Annex A

Specialised Neurology Service Specification

Minimum Service Levels for Neurology Subspecialties

Contents

[Minimum services for neurology subspecialties 2](#_Toc183522785)

[Epilepsy services 3](#_Toc183522786)

[Movement Disorders services 4](#_Toc183522787)

[MS & CNS Neuroinflammation services 5](#_Toc183522788)

[Neuromuscular Disorders services 6](#_Toc183522789)

[Functional Neurological Disorders services 7](#_Toc183522790)

[Cognitive Neurology services 8](#_Toc183522791)

[Headache services 9](#_Toc183522792)

# Minimum service levels for neurology subspecialties

Care for people with most neurological conditions is delivered through ICS-commissioned core neurology services in primary, community, and secondary care settings. Many patients will also require tertiary care from specialised neurology services, which should interface smoothly with core neurology services.

This annex outlines the neurology services that should be available at the secondary care level within each ICS, i.e. they should be accessible through non-specialist units in District General Hospitals as well as being available at Specialised Neurology Centres.

In this document, "local care" refers to care pathways available within an ICS. These pathways may be provided at each individual neurology unit or shared among several units, depending on local service collaborations. Whatever the local organisation of services, all patients within an ICS should have equitable access to the described local services within their ICS footprint. The annex additionally describes neurology services that must be available at Specialised Neurology Centres for subspecialty services, as per the Specialised Neurology Service Specification.

### Interaction with mental health services

Neurological conditions often present with cognitive, emotional and behavioural symptoms usually treated by mental health services. All patients should have access to mental health assessment and treatment through local pathways. As per national guidance, all mental health services should be available based on need and cannot exclude people because of a particular physical health or neurological diagnosis.

Patients should have access to specialist mental health expertise (neuropsychiatry and neuropsychology) where necessary for all conditions described below. Where there are specific mental health support needs for certain neurological condition groups these are highlighted in this annex.

### Interaction with community neurotherapy services

Many neurological conditions are associated with static or progressive neurodisability. Comprehensive support from multiprofessional, multidisciplinary community services is required for rehabilitation, reablement, disability management and end-of-life care. This includes the provision of appropriate equipment, orthotics, assistive technology services, alternative and augmentative communication (AAC) services and wheelchair services. They also serve as a key interface with social care services.

Secondary and tertiary neurology services should work closely with community services to provide seamless care.

# Epilepsy services

Within each Integrated Care System secondary care services should ensure:

* Patients with first seizures are seen within 2 weeks by a clinician with expertise in epilepsy diagnosis for assessment, investigation and treatment, as per [NICE guidance](https://www.nice.org.uk/guidance/qs211).
* Local access to neurologists who can diagnose and explain Epilepsy, and manage the condition.
* Local access within the ICS to epilepsy clinics (first seizure assessment, follow-up, maternity and transition clinics), specialist epilepsy nursing service to provide care planning, risk assessment for SUDEP, seizure safety checks, safe antiepileptic drug prescribing and titration support, and a first point of access to support (for patients and non-specialist professionals).
* Enable local access to investigations required for diagnosis, including brain MRI scanning and specialist reporting, neurophysiology with access to EEG and home telemetry.
* Access to inpatient EEG at sites receiving acute medical admissions.
* Enable local access to appropriate support from maternity services, learning disability services, neuropsychiatry, elderly care, alcohol and drug addiction services, social services, psychology, end of life care, social prescribing.
* Access to case management support for patients through a healthcare professional with appropriate expertise (e.g. through Clinical Nurse Specialists)

As a minimum, in addition to the above, Specialised Neurology Centres must offer:

* An MDT approach including a regional complex case MDT to support Neurology Units in linked District General Hospitals
* 3T MRI and other advanced structural imaging, reported by a neuroradiologist.
* Access to neuropsychiatry and neuropsychology services, including for planning of epilepsy surgery.
* Access to a video EEG telemetry service
* Local access, *or* clear pathways to access from another centre, surgery for epilepsy typically temporal lobectomy, lesionectomy, and vagus nerve stimulation (VNS). This must be undertaken on an MDT basis.
* Decision making and initialising non-standard medical therapies needing specialist support (e.g. ketogenic diet, cannabidiol CBD)
* Epilepsy in-reach advice for inpatients within the regional neurology bed-base.
* Access to neurogenetics
* Access to Clinical Trials

