Annex A

Specialised Neurology Service Specification
Minimum Services for Neurology Subspecialties

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Minimum services 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, that is to say they should be available through non-specialist units in District General Hospitals or community-based settings, as well as being available at Specialised Neurology Centres.

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 community 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 additionally 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.

All patients should also have access to counselling services through primary care mental health pathways.

Interaction with community neurology services

Many neurological conditions are associated with static or progressive neurodisability. For all condition groups listed below multiprofessional, multidisciplinary support from community services is essential for rehabilitation, reablement, disability management and end-of-life care. This should be needs-based. Secondary and tertiary neurology services should collaborate with community services to deliver seamless care. This also includes working with local authority services such as social care where required.

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 for diagnosis, investigation and treatment, as per NICE guidance.
- Local access to clinicians who can diagnose, explain and manage epilepsy.
- 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 Sudden Unexpected Deaths in Epilepsy (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 with 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, palliative and end of life care, social prescribing.
- Access to case management support for patients through specialist nursing or other health professionals (e.g. through Clinical Nurse Specialists, neuropharmacists)

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
- Specialist review of complex patients with epilepsy who cannot be adequately managed in a secondary care setting, (e.g. highly refractory epilepsy, patients with complex comorbidities such as epilepsy with comorbid functional seizures)
- Local access, or clear pathways to access from another centre, to surgery for epilepsy such as temporal lobectomy, lesionectomy, and vagus nerve stimulation (VNS). This must be undertaken on an MDT basis.
- 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
- Decision-making and initiating medical therapies needing specialist support (e.g. cannabidiol)
- Epilepsy in-reach advice for inpatients within the regional neurology bed-base.
- Access to neurogenetics - including testing, MDT discussion and genetic counselling
- Access to clinical trials and research studies

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

- An MDT approach with Specialised Neurology Centres / DGH Neurology Units
- Intracranial EEG monitoring for epilepsy surgical workup
- Single-photon emission computed tomography (SPECT) and Positron emission tomography (PET)
- Complex surgical resections for Epilepsy
- Adult ketogenic dietary services
- Magnetic resonance-guided laser interstitial thermal therapy (MRgLITT)
- Everolimus for Tuberous Sclerosis Complex

Movement Disorder services

Within each Integrated Care System secondary care services should ensure:

- Local access to clinicians who can diagnose and explain Parkinson's Disease (PD) and other movement disorders; initiate treatment and signpost to support.
- Local access to appropriate genetic testing for hereditary movement disorders
- Local access to basic investigations 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 and other progressive movement disorders should be offered review at clinically appropriate intervals by a healthcare professional with expertise
- Local access to geriatric medicine services for Parkinson's disease and other movement disorders, linked to local frailty pathways
- Local access to timely botulinum toxin therapy for patients with dystonia
- Local access to case management support for patients through specialist nurses or allied health professionals
- Enable local access to support from community mental health, psychology, dementia and old age psychiatry services, geriatric medicine, rehabilitation services
- Local access to an MDT within region, including physiotherapy, occupational therapy, psychology, speech and language therapists, dietitians, social care, continence specialists, palliative and end of life care and specialist neuropharmacists
- 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 in place 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
- Provide follow-up review with an MDT member at clinically-appropriate intervals (or patient-initiated follow up) for people with progressive movement disorders. Reviews may take place in secondary or tertiary care, based on clinical need.
- Access to all relevant commissioned specialised treatments
- Local access, or clear joint pathways for access from another centre, to deep brain stimulation for advanced Parkinson's disease or other movement disorders. This must be undertaken on an MDT basis (including neurology, neurosurgery, neuropsychiatry, neuropsychology and specialist nursing).
- Availability of Movement disorders in-reach advice for complex inpatients within the regional neurology bed-base.
- Access to specialist neuropsychiatry and neuropsychology. This is essential given frequent cognitive and behavioural symptomatology.
- Access to neurogenetics - including testing, MDT discussion and genetic counselling.
- Access to clinical trials and research studies.

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

Multiple Sclerosis (MS) & Central Nervous System (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, and who can initiate treatment where appropriate and signpost to support.
- 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).
- 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) with delivery and monitoring as close to home as possible.
- Access to case management support for patients through specialist nurses or allied health professionals 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.
- Access to local MDTs with community services, with pathways established for community care, social care, and voluntary sector support.
- Local access to an MDT within region, including physiotherapy, occupational therapy, psychology, speech and language therapists, dietitians, social care, continence specialists, palliative and end of life care; specialist neuro-pharmacists
- An annual review by a healthcare professional with expertise in MS should be offered, along with rapid access within 2 weeks for assessment of changes in a patient's condition such as relapse.

