GIG CYMRU NHS WALES
Cyd-bwyllgor Comisiynu
Joint Commissioning Committee

Paediatric Endocrinology

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Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy
Document No	SS163
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GIG CYMRU NHS WALES | Cyd-bwyllgor Comisiynu Joint Commissioning Committee

Contents

Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission the service of Paediatric Endocrinology 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

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 Paediatric Endocrinology for children up to the age of 16 years resident in Wales. 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 Plain language summary

Paediatric Endocrinology applies to the diagnosis and management of children with relatively common disorders of growth and puberty as well as a large number of rare conditions, including disorders of the thyroid, adrenal, neuro-endocrine (pituitary) axes, sex development and reproduction, hyperinsulinism, calcium/bone metabolism and cancer predisposition syndromes. Some paediatric endocrinology services are based in secondary care hospitals and other are based in specialist tertiary units in conjunction with the local team.

1.2 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering Paediatric Endocrinology services for people resident in Wales.

The objectives of this policy are to:

- detail the specifications required in Paediatric Endocrinology services for people who are resident in Wales
- ensure minimum standards of care are met for the use of Paediatric Endocrinology
- ensure equitable access to Paediatric Endocrinology
- identify centres that are able to provide Paediatric Endocrinology for Welsh patients
- improve outcomes for people accessing Paediatric Endocrinology services in Wales.

1.3 Background

Endocrine conditions, which vary in incidence from 1 in 500 to <1 in 15,000 in the UK, require specialist care by a paediatric endocrinologist and an associated dedicated MDT within a tertiary centre, and/or shared care with a District General Hospital through an established network. Tertiary Paediatric Endocrinology services are co-located with other paediatric sub-speciality teams (neonatal and paediatric intensive care, genetics, orthopaedics, urology, fetal medicine, diabetes, radiology, oncology, nephrology, neurosurgery, gynaecology and adult endocrine services).

A number of sub-specialist endocrine conditions are nationally commissioned in England for Welsh patients (Alstrom syndrome, Bardet Biedl syndrome, Wolfram syndrome,

Complex osteogenesis Imperfecta (COI), Congenital Hyper-Insulinism (CHI) and Gender Dysphoria).
Some endocrine disorders (e.g. familial short & tall stature, primary hypothyroidism, and simple delayed puberty in boys) can be managed by general paediatricians with an interest in endocrinology where there is a link to expert advice in the tertiary centre.

The specialised Paediatric Endocrine MDT also works in collaboration with other specialist teams to deliver specialist care to children and adolescents with complex medical problems, e.g., late effects of oncology treatments, adolescent gynaecology, and chronic renal failure.

Services for children and adolescents with Type 1 diabetes mellitus are managed by local hospital MDTs which include a paediatrician with a special interest in diabetes. However, specialised diabetes services are required for rarer forms of Type 1 diabetes, neonatal diabetes, Type 2 diabetes, Cystic Fibrosis related diabetes and monitoring of the complications of diabetes.

1.4 National Societies

Paediatric Endocrinology in the UK is represented by the British Society of Paediatric Endocrinology and Diabetes (BSPED),[1] a Royal College of Paediatrics and Child Health (RCPCH) accredited professional group with a membership >450, working to improve the care of children and young people with endocrine disorders and diabetes mellitus.
BSPED members are from a range of disciplines, including tertiary paediatric endocrinology and diabetes, general paediatrics with an interest in endocrinology/diabetes, basic research, nursing and other healthcare professionals (HCPs).

BSPED is the only UK society responsible for governing the training of doctors in paediatric endocrinology and diabetes and actively supports the training and education of specialist allied HCPs.

BSPED has a Clinical Committee responsible for peer review of the tertiary endocrinology centres and promoting evidence-based guidelines.

Paediatric Endocrinology in Europe is represented by the European Society for Paediatric Endocrinology (ESPE)[2] as the parallel European professional body (Membership>1000).
BSPED, ESPE and the specialist (tertiary) centres work to evolving international consensus standards and are best placed to drive forward advances in Paediatric Endocrinology, and to deliver the EU-led focus on rare diseases.

