiring a review of management.

Patients may need to be seen in an inpatient bed, in emergency departments (Accident and Emergency Unit and Medical Admissions Unit), in an acute medical day-case facility, hyperacute stroke unit, Intensive Care Unit, High Dependency Unit, or on a specific neurology ward.

The type of patients seen is varied, but usually have acute symptoms that require assessment and advice within 24 hours. In selected cases, there is an option of transfer to a specialist neurology ward, which will be in a Neurology or Regional Neurosciences Centre.

b. Scheduled care:

The majority of patients in this pathway will have been referred by their GP and placed on a waiting list to be seen in an outpatient clinic. This can be delivered at a number of sites including Regional Neurosciences Centres, Neurology Centres, or DGHs, community clinics or GP surgeries. Patients seen would include new referrals requiring diagnosis and advice and follow-up patients with short term, medium-term or lifelong needs. Those referred by other consultants can also be seen in these locations, though if seen in a regional neuroscience centre, would be funded by NHSE.

c. Semi-scheduled care

Patients in this category do not require urgent admission but they need to be seen in a clinic within 1-2 weeks – for example a first seizure or relapse of MS.

d. Office work

This involves dealing with referrals (letter or electronic), e-mail and other correspondence, telephone queries, texts and telemedicine. Reviewing the results of investigations and scans and then communicating management advice and recommendations to the patient and their general practitioner. All patients should receive a copy of all clinic letters that relates to their consultation.

e. Out of hospital visits

Visiting patients in nursing homes and other long-term care facilities is most commonly done by neurology nurse specialists. These nurses must be part of centre based disease specific MDT, including regular joint clinics with medical team so that they do not work in isolation.
f. Service infrastructure

i. Multidisciplinary Team meetings: for example, neuroradiology, neuropathology, and various clinical teams. These are important for planning care and may avert the need for outpatient review.

ii. Education and training: This is essential to maintain and improve the level of knowledge and understanding about neurological symptoms and of common and rarer conditions. Programmes should be run for nurses, therapists, pharmacists, junior doctors and GPs. Developing and promoting the use of management guidelines for neurological conditions where they exist, such as headache.

iii. Providing information and support: this may be through written leaflets or access to websites. Patient representative organisations have a wealth of information, support and guidance to offer, and hospital services need to signpost people with neurological conditions to the relevant organisation. Contact details of the neurology department and its specialist nurses should be available for all patients.

Patients should be offered access to clinical trials and given information about ongoing research projects that they may wish to enrol in. Structures need to be in place for patients and staff to provide feedback and comments in an open manner on the service provided. These could be collected as informative patient stories.

2. Community Services

CCGs are now responsible for commissioning a range of community health services, including community rehabilitation services and mental health services, but not public health services such as health visiting and family nursing. Commissioning effective and comprehensive services for people with neurological conditions requires that commissioners are aware of the case mix of patients requiring community services and the necessary integration between community services and secondary and tertiary services.

a. The conditions

Patients with neurological conditions, a proportion of whom will have required neurosurgery, are frequently left with long-term disability requiring effective rehabilitation to increase the independence, enhance their quality of life, and, where relevant, maximise their ability to return to work.

Around 40% of those who have a stroke will be left with moderate to severe impairments requiring specialist care. Around 10% require lifelong care in a nursing home. Some conditions such as MS that affects as many as 1:800 of the population experience life-long fluctuations in their symptoms requiring long term care. Many conditions characterised by progressive neurological deterioration such as Parkinson's disease and related disorders eventually result in patients' increasing dependence on services. Acquired brain injury, and spinal cord injury is common. In 2011-12, 353,059 people were admitted to hospital with head injuries, many resulting in long-term physical, behavioural and emotional consequences any hundreds of less common disorders, some genetic, (e.g. muscular dystrophies) some infective (e.g. meningitis), some malignant.
Guidance for Locally Commissioned Neurology Services: Clinical Commissioning Groups (CCGs) Delivering Better Care for Patients with Neurological Conditions: developed by SSC, Association of British Neurologists and Neurological Alliance

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(survivors of childhood and adult brain cancers) result in the need for community-based treatments.

b. Routes of access to community services

The 22 Major Trauma Centres are linked to Major Trauma Networks for adults and children in England. Patients treated at these centres, as well as patients with traumatic and non-traumatic nervous system disorders from Neurology and Neurosciences secondary and tertiary centres, require access to community services for continuing care. Some patients commence their care as hospital in-patient or out-patient, before transitioning to community services. Many patients with progressive neurological conditions, such as dementia require community services sometimes culminating in residential care, accessing community services from primary care.

As well as being cheaper to provide, effective community services reduce unscheduled admission rates to secondary care. The wide range of neurological conditions requires generic neuroscience skills and specialist skills, with specialist skills, from both neurology and neurological rehabilitation, being available in the community as well as in neuroscience centres, so that patients are directed to appropriate services. Such services are required to implement care pathways for patients with long-term neurological conditions in line with National Service Framework for Neurological Conditions and Department of Health recommendations patients in the least intensive setting for their needs.