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

- Access to a multidisciplinary regional MS subspecialty team including specialist neurology and neuropharmacy input, 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 Disease Modifying Therapies (DMTs) which require multidisciplinary approval prior to prescribing (DMT MDT for BluTeq approval).
- Access to all relevant commissioned specialised treatments in line with published clinical commissioning policies.
- Neuroinflammation in-reach advice for inpatients within the regional neurology bed-base.
- Access to Neuropsychiatry and Neuropsychology where required
- Access to clinical trials and research studies.

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

- Autologous Haematopoietic Stem Cell Transplantation

Neuromuscular Disorders services

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

Within each Integrated Care System secondary care services should ensure:

- Access to neurologists who can diagnose and explain MND and neuromuscular disorders 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; palliative and end of life care; dietetics; gastroenterology; orthotics; wheelchair services; assistive technology services; alternative and augmentative communication (AAC) services; counselling; psychology and social care.
- Provide people with MND and other progressive neuromuscular conditions regular follow-up with an MDT member at clinically appropriate intervals with surveillance of respiratory function, nutritional state 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.
- Provide follow-up review with an MDT member at clinically-appropriate intervals (or patient-initiated follow up) for people with progressive neuromuscular conditions. Reviews may take place in secondary or tertiary care, based on clinical need.
- Have mechanisms in place for rapid review during periods of disease instability (e.g. for myasthenia gravis or chronic inflammatory demyelinating polyradiculoneuropathy)
- 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, and palliative and end of life care.
- Facilitate joint care with quaternary centres where required.
- Provide neuromuscular in-reach advice for complex inpatients within the regional neurology bed-base.
- Provide access to neuropathology (testing and MDT discussion).
- Provide access to Neuropsychiatry and Neuropsychology where required.
- Provide access to neurogenetics - testing, MDT discussion and genetic counselling.
- Offer access to clinical trials and research studies.

Quarternary services in a subset of Specialised Neurology Centres provide:

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

Functional Neurological Disorders (FND) services

This specification describes neurology-delivered services for FND. Rehabilitation pathways for FND (and other neurological conditions) are covered by the complex rehabilitation specification.

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 clinically indicated
- Local access to mental health assessment and treatment, including liaison psychiatry and/or psychology
- Processes to discuss patients and access advice from a regional FND subspecialty team e.g. via regular FND multidisciplinary team meetings
- Referral pathways for services for common comorbidities in FND (including pain, fatigue, sleep disorders, neurodivergent conditions)
- Referral pathways for community-based and/or outpatient rehabilitation services including MDT input from physiotherapy, occupational therapy and speech and language therapy and psychology / neuropsychology as required

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

- A specialist FND clinic with an MDT model (led by a clinician in an appropriate specialty e.g. neurology, neuropsychiatry, neurorehabilitation) through which further assessment, formulation and treatment planning can be carried out for patients who have not benefited sufficiently from first line management for FND; and for review of cases of uncertain FND diagnosis
- 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 pathways to specialist or intensive rehabilitation programmes for FND where needed
- Close links with mental health services ensuring timely access to psychiatric or psychological interventions
- FND in-reach advice for complex inpatients within the regional neurology bed-base where required
- Access to clinical trials and research studies

Cognitive Neurology services

Cognitive neurology services manage adult-onset disorders of cognition (distinct from learning disability 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.

Effective integration with local geriatric medicine and old age psychiatry services is essential. There should collaborative working with community services to ensure that guidance and support services are available for patients and carers

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

- Diagnosis and initial management of younger-onset and atypical dementias (such as frontotemporal dementia), 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 and 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. This 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.
- Access to speech and language therapy for patients with progressive aphasias.
- A route for referral to treatment for functional cognitive disorders.
- Access to clinical trials and research studies.

Complex 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. This may include intermediate community services, including GP with extended role headache services and self management programmes.

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 musculoskeletal 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, with appropriate MDTs in place where necessary (e.g. for CSF pressure disorders, complex facial pain).

Examples include:

- Headaches with significant diagnostic uncertainty after general neurology review
- Refractory trigeminal autonomic cephalalgias
- Refractory idiopathic intracranial hypertension, with close working with neuro-ophthalmology services
- Chronic migraine refractory to treatment with CGRP therapies or Botulinum toxin therapy
- Joint care for complex facial pain (with pain, maxillofacial and neurosurgery services)

Services should also provide:

- Access to neurogenetics including testing, MDT discussion and genetic counselling.
- Access to clinical trials and research studies
- Access to psychology / neuropsychology input where required
- Access to neurosurgical support where required.

Quarternary headache services

A very small number of headache services need to be delivered at supraregional level on a multidisciplinary basis. Examples may include:

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