[1] BSPED | Home
[2] ESPE - European Society of Paediatric Endocrinology | Improving the clinical care of children and adolescents with endocrine conditions

1.5 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).
  - All Wales Endocrine Standards for Children and Young People's Specialised Healthcare Services 2009 http://www.wales.nhs.uk/sites3/Documents/355/Endocrine%20Eng%20web.pdf

- **National Institute of Health and Care Excellence (NICE) guidance**
  - Human growth hormone (somatropin) for the treatment of growth failure in children, Technology Appraisal Guidance TA188, May 2010. Human growth hormone (somatropin) for the treatment of growth failure in children | Guidance and guidelines | NICE
  - Diabetes (type 1 and type 2) in children and young people: diagnosis and management, NICE guideline NG18, May 2023. Diabetes (type 1 and type 2) in children and young people: diagnosis and management | Guidance and guidelines | NICE
  - Somatrogon for treating growth disturbance in children and young people aged 3 years and over, Technology Appraisal Guidance TA863, February 2023 Somatrogon for treating growth disturbance in children and young people aged 3 years and over | Techincal Appraisal Guidance | NICE

- **Relevant NHS England policies**
  - NHS England Commissioning Specialised Endocrinology

- **Other published documents**
  - Commissioning Safe and Sustainable Specialised Paediatric Services, A framework of Critical Inter-Dependencies. Department of Health 2008. [ARCHIVED CONTENT] Commissioning safe and sustainable specialised paediatric services: a framework of critical inter-dependencies: Department of Health - Publications
  - UK Standards for Paediatric Endocrinology, British Society for Paediatric Endocrinology and Diabetes, January 2019. uk-standards-for-paediatric-endocrinology-2019.pdf (bsped.org.uk)

2. Service Delivery

The NHS Wales Joint Commissioning Committee will commission the service of Paediatric Endocrinology, in line with the criteria identified in this specification.

2.1 Aims and objectives of the Service

Aims

- To provide an expert diagnostic service for endocrine conditions as set out in Annex ii, many of which are rare and may present either acutely with life-threatening problems or more subtly with potential for serious long-term morbidity and mortality.
- The main diagnostic and monitoring methods include longitudinal assessment of growth and puberty, multiple blood sampling for hormone levels, imaging (including plain X-rays, ultrasound, CT/MRI scan and less commonly diagnostic interventional radiology procedures) in collaboration with other paediatric specialist services surgical diagnostics (e.g., biopsy samples with histological investigations).
- To provide family centred specialist care for children with endocrine disease or complex diabetes in an appropriate, safe setting by healthcare professionals with approved training and experience in the context of a multidisciplinary team (MDT). Family centred care should also consider the socio -economic factors and wider determinants of health that impact on ability to adhere to treatment advice and promote a fulfilling life for the family. Take a "trauma informed" approach advocating for societal approach to understanding preventing and supporting the impacts of the diagnoses.[3]
- To deliver treatments including medical and surgical management of endocrine disease (including adolescent gynaecology, complex urological surgery for Disorder of Sex Development (DSD) and rare endocrine tumour surgery), DEXA scan, treatment for primary metabolic bone conditions (bisphosphonates and burosumab for Ostegenesis imperfecta and primary (not secondary) metabolic bone conditions and X linked hypophosphataemic rickets respectively), nutritional and psychological support for the child and their family, educational support and counselling about preparation for treatment and prognosis, late effects of cancer treatment, complex type 2 diabetes mellitus, adolescent transition, tertiary referrals for complex secondary osteoporosis, fertility discussions depending on the condition in gynaecology clinic and patients with Duchenne Muscular Dystrophy as per the north star guidelines UK.[4] Many children with endocrine disease and all with complex diabetes have a life-long chronic disease, and contact with the paediatric endocrine service will be extensive.
- To deliver diagnostics, monitoring and treatment predominantly in an outpatient setting and through a day-case investigation and treatment centre. However, care

[3] Trauma-Informed Wales (traumaframeworkcymru.com)
[4] North Star Programme Muscular Dystrophy UK

is also delivered in in-patient settings (intensive care, neonatal units, paediatric high dependency) often with extensive shared care with other specialist services (neurosurgery, oncology, paediatric critical care).