Quarternary services in a subset of Specialised Neurology Centres may offer:

* An MDT approach with tertiary services at Specialised Neurology Centres / DGH Neurology Units
* Invasive video EEG telemetry
* Single-photon emission computed tomography (SPECT) and Positron emission tomography (PET) scan
* Complex surgical resections for Epilepsy
* Magnetic resonance-guided laser interstitial thermal therapy (MRgLITT)
* Everolimus for Tuberous Sclerosis Complex

# Movement Disorders services

Within each Integrated Care System secondary care services should ensure:

* Local access to clinicians with expertise in diagnosis who can diagnose and explain Parkinson’s Disease (PD) and other movement disorders, can initiate treatment where appropriate and signpost to support. This will typically be a neurologist or geriatrician.
* Local access to appropriate genetic testing for hereditary movement disorders
* Local access to basic investigations that might be needed as part of the diagnostic process (imaging, neurophysiology, CSF studies).
* Sufficient capacity to offer appropriate follow-up where required. Patients with Parkinson’s disease should be offered at least annual review by a healthcare professional with expertise in PD, and more frequently if necessary.
* Local access to elderly care services for Parkinson’s disease and other neurodegenerative movement disorders, linked to local frailty pathways.
* Local access to botulinum toxin therapy for patients with dystonia.
* Access to case management support for patients through a healthcare professional with appropriate expertise (e.g. through Clinical Nurse Specialists)
* Access to local community pathways for rehabilitation, disability management and end of life care where necessary.
* Sufficient capacity to discuss patients and access advice from specialist regional movement disorders services either through local provision / outreach if possible or a clear pathway for referral to the regional Specialised Neurology Centre.

As a minimum, in addition to the above, Specialised Neurology Centres must offer:

* Specialist diagnostic and treatment services for advanced Parkinson’s disease and other complex movement disorders (e.g. Huntington’s disease and Tourette syndrome)
* An MDT approach including a regional complex case MDT to support Neurology Units in linked District General Hospitals
* At least annual review with an MDT member for people with chronic progressive movement disorders, and more frequently if required.
* Access to all relevant commissioned specialised treatments
* Local access to, or clear joint pathways to access from another centre, deep brain stimulation for patients with advanced Parkinson’s disease or other movement disorders. This must be undertaken on an MDT basis (including neurology, neurosurgery, neuropsychiatry, neuropsychology and specialist nursing and pharmacy).
* Availability of Movement disorders in-reach advice for inpatients within the regional neurology bed-base.
* Access to specialist neuropsychiatry and neuropsychology is essential given frequent cognitive and behavioural symptomatology in Parkinson’s disease and other movement disorders.
* Access to neurogenetics
* Access to Clinical Trials

Quarternary services in a subset of Specialised Neurology Centres may offer:

* Neurosurgical services for Deep Brain Stimulation
* Magnetic Resonance-guided Focused Ultrasound Surgery Thalamotomy for refractory essential tremor

# MS & CNS Neuroinflammation services

Within each Integrated Care System secondary care services should ensure:

* Local access to neurologists who can diagnose and explain Multiple Sclerosis and other neuroinflammatory disorders.
* Local access to MRI imaging required for the diagnosis and monitoring of people with MS and other neuroinflammatory disorders, including access to neuroradiology review.
* Patients diagnosed with MS by general neurologists or other physicians are referred to an MS specialist neurologist for categorisation of the patients’ disease and selection of appropriate disease-modifying therapies (DMT). Ongoing review may occur in secondary care or tertiary care, depending on complexity / need.
* Patients should have access to specialist clinical MDT discussion of their case to enable approval for DMTs which require an MDT. DMTs should be provided promptly (ideally within 12 weeks of decision) as close to home as possible.
* Access to case management support for patients through a healthcare professional with appropriate expertise with an appointment offered ideally within 4 weeks of diagnosis. This should focus on symptom / lifestyle management and referral to professionals from the wider multidisciplinary team.
* Local access to an MDT within region, including physiotherapy, occupational therapy, psychology, speech and language therapists, psychologists, dietitians, social care, continence specialists and specialist neuro-pharmacists or specialist MS pharmacists and consultants in rehabilitation medicine and neuropsychiatry
* At least annual review by a healthcare professional with expertise in MS should be offered, along with rapid access for assessment of changes in a patient’s condition such as relapse or progression.