People need access to skilled rehabilitation and symptom management across the pathway and this demands access to specialist care. Specialist care in this context would mean an appropriately trained physician (neurology or rehabilitation medicine) who can work directly with the community team who also need highly skilled (band 7 and 8 neurology trained staff and extended scope practitioners). This allows patients to be seen in their own home/community but still access skilled care. For this to happen, one approach is shared appointments between neuroscience/neurology centres and local community rehabilitation for both therapists and rehabilitation medicine consultants.

D. What is currently being delivered and what should be commissioned?

The details need to be discussed with local neurologists, but CCGs have responsibility to deliver services outlined in the following broad headings:

i. A comprehensive acute neurology assessment, diagnosis and management service available 7 days per week to all hospital with an acute medical intake.

ii An out-patient service allowing the assessment of patients with neurological symptoms in accordance with NICE standards, and ABN standards where they do not exist (see appendix), including access to appropriate fast track services such as ‘first fit’ clinics.

iii. Long-term neurological condition management service that serves patients and their carers in accordance with patient need. This could be delivered through creating a local Neurocare team.

iv. Integrated primary and secondary care neurological service to support primary
care in the management of more prevalent neurological disorders - primarily headache and seizures - that have a major economic impact on the patient’s ability work,

v. The new strategic clinical network (SCN) for mental health, dementia and neurological conditions should consider establishing groups to explicitly research new models of delivering services, acknowledging that there are insufficient services to deliver the traditional model of care. This might examine better supporting primary care, triage systems, free-standing chronic condition management services, telemedicine, etc. These services need to include access to an expert in neurological rehabilitation, be able to manage rehabilitation complexity, and to deliver appropriate levels of expertise and intensity. This is already underway in several Neurology SCNs link.

vi. All CCGs should have a long term conditions register as recommended in the NSF for LTNC which enables annual review of patients with disabling conditions.

vii patients should be able to access extended scope therapy practitioners and highly skilled therapists whether they are cared for in the community or the hospital.

1. What is needed?

The following would be examples of minimum standards.

- access to telephone neurology advice 24/7
- access to an urgent neurology opinion in outpatient clinic (within 2 weeks)
- access to a neurology opinion in Medical Assessment Unit or on hospital ward (within 24h)
- access to a specialist nurse service in all care plans. This may be for specific conditions such as epilepsy, Parkinson’s disease, MS, MND, neuromuscular diseases, or a generic nurse specialist.
- nurse specialists should be part of the disease specific MDT and be working under the supervision of the relevant consultants. This is especially important for Community based specialist nurses.
- open access through multiple referral pathways (e.g. therapist led or patient initiated) should exist to rehabilitation medicine and multidisciplinary teams to manage both predicted and unpredictable changes in functional status thus preventing hospital admission.

2. Future developments

This should be discussed with local neurologists, other clinicians, allied health professionals, patients and the public. There is an urgent need for the following to be developed: and delivered:

i. Provision of a 7 day service for acute neurological presentations in all hospitals with acute stroke intake.

ii. Long-term neurological condition management to attain similar priority as new referrals, so as not to be disadvantaged by 18 week RTT.

iii. Larger DGHs alongside Neurology and Regional Neurosciences Centres to have
iv. Developments to enable other staff to assist in the management of neurological conditions - working in teams that would include the local neurologists, GPs with an interest in neurology, specialist nurses, old-age psychiatrists with interest in dementia, geriatricians with special interests in long-term Parkinson’s/epilepsy management, neurorehabilitation clinicians.

3. Measuring value/quality

Measuring the value of an intervention or the quality of care is difficult in a specialty that manages a wide range of conditions, including many progressive long-term neurodegenerative illnesses. An evidence base will need to be developed for a range of quality measures that will lead to improved care in all areas of neurological disease rather than just in easily measurable settings. Care will be needed to avoid developing measures of process, unless clearly linked to quality.

A number of easily identified quality measures should be introduced to drive rapid access to quality care for urgent neurological disorders. Examples might include TIA or stroke services, first seizure or multiple sclerosis relapse services, or provision of neurological assessment in acute DGH settings. A biannual review of quality measures should be undertaken to drive improved services. Necessary developments are likely to vary depending on local needs and priorities.

4. What should a high quality neurology service include?

There are already published NICE approved standards for certain neurological conditions (see Appendix 2).

The ABN have produced Quality Standards on the other main conditions not covered by NICE (see Appendix 3)

5. Current costs, efficiencies and cost reduction. Neurological Commissioning Support

Improving the quality of neurology care: A ten point plan for better commissioning
1. Know your population to reduce unplanned admissions
2. Get smart with data
3. Promote the self care agenda
4. Ensure neurology services are in your local Joint Strategic Needs Assessment
5. Promote better medicines management
6. Introduce integrated, multidisciplinary teams
7. Focus on end of life care for neurology
8. Link into or develop local neurology networks
9. Work with the voluntary sector to improve patient outcomes
10. Educate your workforce in neurology
E. Appendices

Appendix 1: What is commissioned as specialised neurology services?