- To promote the best health and quality of life possible within the context of their disorder.
- To seamlessly 'transition' those with an ongoing need for endocrine care to adult services with expertise in their disorder and its management. The service aims to manage these defined disorders to standards agreed by the British Society of Paediatric Endocrinology and Diabetes[5], including International Consensus guidelines[6].Transition should also include transition with other services such as genetics where adult issues and prenatal genetic advice can be given.
- To collect data on outcomes which can be utilised in continuous audit driving quality improvement in paediatric endocrine services in Wales. This should be achieved by using standard reporting tools that are integrated within existing hospital systems to avoid duplication of data entry and create one source of information.

Objectives

- Provide an accurate and timely diagnosis of the endocrine disorder, in conjunction with other specialist opinion.
- Use evidence-based treatments (or internationally accepted best practice for rare disorders where the evidence base is limited) with appropriate monitoring arrangements.
- Deliver the service in a safe, suitably equipped environment whether that be face to face or via technology
- Provide timely access to the service for new referrals or acute episodes in known patients.
- Provide rapid telephone advice to health professionals on paediatric endocrine conditions and complex diabetes.
- Ensure that those with complex multi-system disease have appropriate input from other specialist services, who should be co-located.
- Ensure that relevant psychological, emotional, educational and social needs are being addressed.
- To support secondary and primary care services with adequate diagnostic and treatment information in a timely manner and that, where relevant, shared care arrangements and protocols are in place.
- Ensure documentation regarding care/treatment provided is electronically shared along the patient pathway for safer care.
- For conditions not constantly requiring care within a tertiary setting, provide out-reach clinics in secondary settings so that care can be delivered closer to home, and shared care arrangements can be solidified.

[5] BSPED |Guidelines
[6] International Consensus Guideline on SGA | Endocrine Society

- Manage the transition into adult services for those with on-going needs for endocrine care, ensuring that the young person understands their condition and is developing autonomy to manage their own healthcare.
- Carry out detailed audit of patient outcomes and experience, and share these data with colleagues in other centres, enabling the dissemination of best practice and appropriate benchmarking of quality. Commissioned centres will participate in the British Society of Paediatric Endocrinology and Diabetes (BSPED) review process.
- Sign post relevant patients to national and international research studies.
- All information provided to patients should be given in a format suitable to their needs.

2.2 Service description

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

The Multidisciplinary Team (MDT)

The core members of the paediatric endocrinology MDT are:

- Paediatric Endocrine Consultants with appropriate training as recognised by the British Society of Paediatric Endocrinology and Diabetes (BSPED) and Royal College of Paediatric and Child Health (RCPCH)
- Surgeon with relevant expertise
- Junior medical staff in training
- Specialist nurses with appropriate sub-speciality expertise e.g., in Growth, Diabetes, Disorder of Sex Development (DSD) and Metabolic Bone Disease
- Psychologists
- Clinical biochemistry and Radiology staff with experience in endocrinology
- Specialist paediatric pharmacist.

The MDT requires sufficient administrative support to maintain records and databases, and to maintain co-ordination within and between the core and extended MDT.

The extended MDT (the composition of which will be condition/diagnosis dependent [see list above]) will include:

- Physiotherapy and Occupational therapy for metabolic bone disease
- Dietetics
- Pharmacy
- Genetics (now considered essential for DSD)
- Radiology & Nuclear medicine
- Paediatric Surgery/Urology (and Anaesthetics)
- Paediatric orthopaedic surgery

- Paediatric neurosurgery
- Adolescent gynaecology
- Adult gynaecology
- Adult endocrinology
- Paediatric oncology
- Histology
- Consultants in paediatric and neonatal intensive care
- Urologist
- Adolescent Gynaecologist
- System specific specialist consultants.

The lead endocrine consultant is responsible for convening the appropriate mix of individuals to provide multidisciplinary input into a patient's management.

Care Pathway

The care pathways for children requiring elective and emergency care is set out in Annex i.
The paediatric endocrinology service should offer the following:

- Access to Inpatient Services (including Intensive Care): 24 hours/seven days a week.
- On-call cover: Access to telephone tertiary consultant advice for DGH/Primary care/other tertiary centre colleagues 24 hours/seven days a week.
- Day case/short stay ward: 5 days a week.
- Outpatient Clinics: available during the working week, including outreach activity and joint speciality clinics such as oncology/neuro-oncology, renal, DSD, metabolic bone disease, adolescent gynaecology and transition.
- Discharge processes must ensure timely and appropriate communications with services who are expected to provide other parts of the patient's pathway in compliance with national guidance.

