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Specialised Paediatric Neurology

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Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission the service of Specialised Paediatric Neurology for children aged up to 16 years, in accordance with the criteria outlined in this specification.

In creating this document NWJCC has reviewed the requirements and standards of care that are expected to deliver this service.

Welsh Language

NWJCC is committed to treating the English and Welsh languages on the basis of equality, and endeavour to ensure commissioned services meet the requirements of the legislative framework for Welsh Language, including the [Welsh Language Act \(1993\)](#), the [Welsh Language \(Wales\) Measure 2011](#) and the [Welsh Language Standards \(No.7\) Regulations 2018](#).

Where a service is provided in a private facility or in a hospital outside of Wales, the provisions of the Welsh language standards do not directly apply but in recognition of its importance to the patient experience, the referring health board should ensure that wherever possible patients have access to their preferred language.

In order to facilitate this, NWJCC is committed to working closely with providers to ensure that in the absence of a Welsh speaker, written information will be offered and people have access to either a translator or 'Language-line' if requested. Where possible, links to local teams should be maintained during the period of care.

Decarbonisation

NWJCC is committed to taking assertive action to reducing the carbon footprint through mindful commissioning activities. Where possible and taking into account each individual patient's needs, services are provided closer to home, including via digital and virtual access, with a delivery chain for service provision and associated capital that reflects the NWJCC commitment.

Disclaimer

NWJCC assumes that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this document.

This document may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to

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the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, or Local Authority.

NWJCC disclaims any responsibility for damages arising out of the use or non-use of this policy.

1. Introduction

This document has been developed as the Service Specification for the planning and delivery of Specialised Paediatric Neurology for children aged up to 16 years. This service will only be commissioned by the NHS Wales Joint Commissioning Committee (NWJCC) and applies to residents of all seven Health Boards in Wales.

1.1 Background

Paediatric Neurology is a clinical specialty that covers the investigation and management of neurological conditions in children. Some paediatric neurology services are based in district general hospitals, a community setting and some are based in specialised centres. Specialist centres will have the equipment and expert teams that are needed to treat more complex conditions. The neurological conditions that are categorised as specialised are included in Annex i.

1.2 Epidemiology

The prevalence / incidence varies by condition. Examples include¹:

- Cerebral Palsy has a prevalence of 3 cases per 1000 live births²
- Epilepsy overall childhood incidence of 50-70 cases per 100,000³
- Acquired brain injury 18 cases per 100,000⁴ children
- 4 per 100,000⁵ children aged 0-16 years will be diagnosed with a tumour of the central nervous system.
- Muscular dystrophy has a prevalence of 0.3 cases per 1000 male births.

1.3 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering specialised paediatric neurology for children in Wales.

The objectives of this service specification are to:

- detail the specifications required to deliver specialised paediatric neurology services for children who are resident in Wales
- ensure minimum standards of care are set for the delivery of specialised paediatric neurology

¹ [E09-S-b-Paediatric-Neurosciences-Neurology.pro .2013.04.v2.pdf \(england.nhs.uk\)](#)

² [Maternity and birth statistics: 2020 | GOV.WALES](#)

³ [National level population estimates by year, age and UK country \(gov.wales\)](#)

⁴ [National level population estimates by year, age and UK country \(gov.wales\)](#)

⁵ [National level population estimates by year, age and UK country \(gov.wales\)](#)

- ensure equitable access to specialised paediatric neurology
- identify centres that are able to provide specialised paediatric neurology for Welsh patients
- improve outcomes for people accessing specialised paediatric neurology services.

1.4 Population Covered

The specialised paediatric neurology service is for children and young people aged up to 16 years with suspected and confirmed neurological conditions that require access to specialised care, a full list of conditions is available in Annex i.

1.5 Current Service

Many conditions require specialist multi-disciplinary care, and the specialist team works with local teams to enhance early diagnosis and delivery of optimal care close to the patient's home where possible.