Adult specialist neurosciences services [D3 – Adult Neurosurgery and D4 – Neurosciences] (link)
Appendix 2: Existing NICE Quality Standards to support models of good practice

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<th>Quality Standard</th>
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<tr>
<td>Multiple Sclerosis (<a href="#">link</a>)</td>
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Appendix 3: ABN’s quality standards to support models of good practice

1) Scheduled care: non-urgent neurological conditions
2) Unscheduled care: neurological emergencies and acute neurology
3) Parkinson’s disease
4) Treatment of dystonia with botulinum toxin
5) Huntington’s disease
6) Motor neurone disease
7) Neuromuscular disorders
8) Peripheral neuropathy
9) Multiple Sclerosis
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1) Scheduled care: non-urgent neurological conditions

Revised February 2016 by the ABN Acute Neurology Advisory Group

Introduction

Patients are frequently referred to neurologists for advice on diagnosis and management of their symptoms. As a result, quality standards that are written on the basis of diagnosis are not applicable. For example, patients with numbness and tingling of the hand might have carpal tunnel syndrome, a cervical disc, multiple sclerosis, or a brain tumour. Thus many patients will be referred to general neurology out-patients for which generic standards are required. These standards refer to a pre-diagnosis care pathway.

Statement 1
New patients referred to the general neurology service will be seen in a timely fashion: in keeping with NICE guidance where appropriate (eg first seizure, 2 weeks) and within NHS waiting time standards for England, Scotland Wales or N Ireland (eg 13 weeks to meet 18 week standard in England)

Statement 2
General practitioners will have access to advice from a neurologist by letter, phone or email.

Statement 3
All neurology patients should have a plan of care indicating the diagnosis intended investigation pathway, treatment and where necessary the arrangement for follow up. In most cases, hospital policy dictates that all clinic letters are copied to the patient, which provides the relevant information. Patients should be entitled to receive written information within 5 days following their appointment.

Statement 4
Patients will have appropriate access to follow up appointments with the neurology team, to discuss results or monitor progress, at the time interval stated in their care plan. Patients with long term neurological conditions will have a named point of contact for re-accessing the service, in keeping with appropriate Quality Standard/NICE guidance) (eg Parkinson’s disease, 2 weeks)

Statement 5
The service will be provided by appropriately trained and revalidated neurologists and members of the neurological care team, including specialist nurses, General Practitioners with a special interest (GPSI) and junior doctors, who will be appropriately trained and work within an appropriate framework of supervision and clinical governance.

Statement 6
Patients accessing the neurology service will have appropriate and timely access access to neuro-imaging (MRI and CT), neurophysiology, neuropsychological testing, and ancillary investigations (serology and lumbar puncture), including in-patient assessment where indicated.

Statement 7
The service will have appropriate access to neurological rehabilitation including physiotherapy, occupational therapy, speech and language therapy, dietetics and neuro-psychology. Any patient discharged from hospital should have an appropriate handover to a ‘named, accountable GP’.

Statement 8
The service will have clear referral pathways to neurosurgery and orthopaedic spinal surgery.

Statement 9
The service will provide, where appropriate, information facilitating access for patients to enrol in clinical trials.
Statement 10  The service will maintain expertise through training, audit, and continued professional development.

2) Unscheduled care: neurological emergencies and acute neurology

Revised February 2016 by the ABN Acute Neurology Advisory Group

Introduction: These quality standards apply to patients with symptoms and signs consistent with an acute neurological problem (e.g. acute headache, confusion, seizure, progressive weakness). The problem in some patients will constitute a neurological emergency that may require inpatient care supervised by a neurologist. Patients with acute neurological problems will benefit from, and can be managed effectively and safely in a general medical setting if adequate neurology liaison services are available, coupled with rapid access outpatient neurology services. Patient presenting with features of a stroke will have access to a stroke pathway, but as many will turn out not to have had a stroke (stroke mimics), close cooperation between stroke and acute neurology services is important.

Statement 1 - Adults referred to hospital as a neurological emergency should have access to care in an appropriate inpatient setting without delay (no more than 2 hours after presentation to hospital).  

Statement 2 - Adults admitted as a neurological emergency should be able to receive advice on their management from a neurology specialist at all times.

Statement 3 - Adults admitted as a neurological emergency should see a neurology specialist within 24 hours of admission to hospital.

Statement 4 - Adults referred to hospital with an acute neurological problem should have access to care in appropriate inpatient setting within 4 hours after presentation to hospital.

Statement 5 - Adults admitted to Acute Medical Units with an acute neurological problem should have access to daily consultation or advice from neurology specialists, if necessary by telemedicine.

Statement 6 - Adults admitted to hospital with an acute neurological problem should have access to urgent inpatient imaging (CT and MRI) where indicated.

Statement 7 - Lumbar Puncture, when indicated, should be available 24/7 to all patients admitted with an acute neurological problem

Statement 8 - Rapid access pathways need to be established for adults referred from Emergency Departments and Acute Medical Units to neurology outpatient services on discharge.

Statement 9 - No patient should be discharged from a hospital setting without documentation of the neurological examination, including fundoscopy.

Statement 10 - Immediate transfer of care information should be sent electronically to a named GP for all patients, as well as printed information for the patient.