Outreach clinics as necessary to ensure patients are managed close to home

Shared Care

Shared care protocols are available for some conditions (e.g. Growth Hormone deficiency management, precocious puberty management) to provide guidance to general paediatricians and general practitioners in day-to-day care.

Some children will need to access services identified as "supra-regional" which are accessed in England. These are highly specialised Endocrine services. Access to these services will be through the tertiary centre. These include:

- congenital hyperinsulinism not responding to medical management who may require PET DOPA scanning and/or pancreatic surgery after referral
- complex metabolic bone disease requiring specialist medical/surgical management (e.g. complex Osteogenesis Imperfecta)
- gender dysphoria services
- second opinions in complex situations where external expertise is considered necessary by the lead consultant.

2.3 Acceptance Criteria

The service will accept referrals from secondary or tertiary care (the latter including both other tertiary specialised services and other tertiary endocrine services from outside Wales).

The service will accept referrals for those conditions listed in this specification (see Annex ii), either suspected or with the diagnosis established. New patients presenting at 16 years or younger will be accepted. Young adolescent patients aged 16-18 years who satisfy the acceptance criteria should be discussed with the Paediatric Endocrinology MDT and Nursing Manager of Children's Hospital for Wales (CHfW).

Follow-up of patients already under paediatric endocrine care can occur at a later age, which will be dependent on the condition and the local transition arrangements.

The services operate with a team of consultants. Referrals will be handled in a number of ways:

- Acute ± unwell: Urgent in-patient admission under on-call consultant.
- Non-acute:
  - go into next available new patient appointment and remain under the care of the paediatric endocrine service
  - see named consultant and stay under their care with advice from tertiary endocrine consultant.
- After acceptance into the service, may transfer and/or be shared between consultant's dependent on diagnosis and interests/expertise of local team.

A number of disorders are nationally commissioned through other mechanisms, including Congenital Hyperinsulinism, Bardet-Biedl and Alstrom syndromes, and complex/atypical osteogenesis imperfecta.

2.4 Exclusion Criteria

The service will not accept new referrals >16 years of age. However, between 16 to <18 years of age, new referrals should be made to the consultant with the most appropriate expertise to deal with the presenting problem. The exception to this is disorders of

growth and puberty as this age group are often better managed by a paediatric endocrinologist rather than an adult endocrinologist. Liaison between paediatric and adult services may be required to ensure optimal management arrangements. In this age range, discussion between the referring clinician and the specialist centre is advised.

Common conditions, such as constitutional growth and pubertal delay in boys, acquired hypothyroidism and pubertal variants, such as adrenarche, may not need to be seen by the specialist service depending on local expertise. However, there may be circumstances where an opinion is requested (by phone, letter or face-to-face consultation) prior to discharge back to on-going secondary or primary care.

The metabolic bone clinic is commissioned to see children and young people with primary metabolic bone conditions such as Osteogenesis Imperfecta and other conditions that may predispose to primary osteopaenia and X linked Hypophosphataemic ricketts. It is not commissioned to see those with secondary osteopaenia or skeletal dysplasia.

Services for children with type 1 diabetes are managed by designated local hospital MDTs which include a paediatrician with a special interest in diabetes. These local services do not meet the remit of a specialised commissioned service. However, some specialised diabetes service as defined come under this tertiary service specification.

2.5 Transition arrangements

All transition arrangements should be in line with Transition from children's to adults' services for young people using health or social services (NG43) and Welsh Government guidance the transition and handover from children's to adult services (February 2022)

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 12–13-year-olds. 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.

The manner in which this process is managed will vary on an individual case basis with multidisciplinary input often required and patient and family choice taken into account together with individual health board and environmental circumstances factored in.