As a minimum, in addition to the above, Specialised Neurology Centres must offer:

* Access to a multidisciplinary regional MS subspecialty team who can assess and manage treatment in an outpatient and/or inpatient setting.
* Access to an MS neurologist or MS nurse to enable discussion and approval for DMTs which require a DMT MDT for BluTeq approval.
* Access to all relevant commissioned specialised treatments.
* Access to appropriate treatments including Immunoglobulin and plasma exchange for other neuroinflammatory disorders
* Neuroinflammation in-reach advice for inpatients within the regional neurology bed-base.
* Access to Neuropsychiatry and Neuropsychology where required
* Access to Clinical Trials

Quarternary services in a subset of Specialised Neurology Centres may offer:

* Autologous Haematopoietic Stem Cell Transplantation

# **Neuromuscular Disorders services**

including services for Motor Neurone Disorders, Muscle Diseases, Myasthenia, and Peripheral Nerve Diseases.

Within each Integrated Care System secondary care services should ensure:

* Access to neurologists who can diagnose and explain MND and neuromuscular disorders who can initiate treatment and signpost to support and services.
* Access to basic investigations that might be needed as part of the diagnostic process (imaging, neurophysiology, CSF studies).
* Sufficient capacity to offer appropriate follow-up where required
* Pathways are in place to discuss patients and access advice from specialist regional neuromuscular services either through local provision / outreach or a clear pathway for referral to a regional Specialised Neurology Centre for specialist MND, myasthenia, muscle or peripheral nerve services.
* Access to local MDTs with community services, with pathways established for community care, social care and voluntary sector support.
* The multidisciplinary team should work closely with community neurotherapy teams providing prompt access to: occupational therapy; physiotherapy; speech & language therapy; dietetics; respiratory ventilation and cough services; specialist palliative care; dietetics; gastroenterology; counselling; psychology and social care.
* Provide people with MND regular follow-up with an MDT member at clinically appropriate intervals with regular surveillance of respiratory function, nutritional state (including weight) and bulbar function

As a minimum, in addition to the above, Specialised Neurology Centres must:

* Have specialist diagnostic and treatment services in place for rare muscle diseases, peripheral nerve diseases, myasthenic syndromes and motor neurone disorders.
* Offer at least annual review with an MDT member for people with chronic progressive neuromuscular conditions, and more frequently if required. This annual review can occur in secondary care or tertiary care, depending on need.
* Have mechanisms in place for rapid review during periods of disease instability (e.g. for myasthenia gravis crisis)
* Ensure pathways are in place for respiratory review and home ventilation, cardiology review, gastroenterology review, and endocrinology services where required
* Ensure availability of a specialist MDT, including: neurologist, specialist nurse, dietitian, physiotherapist, occupational therapist, speech & language therapist, respiratory physiologist, pharmacist and palliative care expertis as required.
* Facilitate joint care with quaternary centres where required
* Access to appropriate treatments including Immunoglobulin and plasma exchange for neuroinflammatory disorders
* Provide neuromuscular in-reach advice for inpatients within the regional neurology bed-base.
* Provide access to Neuropsychiatry and Neuropsychology where required
* Provide access to neurogenetics
* Provide access to Clinical Trials

Quarternary services in a subset of Specialised Neurology Centres provide:

* Nationally commissioned Highly Specialised Services (listed in the Neurology Service Specification)
* Diagnostic / treatment services for some rarer neuromuscular conditions, e.g. complex / refractory Myasthenia Gravis or Spinal Muscular Atrophy