1 Depending on the nature of the emergency this may be Critical care, High Dependency Unit or specialist neurology inpatient care. If a hospital lacks appropriate facilities to care for a neurological emergency, pathways need to be established for patients to be transferred to such a setting with staff trained in the care of adults with neurological emergencies

2 Depending on the nature of the acute neurological problem and the setting, this may be an Acute Medical Unit or specialist neurology inpatient care.
Where doubt exists over suitability for early discharge and for any referral to a rapid access neurology clinic this is best discussed with a neurology specialist.
3) Parkinson's disease

Revised February 2016 by the ABN Movement Disorders Advisory Group

Statement 1: People with suspected Parkinson's disease should be referred untreated to a specialist with expertise in the differential diagnosis and treatment of the condition and seen within 13 weeks of referral.

Statement 2: The diagnosis of Parkinson's disease should be reviewed at 6 to 12 month intervals and reconsidered if atypical clinical features develop.

Statement 3: $^{123}$I-FP-CIT SPECT should be available to specialists with expertise in its use and interpretation for appropriately selected patients.

Statement 4: People with Parkinson's disease should be reviewed regularly to monitor and treat the motor and non-motor features of the condition, including neuropsychiatric symptoms.

Statement 5: People with advanced Parkinson's disease, where oral and transdermal therapies are insufficient to control the condition, should be considered for apomorphine infusion, deep brain stimulation surgery or levodopa-carbidopa gel infusion.

Statement 6: People with Parkinson's disease should have regular access to a multidisciplinary team comprised of at least a Parkinson's Disease Nurse Specialist, physiotherapist, occupational therapist, dietician, speech and language therapist and mental health team with experience in managing the neuropsychiatry of Parkinson’s and related disorders.

Statement 7: People with Parkinson's disease and their carers should be given the opportunity, at an appropriate stage, to discuss end-of-life issues with appropriate healthcare professionals.

Statement 8: People with Parkinson’s have a right to their prescribed medication at the right time specified by their prescription.

Statement 9: End of life care includes health care professionals to be responsible to continue to administer medications in the patient’s best interests.
4) Treatment of dystonia with botulinum toxin

Revised February 2016 by the ABN Movement Disorders Advisory Group

**Statement 1** Patients with suspected dystonia should be referred to a specialist with expertise in the differential diagnosis and treatment of the condition.

**Statement 2** Botulinum toxin injections are the main treatment approach for patients with primary focal dystonia such as blepharospasm, cervical dystonia, upper limb dystonia and laryngeal dystonia.

**Statement 3** Adults, who require Botulinum toxin injections, have access to specialised Botulinum toxin services within 2 months of diagnosis.

**Statement 4** The Botulinum toxin service will be located within reasonable travelling distance from the patient’s home address.

**Statement 5** The patients who benefit from Botulinum Toxin injections, are treated at intervals, adjusted to the duration of the therapeutic benefit of the treatment (usually 2 to 4 months, sometimes longer).

**Statement 6** Patients treated with Botulinum toxin can contact member of the medical team in case of side effects, discussed at the time of consultation.

**Statement 7** Patients who do not benefit from Botulinum toxin (non responders) are identified early and referred to a specialist centre with EMG and/or ultrasound facilities to review diagnosis, treatment and injection procedure.

**Statement 8** Each treatment centre records at the time of each injection, interval time, duration of benefit, response, side effects from last injection and brand of Botulinum toxin injected, dosage and sites of injection.

**Statement 9** Each treatment centre should audit outcome and safety.
5) Huntington’s disease

Revised February 2016 by the ABN Movement Disorders Advisory Group

Statement 1 People with suspected or proven Huntington’s disease should be referred to a specialist with expertise in the differential diagnosis and treatment of the condition and seen within 6 weeks of referral.

Statement 2 All relevant investigations, in particular direct genetic testing, should be available to specialists with expertise in their use and interpretation.

Statement 3 Clear local or regional referral guidelines and care pathways should be in place to ensure that people with Huntington’s disease will be reviewed in a multidisciplinary setting with input from neurologists, psychiatrists, clinical geneticists and other relevant specialties.

Statement 4 Management of Huntington’s disease should focus on the priorities of the patient and their family with the aim of preventing avoidable complications and retaining function and autonomy. Their management should include both pharmacological therapy and non-pharmacological treatment options (e.g. physiotherapy, occupational therapy, speech and language therapy).

Statement 5 Huntington’s disease specialists should work closely together with Huntington’s Disease Association (HDA)-regional care advisors to improve continuity of care.

Statement 6 People with Huntington’s disease and their carers should be given the opportunity, at an appropriate stage, to discuss advance care planning/end-of-life issues with appropriate healthcare professionals.
6) Motor neurone disease

Revised February 2016 by the ABN Neuromuscular Disorders Advisory Group

**Statement 1** Patients with symptoms suggestive of motor neuron disease (also called amyotrophic lateral sclerosis) should be assessed as soon as possible by an experienced neurologist. Early diagnosis should be pursued, and investigations, including neurophysiology, performed with a high priority.