2.6 Interdependencies with other services or providers

Many children with endocrine disorders may have involvement of more than one system. This is recognised in 'Commissioning Safe & Sustainable Specialised Paediatric Services: A Framework of Critical Interdependencies, 2009.'[7]

Key interdependencies would be the availability of specialist paediatric endocrinology expertise to Paediatric and Neonatal Intensive Care, and Paediatric Neuro-Surgical and Oncology patients. In addition, all specialist paediatric endocrinology requires close working arrangements with Paediatric Radiology, Chemical Pathology and Clinical Genetics services.

It should be noted that there are a broad range of other specialised services that have important interfaces with endocrinology and diabetes as noted below.

Children who require the input of a multi-specialty team should be able to access the specialist teams on the same tertiary site.

- Co-located Services
  - Clinical Biochemistry
  - Radiology
  - Nutrition and Dietetic Services
  - CAMHS/Psychosocial Support
  - Paediatric Intensive & High Dependency Care
  - Paediatric Neurosurgery
  - Paediatric Anaesthesia & Surgery
  - Paediatric Urology
  - Pharmacy

- Interdependent Services
  - Adult Endocrinology
  - Genetics
  - Neonatal intensive care
  - Cardiology
  - Dermatology
  - Gastroenterology
  - Gynaecology
  - Haematology
  - Immunology

[7] Commissioning safe and sustainable specialised paediatric services a framework of critical inter dependencies Practice Guideline from Department of Health May 2009f

  - Metabolic
  - Nephrology
  - Neurology
  - Oncology
  - Paediatric Orthopaedics
  - Palliative Care
  - Physiotherapy and OT
  - Psychology
  - Respiratory
  - Rheumatology

- Related Services
  - Social work and Family support
  - Patient/Family support groups (local, regional, national)
  - Third sector services (e.g., Turner Syndrome Society)

- Shared care arrangements and protocols are available for some endocrine treatments:
  - Recombinant Human Growth Hormone is initiated in the specialised service, with prescriptions continued in secondary care via homecare delivery service, and occasionally in primary care.
  - Gonadotrophin Releasing Hormone Analogue (GnRHa) treatment is initiated in the specialised service, and continued either in secondary or primary care.

2.7 Continuation of treatment

Healthcare professionals are expected to review a patient's health at regular intervals to ensure they are demonstrating an improvement to their health due to the treatment being given.

If no improvement to a patient's health has been recorded, then clinical judgement on the continuation of treatment must be made by the treating healthcare professional.

2.8 Population covered

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.

Each tertiary service will provide support for the surrounding childhood population in partnership with their local district general hospital services. Specifically, the service is

for those children and adolescents with paediatric endocrine conditions or complex diabetes as outlined within this specification.

2.9 Patient Pathway (Annex i)

This service is comprised of the following elements:

- Out-patient assessment of non-acute endocrine & complex diabetes disorders.
- Diagnostic investigations and some treatments in a day-case setting.
- Monitoring of the condition and treatments through out-patient assessment – this may be throughout childhood and adolescence for complex life-long conditions, or for the duration of a self-limiting condition, or for less complex conditions a return to secondary or primary care follow-up.
- In-patient admission of acute, ill children with endocrine and complex diabetes disorders for diagnosis and treatment.
- In-patient referrals from other specialist teams (e.g. NICU, PICU, neurosurgery, and gastroenterology) for input into the management of acutely/critically ill children with complex/multisystem disorders.
- Telephone advice for the District General Hospital consultant for new and known patients.
- Telephone advice and home visit support from paediatric endocrine / diabetes nurse specialists.

The endocrine disorders outlined in Annex ii, section A, are either managed by the specialist paediatric endocrinology centre or, where appropriate, through outreach clinics run by the specialist team at the local centre:

The diabetes disorders that require specialised services are outlined in Annex ii, section B.

2.10 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.

3.1 Quality Indicators (Standards)

Locally defined outcomes

The Paediatric Endocrinology Service should aim to:

- minimise morbidity and mortality by providing the most appropriate care for paediatric endocrine and diabetes disorders
- ensure optimal age-appropriate care and transition into adult services
- ensure that there is a sufficient, skilled and competent multi-disciplinary workforce to manage children with paediatric endocrine and diabetes disorders
- ensure that children with paediatric endocrine and diabetes disorders are treated in line with agreed national and international guidelines
- ensure shared care and clinical networks deliver good specialist care closest to home
- collect data on defined conditions. A secure internet-based database with data entry staff is required for audit purposes.
- conduct regular local and national audits of service performance to drive improvement.