North Wales

Children from North Wales access specialised paediatric neurology services from Alder Hey Children's Hospital either by attending Alder Hey Children's Hospital or outreach clinics delivered by the specialist team in conjunction with the local paediatric team at:

- Ysbyty Gwynedd
- Ysbyty Glan Clwyd
- Wrexham Maelor Hospital
- Robert Jones Agnes Hunt Hospital

South Wales

The Specialised Paediatric Neurology service is based at the Children's Hospital for Wales with outreach clinics delivered by the specialist team at:

- The Royal Gwent Hospital
- Royal Glamorgan Hospital
- Prince Charles Hospital
- Princess of Wales Hospital
- Morriston Hospital
- Glangwili Hospital
- Withybush Hospital
- Bronglais Hospital

Powys

Children from Powys access specialised paediatric neurology services at Alder Hey Children's Hospital, the Children's Hospital for Wales or Birmingham Children's Hospital.

1.6 Relationship with other documents

This document should be read in conjunction with the following documents:

- **NHS Wales**
 - All Wales Policy: [Making Decisions in Individual Patient Funding requests \(IPFR\)](#).
- **NHS Wales Joint Commissioning Committee policies and service specifications**
 - [Atidarsagene autotemcel for treating metachromatic leukodystrophy in children](#), PP257, April 2023
 - [Ataluren for treating Duchenne muscular dystrophy with a nonsense mutation in the dystrophin gene](#), PP118, July 2023
 - [Specialised Paediatric Neurological Rehabilitation](#), CP160, April 2018
 - [Nusinersen for treating spinal muscular atrophy](#), PP191, January 2022
 - [Children's Epilepsy Surgery Services](#), CP174, September 2022
 - [Risdiplam for Spinal Muscular Atrophy for people aged under 16 years](#), PP240, May 2022
- **National Institute of Health and Care Excellence (NICE) guidance**
 - [Epilepsies in children, young people and adults](#), NG217, April 2022
 - [Suspected Neurological conditions: recognition and referral](#), NG127, May 2019
 - [Spasticity in under 19s: management](#), CG145, July 2012
 - [Epilepsy in children and young people](#), QS27, February 2013
 - [Cerebral palsy in children and young people](#), QS162, October 2017
 - [Cerebral palsy in under 25s: assessment and management](#), NG62, January 2017
 - [Suspected neurological conditions: recognition and referral](#), QS198, January 2021
 - [Nusinersen for treating spinal muscular atrophy](#), TA588, July 2019
- **Relevant NHS England policies**
 - [Paediatric Neurosciences – Neurology](#), E09/S/b, 2023/24

2. Service Delivery

The NHS Wales Joint Commissioning Committee will commission the service of Specialised Paediatric Neurology for children aged up to 16 years, in line with the criteria identified in this specification.

2.1 Access Criteria

The service will accept referrals from secondary or tertiary care clinicians for children aged up to 16 years require specialist investigation or management within agreed protocols.

2.2 Service description

The Specialised Paediatric Neurology service will provide accurate diagnosis for children aged up to 16 years, presenting with symptoms or signs of dysfunction of the central and peripheral nervous system, which includes the brain, spinal cord, peripheral nerves and muscles. The service will provide support in the antenatal diagnosis of such disorders. The majority of patients cared for by Specialised Paediatric Neurology services are referred from secondary level paediatric services.

Paediatric neurology will provide holistic, evidence-based management for patients. This includes provision of curative treatments, symptomatic treatments, neuro-rehabilitation, disability management, palliative care and end of life care⁶.

In addition to the standards required within the Contract, specific quality standards and measures will be expected. The provider must also meet the standards as set out below.

Diagnostic Investigation

Investigations are done in a variety of settings, including out-patients, day case units and onwards. Paediatric neurology services need to be able to access many investigations out of normal working hours. This includes haematological, biochemical and microbiological services, conventional x-ray services, CT and MRI brain scans and standard EEG. Access to out-of-hours neuropathological services, including processing of samples to be analysed later, is occasionally required. Some investigations, including neuroimaging, can only be undertaken under general anaesthesia in some or all patients. 24h hour access to general anaesthetic services is necessary to provide an acute paediatric neurology service. Diagnostic investigations are necessary for the care and management of children with neurological disorders, these may be undertaken in the child's local hospital or within the designated specialist centre (section 2.7).

⁶ [E09-S-b-Paediatric-Neurosciences-Neurology.pro .2013.04.v2.pdf \(england.nhs.uk\)](#)

Inpatient Care

Specialised Paediatric Neurology inpatients are cared for in designated paediatric neurology beds, paediatric intensive care beds and on neonatal units. Inpatients may be under the joint care of other consultants, including general paediatricians, paediatric intensivists, neonatologists and paediatric neurosurgeons. Some inpatients will remain in their local hospital on a shared care basis, under the care of the local General Paediatrician with advice from the Paediatric Neurologist.