**Statement 2** The patient should be informed of the diagnosis in a sensitive manner by a consultant with a good knowledge of the patient and the disease, in an appropriate private setting, with a relative or friend present if the patient wishes one to be. A follow up appointment should be arranged to review the patient within 4 weeks.

**Statement 3** Following diagnosis, the patient and relatives/carers should receive regular support from a multidisciplinary care team, with a single point of contact for all information, and review appointments every 3 months in typical cases, but tailored to individual needs.

**Statement 4** Medication with riluzole should be initiated as early as possible.

**Statement 5** Where available, patients should be managed according to accepted care pathways (e.g. NICE guidance on Motor Neuron Disease, non-invasive ventilation, treatment with riluzole)

**Statement 6** Control of symptoms such as sialorrhoea, thick mucus, emotional lability, cramps, spasticity and pain should be attempted. Percutaneous endoscopic gastrostomy feeding improves nutrition and quality of life, and gastrostomy tubes should be placed before respiratory insufficiency develops. Non-invasive positive-pressure ventilation also improves survival and quality of life. Maintaining the patient’s ability to communicate is essential.

**Statement 7** During the entire course of the disease, every effort should be made to maintain patient autonomy. Advance directives for palliative end-of-life care should be discussed early with the patient and carers, respecting the patient’s social and cultural background.

**Statement 8** Patients should have access to research programmes, including involvement in clinical trials and other studies to determine the cause and management of this condition, for which there is no effective cure, and the cause remains largely unknown.

**Statement 9** There should be access to training and education for professionals involved in supporting and treating patients with motor neuron disease.

**Statement 10** The appropriate diagnosis and management of motor neuron disease includes a recognition of the overlap with frontotemporal dementia and access to specialist input to assess cognitive function.

**References**

NICE guidance: The use of non-invasive ventilation in the management of motor neurone disease. July 2010
NICE pathways: Motor neurone disease overview

ABN guidance: Guidelines for the management of motor neurone disease. 1999


Motor Neurone Disease: A Problem-Solving Approach (MND Association, 2012)
‘Red Flags’ tool for diagnostic referral (MND Association, 2014)
7) Neuromuscular disorders

Revised February 2016 by the ABN Neuromuscular Disorders Advisory Group

**Statement 1** Each Region should provide a fully integrated multidisciplinary service for patients of all ages with neuromuscular disorders

**Statement 2** Management of individual patients may be at a specialist centre, or through a shared-care protocol at a district hospital

**Statement 3** Except for the rare curable neuromuscular disorders, specialist care should generally continue life-long

**Statement 4** A regional Centre should provide advanced diagnostic facilities (e.g. specialist neurophysiology, muscle pathology) and collaboration with National reference services (e.g. NCG services)

**Statement 5** Prompt assessment (First appointment) should be available at the specialist centre for new referrals from primary or secondary care

**Statement 6** Where available, patients should be managed according to accepted care pathways (e.g. Duchenne dystrophy)

**Statement 7** All patients should have ready access to a neuromuscular care advisor/specialist nurse. They should provide signposting to appropriate services including voluntary agencies and community groups.

**Statement 8** Patients should be made aware of national and international disease-specific registries that enhance development of treatment guidelines and standards of care, as well as enabling access to research studies for interested patients and families.

**Statement 9** Multidisciplinary care should include appropriately trained and experienced specialists in respiratory care (physicians and physiotherapists), non-invasive ventilation, cardiology, genetics, orthopaedics (spinal and tendon surgery), gastroenterology (PEG/RIG), physiotherapy, occupational therapy, speech therapy, dietetics, and orthotics

**Statement 10** Specialist multidisciplinary transition clinics should be available for adolescents moving from paediatric to adult care

**Statement 11** When appropriate, patients should have a personalised emergency care plan, for example with respect to managing respiratory and cardiac issues

**Section 12** There should be access to training and education for professionals involved in supporting and treating patients with neuromuscular disorders

**Section 13** Psychological support services should be available to help individuals at all stages of their journey, from initial diagnosis to end of life care, where appropriate

References:

- Duchenne Standards of Care - (NICE accredited) - from Lancet Neurology 2009/10
- NHS Commissioning Board, Service Specification No. 8 – Specialised Neurosciences. 2012/13
8) Peripheral neuropathy

Revised February 2016 by the ABN Neuromuscular Disorders Advisory Group

Statement 1: Patients with symptoms suggestive of a peripheral neuropathy should be assessed within 13 weeks by an experienced neurologist. Early diagnosis should be pursued, and investigations, including neurophysiology, performed within 18 weeks of referral.

Statement 2: Complex patients should be referred to a specialist peripheral nerve clinic, which should have access to advanced diagnostic facilities including neuropathology in collaboration with National reference services (e.g. NCG services)

Statement 3: Each Region should provide a fully integrated multidisciplinary service for patients of all ages with neuromuscular disorders. Patients should have access to a neuromuscular care advisor/specialist nurse. They should provide signposting to appropriate services including voluntary agencies and community groups

Statement 4: Multidisciplinary care should include appropriately trained and experienced specialists in immunology, pain management, respiratory care, non-invasive ventilation, cardiology, genetics, orthopaedics (spinal and tendon surgery), physiotherapy, occupational therapy, speech therapy, dietetics, and orthotics

Statement 5: There should be access to training and education for professional involved in supporting and treating patients with neuromuscular disorders

Statement 6: Psychological support services should be available to help individuals at all stages of their journey, from initial diagnosis to end of life care, where appropriate.