3.2 National Standards

- The service will be provided from a child facility with equipment to national standards and co-location with other paediatric specialties. [DH Report 2008 "Commissioning a Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies"[8]]
- The service should be delivered in line with the 'UK Standards for Paediatric Endocrinology 2019.[9]

[8] http://www.symmetricpartnership.co.uk/userfiles/Documents/Spec_Paeds_Final_Oct_08_dh_088069.pdf
[9] https://www.bsped.org.uk/media/1370/bspedpaediatricendocrinestandardsvs130710.pdf

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 June 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)

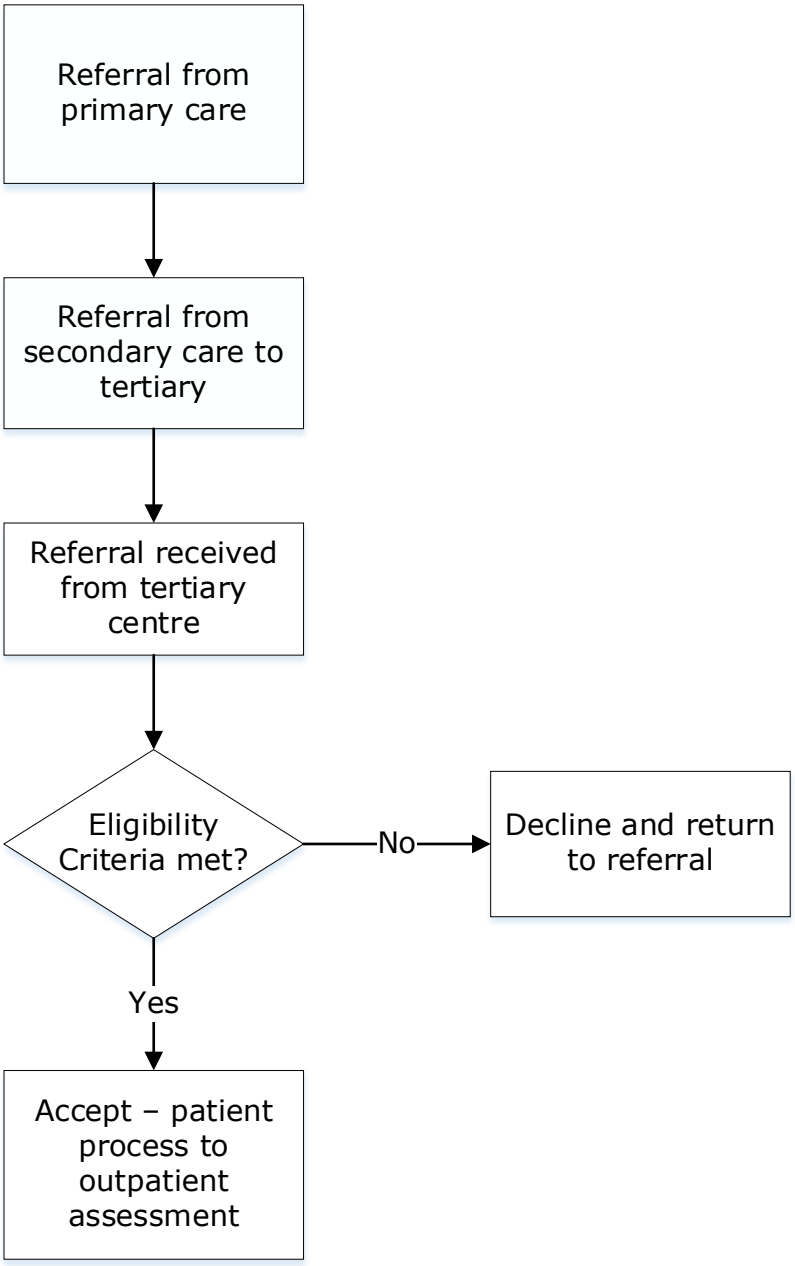
If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All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