Most inpatients will have acute neurological disorders or acute medical problems caused by an underlying neurological disorder. Hospital admission will have been necessary to enable diagnostic tests only reasonably available in an inpatient setting to be undertaken, or to allow inpatient based therapeutic interventions to be undertaken. Many such patients will need to be nursed in an intensive care setting or on a high dependency unit. Inpatients with disorders principally involving other body organs and systems often have associated neurological problems or complications. Paediatric neurology services provide advice for such children.

Paediatric neurology, in collaboration with other services, provides rehabilitation services for patients following neurological and neurosurgical problems, including traumatic brain injury and spinal injury. This often begins in an inpatient setting in the regional neuroscience centre, being continued in the local secondary care centre or as an outpatient.

Outpatient Care

Outpatient services are provided from a range of outpatient clinics, which will include general paediatric neurology clinics and sub-specialist clinics, such as epilepsy, neuro-oncology and neuromuscular clinics. Many such clinics are multi-disciplinary, involving other medical specialists, therapists and other allied professions. Outpatient clinics will be held in tertiary centres as well as via outreach clinics in local Health Boards, school and the wider community. The multi-disciplinary teams in the local hospitals as well as the specialist centres will work closely to manage patients.

Facilities and equipment

The specialised paediatric neurology service should have access to:

- an anaesthetic service appropriate for the age of the patient
- an appropriate child friendly clinical environment for all aspects of the service, including therapy space
- a level 3 commissioned paediatric radiology service.
- Neurophysiology services including video telemetry.

Imaging

All services will be supported by a three tier imaging network [Interventional Radiology: Guidance for Service Delivery - A report from the National Imaging Board, November 2010](#). Within the network:

- it will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements
- robust arrangements will be in place for patient transfer if more complex imaging or intervention is required
- common standards, protocols and governance procedures will exist throughout the network
- all radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development (CPD)
- all equipment will be optimised for paediatric use and use specific paediatric software.

Staffing

The provider should ensure there is access to a broad range of professionals, and the service is staffed appropriately for the size of the population.

Core Team (Essential)

- Paediatric Consultant Neurologist
- Consultant Neurosurgeon
- Paediatric Neurology Clinical Nurse Specialist
- Paediatric Neuroradiologist
- Orthopaedic Surgeon
- Spinal Surgeon
- Endocrinologist
- Speech and Language Therapist
- Paediatric Dietitian
- Paediatric Physiotherapist
- Paediatric Neuropsychologist
- Paediatric Consultant Neurophysiologist
- Paediatric Neurophysiology technician
- Paediatric Occupational therapist
- Podiatrist or Orthotist
- Paediatric pharmacy support

- Administrative support

Patients will require access to a wider team that will be provided by local services.

Access to an extended team

- Paediatrician with an interest in Paediatric Epilepsy
- Children's community nursing team
- General practitioner
- Health visitor or school nurse
- Play specialist
- Youth worker
- Additional Learning Needs Co-ordinator (ALNCO)
- Designated Education Clinical Lead Officer
- Specialist Children and Young Peoples Weight Management Services
- Social Worker
- Adult Neurologist (for transition)
- Research nurses and clinical studies support
- Relevant third sector organisations

Paediatric Surgery and Anaesthesia

Where a paediatric patient requires anaesthesia for other procedures, the service provider should ensure that the patient is cared for in suitable facilities and by appropriately trained and experienced members of staff.

Clinical Safety and Medical Emergency Measures

The service provider will:

- ensure they operate within a clinically safe environment, with safe practices
- have adequate levels of equipment to deal effectively with medical emergencies
- ensure that all staff are appropriately trained and accredited, and hold a Life Support certificate which meets the standards set out by the Resuscitation Council (www.resus.org.uk)
- have at least one member of staff qualified to Intermediate Life Support (ILS) level
- ensure all medicines and tracers are managed safely and securely, in accordance with local radiological rules, the NHS Litigation Authority (NHSLA) and relevant consents and law
- be responsible for arranging and rehearsing medical emergency procedures on site
- ensure they have access to a medical emergency response 'crash team'
- ensure the service operates within the appropriate governance structures.
- ensure appropriate research into Neurological conditions and therapy.