References
- NHS Commissioning Board, Service Specification No. 8 – Specialised Neurosciences. 2012/13
9) Multiple Sclerosis

Prepared April 2014 by the ABN Multiple Sclerosis and Neuroinflammation section.

**Statement 1:** MS patients must have access to a specialist neurological service providing an effective care pathway. It is the responsibility of the Commissioners to ensure that there is an accessible and comprehensive service for patients with MS across England based on local population needs.

**Statement 2:** Patients are entitled to a timely and ready access to a diagnostic service, seeing a neurologist within 2-4 weeks from the time of onset of suggestive symptoms who can offer a diagnosis of MS based on contemporary practice. MRI and other investigations (e.g., lumbar puncture, evoked potentials) should be undertaken, if required, within 2-4 weeks of seeing the neurologist. The results should be explained to patients and therapeutic options discussed within a further 2-4 weeks, preferably by a neurologist with specialist interest in MS.

**Statement 3:** There should be an agreed pathway for consultant-to-consultant referral to specialised services in a regional neurosciences centre or to tertiary clinics for selected MS patients attending the local service. This may apply when there is a lack of diagnostic clarity for further clinical assessment, additional investigations and consideration of invasive procedures (e.g., diagnostic biopsy in rare cases); for specialised management of acute MS relapses (e.g., plasma exchange), for aggressive relapsing disease; for specialised treatments (e.g., botulinum toxin), for refractory chronic symptoms, or for access to specialist input (e.g. neurorehabilitation, neuropsychiatry).

**Statement 4:** Patients receiving a diagnosis of MS should be provided with contact details of a local MS nurse specialist: unless declined by patient, the MS Nurse should establish contact within 5-10 working days of the diagnosis. Where appropriate, life-style issues should be discussed, and advice on employment and equality, access to physical rehabilitation, genetics, family and career planning, and access to counselling and/or psychological support offered.

**Statement 5:** Patients with acutely relapsing episodes should be seen in a rapid access “relapse” clinic for appropriate assessment, investigations and advice. They should be supported by the multi-disciplinary team and seen within 2-5 working days of reporting a suspected relapse.

**Statement 6:** Patients with relapsing MS are to be offered disease modifying therapy according to current ABN Treatment Guidelines – or an appropriate treatment switch, if disease activity continues on treatment.

**Statement 7:** Patients with persistent problems require appropriate symptomatic management to improve quality of life and self-care abilities. For example, patients with urinary symptoms should have access to a continence nurse specialist or uroneurology service. Prevention of recurrent urinary tract infections should be considered a priority to reduce hospital visits or acute admissions.

**Statement 8:** Patients with MS should have access to a review by an MS specialist service and multi-disciplinary team at least once a year; and the opportunity to self-refer to the clinic earlier if necessary.

**Statement 9:** Patients with chronic MS who may be at risk of osteoporosis (post-menopausal women, patients with mobility impairment, frequent use of steroids...
and long term use of anti-epileptic drugs like phenytoin or carbamazepine) should be considered for bone densitometry to prospectively identify and treat osteoporosis in order to reduce fracture-related hospital admissions.

**Statement 10:** Patients with chronic disability from MS require needs assessment of long-term care support addressing key components of individual patients in terms of current health status and HRQoL. The care plan should identify community nursing, rehabilitative, psychological and social resources for continuation of support. There should be named care provider and home support teams for MS patients that must set out clear targets to meet patient’s and family’s educational, emotional, physical and cognitive needs.

**Statement 11:** Participation in clinical research should become an expected standard of MS services as it offers the opportunity of linking with local academic clinical networks and national clinical trial units. MS patients should be made aware of research projects where they may volunteer and participate.
Appendix 2. Basic resources and facilities

**Neuroscience centre**
- A hospital where both neurology and neurosurgery services are based.
- Neurology consultants and neurological trainees including specialist registrars.
- A 7 day acute neurology referral service.
- 24 hour a day consultant supervision of neurology inpatients (on call rota).
- Secretarial and supporting clerical staff.
- There will be a dedicated neurology ward as well as neurosurgical ward staffed by neurologically trained nurses with access to a day unit for investigation and out-patient treatment.
- There will be access to out-patient facilities.
- This will have the following support services on site:
  - Neurophysiology: a consultant led service with technician support, with access to EEG, video-telemetry and EMG and nerve conduction studies.
  - Neuropathology: with appropriate laboratory support.
  - Neuroradiology: with MRI, CT and interventional radiological facilities.
  - Neurorehabilitation services.
  - Specialists allied health professionals including physiotherapists, occupational therapists, speech therapists, dieticians, social workers and orthotics.
  - Neuropsychologists.
  - Neuropsychiatric service.
  - Specialist nurses in MS, epilepsy, Parkinson's disease and motor neurone disease.