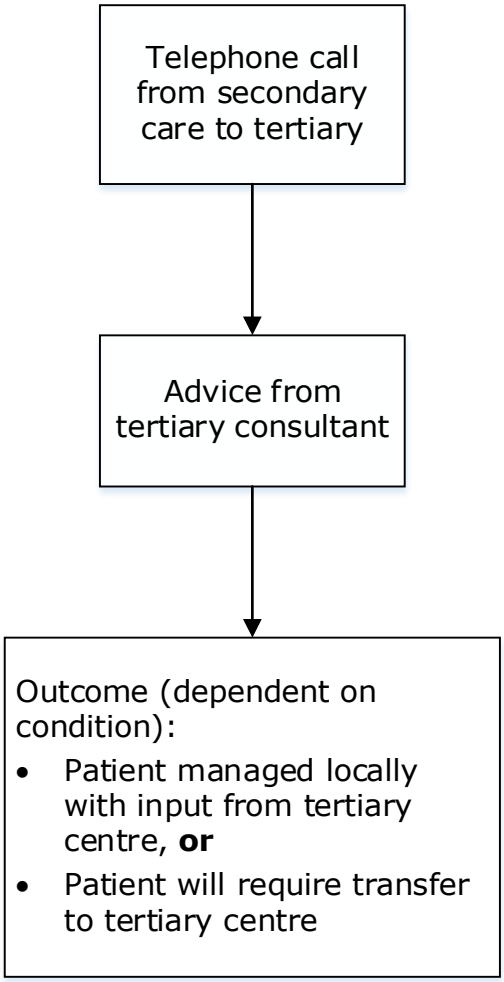
If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: Individual Patient Funding Requests

Annex i Patient Pathway



Emergency Pathway



Annex ii Endocrine and Diabetic Disorders

Section A - Endocrine disorders

The endocrine disorders as outlined below are either managed by the specialist paediatric endocrinology centre or, where appropriate, through outreach clinics run by the MDT at the local centre:

- complex growth problems including Turner syndrome and growth hormone deficiency; puberty disorders including precocious, delayed or absent puberty
- pituitary disease including hypopituitarism, pituitary and peri-pituitary tumours
- complex fluid balance problems (e.g. in neurosurgery)
- thyroid and parathyroid associated disease including thyroid malignancy and thyrotoxicosis and parathyroid disease
- disorders of the adrenal glands
- endocrine disorders associated with chronic disease e.g. care of endocrine problems in cancer survivors, cystic fibrosis related diabetes, growth and pubertal problems associated with chronic renal failure and inflammatory bowel disease
- severe or repeated hypoglycaemia
- disorders of bone and calcium metabolism and primary osteopaenia and metabolic bone disorders
- multiple endocrine neoplasia (MEN) syndromes and other familial endocrine disorders
- DSD (disorders of sex development)

Section B – Diabetic disorders

The diabetes disorders outlined below require specialised services and require ongoing collaboration with level 3 paediatric obesity services:

- diabetes complications in childhood (e.g. nephropathy, complex compliance problems such as eating disorders)
- Type 2 or rare forms of diabetes (e.g. neonatal diabetes, maturity onset diabetes of the young – MODY)
- insulin resistance syndromes
- diabetes associated with chronic disease (e.g. cystic fibrosis or high dose steroid usage in the treatment of some cancers)

Annex iii Abbreviations and Glossary

Abbreviations

BSPED British Society of Paediatric Endocrinology and Diabetes

CHI Congenital Huper-Insulinism

CHfW Children's Hospital for Wales

COI Complex Osteogenesis Imperfecta

CT Computed Tomography

DEXA Dual Energy X-ray Absorptiometry

DOPA Dihydroxy fluoro-L-phenylalanine

DSD Disorder of Sex Development

EQIA Equality Impact Assessment

ESPE European Society for Paediatric Endocrinology

GnRHA Gonadotrophin Releasing Hormone Analogue

GP General Practice

HCP Health Care Professional

IPFR Individual Patient Funding Request

MDT Multi-Disciplinary Team

MRI Magnetic Resonance Imaging

NHS National Health Service

NICU Neonatal Intensive Care Unit

NWJCC NHS Wales Joint Commissioning Committee

OT Occupational Therapy

PET Postron Emission Tomography

PICU Paediatric Intensive Care Unit

RCPCH Royal College of Paediatrics and Child Health

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.