# Functional Neurological Disorders services

Within each Integrated Care System secondary care services should ensure:

* Access to neurologists who can diagnose and explain FND, and who can initiate or signpost to first line management
* Access to investigations that might be needed as part of the diagnostic process
* Capacity to offer at least one follow-up appointment, and longer term follow-up where required
* Processes to discuss patients and access advice from a regional FND subspecialty team e.g. via regular FND multidisciplinary team meetings

As a minimum, in addition to the above, Specialised Neurology Centres should offer:

* A specialist FND clinic (run by clinicians in an appropriate specialty e.g. neurology, psychiatry, neurorehabilitation) through which further assessment, formulation and treatment planning can be carried out for patients who have not benefited sufficiently from first line management
* Access to a multidisciplinary regional FND subspecialty team who can assess and manage second line treatment in an outpatient and/or inpatient setting as required. This should include neuropsychiatry and psychology input.
* Referral to appropriate rehabilitation pathways, including physiotherapy input.

Mental health care:

* All patients should have access to appropriate mental health assessment and treatment including, where needed, access to assessment and/or treatment by a psychiatrist and/or psychologist with FND expertise

# **Cognitive Neurology services**

The significant majority of cases of dementia (including Alzheimer’s disease, vascular dementia and mixed dementias) will be assessed and managed primarily through memory clinics commissioned through NHS Mental Health services.

However, early or complex cognitive presentations may be better supported by cognitive neurology services, and patients with a wide range of neurological conditions may have complex cognitive issues. Specialist Cognitive Neurology services are required for this cohort.

**Specialised Cognitive Neurology services** should be available in all Specialised Neurology Centres. These services should provide:

* Diagnosis and initial management of young-onset and atypical dementias including those suspected to be due to genetic causes
* Diagnosis, and where appropriate management, of non-dementia cognitive disorders associated with, for example, encephalitis, epilepsy, neuro-inflammatory disorders, static acquired brain injuries.
* Providing advice via an MDT arrangement to memory services within their region and where appropriate facilitating access to molecular diagnostics
* Offering cognitive neurology in-reach to inpatients in the regional neurology bed base.
* Access to clinical neuropsychology for psychometry is an essential requirement for cognitive profiling.
* Access to neuropsychology and neuropsychiatry for MDT input into complex cases.
* Access to advanced imaging modalities such as PET-CT and CSF studies where appropriate.

# **Headache services**

Headache is the commonest neurological presentation. Headache assessment and treatment for common headache disorders such as migraine, should be undertaken jointly between primary and secondary care, through ICB-commissioned services.

**Core headache care services, commissioned by Integrated Care Systems**

This includes many treatments that are not specialised and should be available to patients in all Integrated Care Systems in line with existing NICE guidance and technology appraisals. These may be delivered through primary care, secondary care neurology services or intermediate services such as GP with extended role clinics or community headache clinics.

* Diagnosis and management of headache disorders
* Cranial nerve blockade
* Botulinum toxin therapy for Mìgraine
* Access to advanced therapies for the management of refractory migraine including CGRP therapies.
* Specialist MSK physiotherapy where appropriate

**Specialised complex headache services:**

Regional tertiary complex headache clinics should be available to support diagnosis and management of rare or complex / refractory headache disorders.

Examples would include:

* Headaches with significant diagnostic uncertainty after general neurology review
* Refractory trigeminal autonomic cephalalgias
* Refractory idiopathic intracranial hypertension
* Chronic migraine refractory to treatment with CGRP therapies or Botulinum toxin therapy
* Joint care for complex facial pain (with pain, maxillofacial and neurosurgery services)
* Neurosurgical support where required.

Services should also provide:

* Access to neurogenetic testing
* Access to clinical trials

**Quarternary headache services**

A very small number of headache services need to be delivered at supraregional level.

Examples include:

* Invasive nerve stimulation such as occipital nerve stimulation
* Management of refractory spontaneous intracranial hypotension