**Neurology centre**
- A hospital where neurology services are based.
- Neurology consultants and neurological trainees including specialist registrars.
- A 7 day acute neurology referral service.
- Secretarial and supporting clerical staff.
- There will be a neurology ward (which may be shared with stroke) staffed by neurologically trained nurses with access to a day unit for investigation and out-patient treatment.
- There will be access to out-patient facilities.
- The following support services on site:
  - Neurophysiology: a consultant led service with technician support, with access to EEG, and EMG and nerve conduction studies.
  - There will be access to neuropathology (with appropriate laboratory support) at the regional neuroscience centre.
  - There will be MRI, CT and interventional radiological facilities, with radiologists with particular interest in neuroradiology and access to neuroradiology services at the regional centre.
  - Neurorehabilitation services.
  - Specialists allied health professionals including physiotherapists, occupational therapists, speech therapists, dieticians, social workers and orthotics.
  - Neuropsychologists.
  - Liaison psychiatrists.
  - Specialist nurses in MS, epilepsy, Parkinson's disease and motor neurone disease.

**DGH**
- A hospital where neurologists visit from a neuroscience or neurology centre.
- Neurology consultants.

*Guidance for Locally Commissioned Neurology Services: Clinical Commissioning Groups (CRGs) Delivering Better Care for Patients with Neurological Conditions: developed by SSC, Association of British Neurologists and Neurological Alliance*
• Secretarial and supporting clerical staff.
• Access to inpatient beds at either a neuroscience or neurology centre.
• Here will be access to out-patient facilities.
• Access to neurophysiology, neuroradiology and neurorehabilitation at the associated neuroscience or neurology centre.
• Access to Specialists allied health professionals including physiotherapists, occupational therapists, speech therapists, dieticians, social workers and orthotics.
• Neuropsychologists.
• Liaison psychiatrists.
• Specialist nurses in MS, epilepsy, Parkinson's disease and motor neurone disease.

**Human**

Consultant neurologists (approximately 750 non WTE in UK)
Neurology SpRs
Skilled neurology secretaries
Dedicated neurology clerical staff
Specialist nurses
GPSIs (in some centres)
Paramedical therapists: physio, OT, speech, diet, psychology
Orthotic staff
Social workers
Supporting medical and surgical colleagues in other specialties

Access to:
Neuroradiologists
Neurophysiologists
Neurosurgeons
Neuropsychologists
Liaison psychiatrists or psychological therapists
Neuropathologists
Specialised lab staff

**Facilities**

Departmental office space
Outpatient space and time
MAU, day unit, medical beds and ITU beds in DGH and specialist hospital
Acute stroke unit in DGH or a nearby centre
Access to diagnostic equipment: mainly radiology, neurophysiology and blood sciences
Neurology and neurosurgery beds in neuroscience centre
Theatre and radiology suites for surgery and endovascular procedures
Access to specialist rehabilitation centre

For management of patients with chronic disorders, access to:
- neurorehabilitation services
- facilities for respite and long term care
- hospice day service and beds for terminal care
**Appendix 4: Important contact details**

**ABN list of SSC members:**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Ralph Gregory</td>
<td>Chair</td>
<td><a href="mailto:ralphgregory@doctors.org.uk">ralphgregory@doctors.org.uk</a></td>
</tr>
<tr>
<td>Dr Raeburn Forbes</td>
<td>N.Ireland</td>
<td><a href="mailto:raeburnforbes@gmail.com">raeburnforbes@gmail.com</a></td>
</tr>
<tr>
<td>Dr David Nicholl</td>
<td>Scot-E</td>
<td><a href="mailto:david.nicholl@uhb.nhs.uk">david.nicholl@uhb.nhs.uk</a></td>
</tr>
<tr>
<td>Dr Nick Silver</td>
<td>Mersey</td>
<td><a href="mailto:Nicholas.Silver@thewaltoncentre.nhs.uk">Nicholas.Silver@thewaltoncentre.nhs.uk</a></td>
</tr>
<tr>
<td>Dr Adrian Wills</td>
<td>Trent</td>
<td><a href="mailto:adrian.wills@nuh.nhs.uk">adrian.wills@nuh.nhs.uk</a></td>
</tr>
<tr>
<td>Dr Lucy Kinton</td>
<td>Wessex</td>
<td><a href="mailto:lucy.kinton@bhnft.nhs.uk">lucy.kinton@bhnft.nhs.uk</a></td>
</tr>
<tr>
<td>Dr Ed Fathers</td>
<td>South West</td>
<td><a href="mailto:e.fathers@btinternet.com">e.fathers@btinternet.com</a></td>
</tr>
<tr>
<td>Dr Cath Mummery</td>
<td>NHNN</td>
<td><a href="mailto:cath.mummery@uch.nhs.uk">cath.mummery@uch.nhs.uk</a></td>
</tr>
<tr>
<td>Dr John Janssen</td>
<td>Thames NW</td>
<td><a href="mailto:jc@thejanssens.co.uk">jc@thejanssens.co.uk</a></td>
</tr>
<tr>
<td>Dr Tracey Graves</td>
<td>E-Anglia</td>
<td><a href="mailto:tracey.graves@btinternet.com">tracey.graves@btinternet.com</a></td>
</tr>
<tr>
<td>Dr David Nicholl</td>
<td>W.Midlands</td>
<td><a href="mailto:david.nicholl@uhb.nhs.uk">david.nicholl@uhb.nhs.uk</a></td>
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<td>NHNN</td>
<td><a href="mailto:cath.mummery@uch.nhs.uk">cath.mummery@uch.nhs.uk</a></td>
</tr>
</tbody>
</table>