2.3 Interdependencies with other services or providers

The provider should work directly with, but not limited to, the following key healthcare professionals to ensure a seamless service⁷:

- Paediatric Intensive Care Unit (PICU)
- Neurosurgery
- Neonatal Unit
- Neuro-radiology
- Specialised paediatric rehabilitation
- Neurophysiology
- Endocrinology
- Gastroenterology
- Respiratory
- Oncology
- General Paediatrics
- Palliative Care

2.4 Transitional Care

All children and young people with a specialist neurological condition need a coordinated transitional care programme leading to transfer of care to an adult neurologist and neurology MDT services at an appropriate age.

All transition arrangements should be in line with [Transition from children's to adults' services for young people using health or social care services NICE guidance NG43 and Welsh Government guidance on transition and handover from children's to adult health services.](#)

Transition involves a process of preparation for young people and their families for their transition to adulthood and their transition to adult services. This preparation should start from early adolescence. The exact timing of this will ideally be dependent on the wishes of the young person but will need to comply with local resources and arrangements.

The transition process should be a flexible and collaborative process involving the young person and their family as appropriate and the service with the support of the third sector where relevant.

⁷ [Commissioning Safe and Sustainable Specialised Paediatric Services | The Commissioner \(wordpress.com\)](#)

2.5 Exclusion Criteria

The service will not accept new referrals for people of 16 years of age and above, or for the following conditions:

- 'Simple' headache (primary care and secondary care paediatrics)
- Febrile seizures (secondary care paediatrics)
- Some epilepsy as defined in relevant NICE guidelines⁸ (secondary paediatrics,)
- Development delay⁹ and Learning problems (the investigation of the cause of developmental delay and learning problems is usually under secondary care paediatric and community paediatric services, with discussion with Specialised Neurology on an individual case basis)
- Behavioural problems including autistic spectrum disorders
- Child and Adolescent Mental Health disorders
- Meningitis without significant neurological complications impact on the child's neurological function (general paediatrics)
- Tics and tic-like disorders

2.6 Acceptance Criteria

The service outlined in this specification is for patients ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP practice in England, but includes patients resident in England who are registered with a GP Practice in Wales.

2.7 Service provider/Designated Centre

Children resident in North Wales will access specialised neurology services at Alder Hey Children's Hospital. Ongoing outpatient treatment where possible will be provided as close to the patients home as possible via outreach clinics, in the three main acute hospitals in North Wales:

- Glan Clwyd Hospital
Rhuddlan Rd
Bodelwyddan
Rhyl
LL18 5UJ

⁸ [3 Referral to tertiary specialist services | Epilepsies in children, young people and adults | Guidance | NICE](#)

⁹ [Early developmental impairment or intellectual disability \(WHC/2023/03\) | GOV.WALES](#)

- Wrexham Maelor Hospital
Croesnewydd Rd
Wrexham
LL13 7TD
- Ysbyty Gwynedd
Penrhosgarnedd
Bangor
LL57 2PW

Alternatively, it may be possible for the patient to have ongoing outpatient care provided virtually through the use of "Attend Anywhere".

South Wales

Children resident in South Wales will access specialised paediatric neurology services at the Children's Hospital for Wales. Ongoing outpatient treatment where possible will be provided as close to the patients home as possible via outreach clinics in each of the following Health Boards:

- Aneurin Bevan UHB
- Cwm Taf Morgannwg UHB
- Hywel Dda UHB
- Swansea Bay UHB

Alternatively, it may be possible for the patient to have ongoing outpatient care provided virtually through the use of "Attend Anywhere".

Powys

Children resident in Powys will access specialised paediatric neurology services from Alder Hey Children's Hospital, Birmingham Children's Hospital and the Children's Hospital for Wales dependent on their geographical location.

Specialist providers

- **North Wales**
Alder Hey Children's Hospital
East Prescott Road
Liverpool
L14 5AB
- South Wales
Noah Ark Children's Hospital
University Hospital of Wales
Heath Park Way

Cardiff
CF14 4XW

- **Powys**
Birmingham Children's Hospital
Steelhouse Lane
Birmingham
B4 6NH

2.8 Exceptions

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted.