**ABN Officers and other committee members**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Andrew Gale</td>
<td>BMA CCSC Specialty</td>
<td><a href="mailto:andrewgale@nhs.net">andrewgale@nhs.net</a></td>
</tr>
<tr>
<td>Prof Graham Venables</td>
<td>Chair of Neurology CRG</td>
<td><a href="mailto:graham.venables@sth.nhs.uk">graham.venables@sth.nhs.uk</a></td>
</tr>
<tr>
<td>Dr David Bateman</td>
<td>National Clinical Director for neurology</td>
<td><a href="mailto:david.bateman@chsft.nhs.uk">david.bateman@chsft.nhs.uk</a></td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Phil Smith</td>
<td>ABN President</td>
<td><a href="mailto:smithpe@cardiff.ac.uk">smithpe@cardiff.ac.uk</a></td>
</tr>
<tr>
<td>Prof Mary Reilly</td>
<td>ABN President Elect</td>
<td><a href="mailto:m.reilly@ucl.ac.uk">m.reilly@ucl.ac.uk</a></td>
</tr>
<tr>
<td>Dr Kevin Talbot</td>
<td>ABN Hon Secretary</td>
<td><a href="mailto:kevin.talbot@ndcn.ox.ac.uk">kevin.talbot@ndcn.ox.ac.uk</a></td>
</tr>
<tr>
<td>Prof David Burn</td>
<td>ABN Hon Asst Secretary</td>
<td><a href="mailto:d.j.burn@ncl.ac.uk">d.j.burn@ncl.ac.uk</a></td>
</tr>
<tr>
<td>Dr Richard Davenport</td>
<td>Chair, Training and Education Committee</td>
<td><a href="mailto:rjd@skull.dcn.ed.ac.uk">rjd@skull.dcn.ed.ac.uk</a></td>
</tr>
<tr>
<td>Vacancy</td>
<td>Less than full time working adviser</td>
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<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Rhys Thomas</td>
<td>ABNT Treasurer</td>
<td><a href="mailto:Rhys-Thomas@doctors.org.uk">Rhys-Thomas@doctors.org.uk</a></td>
</tr>
<tr>
<td>Ms Arlene Wilkie</td>
<td>Neurological Alliance</td>
<td><a href="mailto:arlene.wilkie@neural.org.uk">arlene.wilkie@neural.org.uk</a></td>
</tr>
</tbody>
</table>
**ABN office**
Telephone: 020 7405 4060
e-mail: info@abn.org.uk
Joanne Lawrence Executive Director

**Neurological Alliance office**
Telephone: 020 7963 3994
Arlene Wilkie arlene.wilkie@neural.org.uk
Alex Massey alex.massey@neural.org.uk
c/o Parkinson's UK
215 Vauxhall Bridge Road
London
SW1V 1EJ
### Appendix 5: Strategic clinical networks and their neurology clinical leads

<table>
<thead>
<tr>
<th>Region</th>
<th>Title</th>
<th>first name</th>
<th>last name</th>
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<tr>
<td>Overall</td>
<td>Dr</td>
<td>David</td>
<td>Bateman</td>
</tr>
<tr>
<td>Cheshire &amp; Merseyside</td>
<td>Dr</td>
<td>Nick</td>
<td>Fletcher</td>
</tr>
<tr>
<td>London</td>
<td>Dr</td>
<td>Nicolas</td>
<td>Losseff</td>
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<td>Cader</td>
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<td>Chris</td>
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<td>Dr</td>
<td>Helen</td>
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<tr>
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<td></td>
<td>McCloughry</td>
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<tr>
<td>Greater Manchester, Lancashire and South Cumbria</td>
<td>Dr</td>
<td>David</td>
<td>Footitt</td>
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<tr>
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<td>Nicola</td>
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<tr>
<td>West Midlands</td>
<td>Prof</td>
<td>Adrian</td>
<td>Williams</td>
</tr>
<tr>
<td>South East England</td>
<td>Dr</td>
<td>Neil</td>
<td>Munro</td>
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Appendix 6: Other useful documents/links

- Consultant Physicians working with patients RCP (2015) (link)
- Public Accounts Committee Review into services to people with neurological conditions (link)
- Epilepsy Commissioning Toolkit (link)
- Association of British Neurologists (link)
- Neurological Alliance (link)
- Compendium of Neurology Data March 2014 (link)
- Public Health England National Neurology Network Neurology profiles (link)
- Brain ans Spine Foundation: Neurology Centres in the UK (link)
- ABN Policy Statement on Stroke 2012 (link)
- National Stroke Audit (link)
- National audit of services for people with multiple sclerosis: 2011(link).