Further information on making IPFR requests can be found at: [Individual Patient Funding Requests](#)

3. Quality and Patient Safety

The provider must work to written quality standards and provide monitoring information to the lead commissioner. The quality management systems must be externally audited and accredited.

The centre must enable the patients, carers and advocates informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties and for children, teenagers and young adults.

3.1 Quality Indicators (Standards)

Locally defined outcomes

The service for Specialised Paediatric Neurology for children aged up to 16 years should aim to deliver the following:

- Ensure optimal and age-appropriate care and transition into adult services.
- Ensure that there are sufficient, skilled and competent multi-disciplinary workforce to manage children with neurological conditions both in tertiary and secondary care through education
- Ensure children with neurological conditions are treated in line with agreed national guidelines
- Ensure shared care and clinical networks deliver good specialist care closest to home
- Conduct local and national audits of service performance to drive improvement.

Provider outcomes

The provider must:

- Reduced mortality for potentially fatal but treatable conditions
- Reduced morbidity for children with potentially disabling but treatable conditions (e.g. SMA, traumatic brain injury, epilepsy)
- Increased remission rate for children with potentially surgically treatable epilepsy
- Reduced seizure frequency in children with non-surgically treatable epilepsy
- Improved quality survival in Duchenne Muscular dystrophy
- Improved quality of life in children and young people who survive brain tumours and those with epilepsy
- Improved antenatal diagnosis of severe neurological disorders leading to improved pregnancy planning for families.
- Reduction in emergency admissions of those with long term neurological conditions.

3.2 National Standards

- Proportion of nursing staff with paediatric training and neuroscience experience.
- Proportion of patients refused admission due to lack of ward beds either delaying admission or requiring admission to another centre
- Rate of patients and carers responding positively in experience surveys

3.3 Other quality requirements

- the provider will have a recognised system to demonstrate service quality and standards
- the service will have detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site
- the quality system and its treatment protocols will be subject to regular clinical and management audit
- the provider is required to undertake regular patient surveys and develop and implement an action plan based on findings

4. Performance Monitoring and Information Requirement

4.1 Performance Monitoring

NWJCC will be responsible for commissioning services in line with this policy. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- Service providers to evidence quality and performance controls
- Service providers to evidence compliance with standards of care

NWJCC will conduct performance and quality reviews on an annual basis

4.2 Key Performance Indicators

The providers will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Section 2.2.

The provider should also monitor the appropriateness of referrals into the service and provide regular feedback to referrers on inappropriate referrals, identifying any trends or potential educational needs.

4.3 Date of Review

This document is scheduled for review before 2027, where we will check if any new evidence is available.

If an update is carried out the policy will remain extant until the revised policy is published.

5. Equality Impact and Assessment

The Equality Impact Assessment (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable NHS Wales Joint Commissioning Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.

6. Putting Things Right

6.1 Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for [NHS Putting Things Right](#). For services provided outside NHS Wales the patient or their representative should be guided to the [NHS Trust Concerns Procedure](#), with a copy of the concern being sent to NWJCC.

6.2 Individual Patient Funding Request (IPFR)

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated

If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: [Individual Patient Funding Requests](#)

Annex i Neurological Conditions covered by the Specification

Paediatric Epilepsy

The role of specialised paediatric neurology services in the management of children with epilepsy is defined by NICE guidelines¹⁰. These indicate the need for specialised paediatric neurology services in epilepsy beginning under the age of 2 years; epilepsy accompanied by other neuro developmental problems, such as learning difficulties; epilepsy associated with abnormal brain imaging; in cases of diagnostic doubt; and epilepsy not responding to appropriate first line anti-epileptic drugs. The role of specialised paediatric neurology services includes the use of newer anti-epileptic drugs, the use of non-drug treatments such as the ketogenic diet and vagus nerve stimulation, and the further management and selection of patients for surgical referral. The coordination of this service involves interaction with paediatric neuroradiology and paediatric neurophysiology, as well as with English CESS centres.

Motor disorders (including cerebral palsy and movement disorders)

Specialised Paediatric neurology is involved in diagnosis and investigation of children with abnormal movement patterns, usually requiring careful diagnosis and considered investigation and management. Children with cerebral palsy are primarily managed by secondary level disability services, with specialised paediatric neurology providing advice about refractory spasticity management, usually working in partnership with orthopaedic services as well as other specialist services.

Cerebrovascular disorders, including childhood stroke

Specialised Paediatric neurology, together with paediatric neuroradiology and paediatric neurosurgery, are responsible for the acute management, as well as defining the aetiology and the subsequent rehabilitation. The management and investigation of this group of children also involves haematology, cardiology and coordination with other centres.

Infectious and inflammatory diseases of the nervous system

This group includes both infectious causes of meningitis and encephalitis and increasingly non-infectious causes of acute paediatric encephalopathies. Some children with infective causes are managed by secondary level paediatric services with advice from the specialised paediatric neurology service, but the majority of children with autoimmune encephalitides and demyelination will warrant management by specialised paediatric

¹⁰

neurology, in collaboration with other paediatric services, such as neuroradiology, neurophysiology and neuro-rehabilitation.

Traumatic brain injury, including non-accidental head injury and spinal injury.

Specialised paediatric neurology services generally provide advice regarding specific aspects of medical and surgical management of this group of children as part of a multidisciplinary team. The paediatric neuro-rehabilitation service will frequently lead and coordinate rehabilitation. The diagnosis of suspected non-accidental head injury involves a multidisciplinary and multiagency approach involving primarily the child protection services, but will in some cases also have input from paediatric neurology, paediatric neurosurgery and paediatric neuroradiology.

Neuromuscular disorders (including myopathies, muscular dystrophies and neuropathies)

Specialised paediatric neurologists are involved in the evaluation and diagnosis of this group of children, and work in conjunction with other elements of the wider paediatric team to manage these children. These usually include specialised physiotherapy, orthopaedic surgery, spinal surgery, specialist respiratory paediatricians (including non-invasive ventilation and sleep services) and paediatric cardiology, SALT services and bone health are also necessary in this group. Transition to adult care and end of life care is an important aspect of this service.

Brain and spinal cord tumours

Brain tumours are the most common solid malignancies in childhood. The multidisciplinary team responsible for diagnosing and managing children includes paediatric neuroradiology, paediatric oncology, paediatric neurology and paediatric neurosurgery, as well as paediatric neuro-rehabilitation. A proportion of children in this group will need longer term follow-up with paediatric neurology, sometimes in collaboration with paediatric neurosurgery and paediatric urology.

Fetal neurology

This is a specialised area of neurology, and requires coordination with obstetric fetal medicine specialists, radiologists, geneticists and neurosurgeons. The follow-up of children with this group of disorders should be carefully defined perinatally. Children with spinal dysraphism fit into this group, as the majority are identified antenatally, but where they require a specific follow-up in a clinical context involving paediatric urology, neurology and neurosurgery along with highly specialised continence nurses.

Complex headache syndrome

Specialised paediatric neurology can be involved in the diagnosis and management of a minority of children with complex headache syndromes, including migraine. The

diagnosis and management of children with idiopathic intracranial hypertension should occur with guidance from specialised paediatric neurology and also involve specialist paediatric ophthalmology, and also, where appropriate, paediatric neurosurgery and paediatric haematology.

Neurogenetic disorders and dysmorphic syndromes

These are anatomic and functional disorders involving central nervous system malformations, and might require neurology assessment, and sometimes be followed by specialised paediatric neurology. Children in this group can present with epilepsy, neuromuscular problems or movement disorders, and will need appropriate assessment and management.

Annex ii Abbreviations and Glossary

Abbreviations

AWMSG	All Wales Medicines Strategy Group
IPFR	Individual Patient Funding Request
NWJCC	NHS Wales Joint Commissioning Committee
SMC	Scottish Medicines Consortium

Glossary

Individual Patient Funding Request (IPFR)

An IPFR is a request to NHS Wales Joint Commissioning Committee (NWJCC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

NHS Wales Joint Commissioning Committee (NWJCC)

NWJCC is a joint committee of the seven local health boards in Wales. The purpose of NWJCC is to ensure that the population of Wales has fair and equitable access to the full range of Tertiary Services. NWJCC ensures that services within our portfolio are commissioned from providers that have the appropriate experience and expertise. They ensure that these providers are able to provide a robust, high quality and sustainable services, which are safe for patients and are cost effective for NHS Wales.