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Pwyllgor Gwasanaethau Iechyd  
Arbenigol Cymru (PGIAC)  
Welsh Health Specialised  
Services Committee (WHSSC)

## **Specialised Services Service Specification: CP211**

### **Specialised Paediatric Gastroenterology, Hepatology and Nutrition (PGHAN)**

*May 2023  
Version 1.0*



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## **Statement**

Welsh Health Specialised Services Committee (WHSSC) will commission the service of paediatric gastroenterology (including paediatric hepatology and complex nutritional care) for children aged up to 16 years in accordance with the criteria outlined in this specification.

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

## **Welsh Language**

WHSSC 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 WHSSC 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**

WHSSC 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 WHSSC commitment.

## **Disclaimer**

WHSSC 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.

WHSSC disclaims any responsibility for damages arising out of the use or non-use of this document.

## 1. Introduction

This document has been developed as the Service Specification for the planning and delivery of specialised paediatric gastroenterology (including paediatric hepatology and complex nutritional care (PGHAN)) for children aged up to 16 years and resident in Wales. This service will only be commissioned by the Welsh Health Specialised Services Committee (WHSSC) and applies to residents of all seven Health Boards in Wales.

### 1.1 Background

Paediatric Gastroenterology is a clinical speciality that covers the investigation and management of disorders of the gastrointestinal tract, including diagnostic endoscopy and therapeutic endoscopy, inflammatory bowel disease (IBD), motility disorders liver disease and intestinal failure (including the provision of home parenteral nutrition).

### 1.2 Epidemiology

The prevalence/incidence varies by condition. Examples include<sup>1</sup>:

- Inflammatory bowel disease has a prevalence of 40 cases per 100,000, children under age 16 years, with an incidence of 10 new cases per 100,000<sup>2</sup>.
- Diagnostic endoscopy rates vary around 200 per 100,000 population under age 17 years<sup>3</sup>.
- Intestinal failure (parenteral nutrition/intravenous feeding) >28 days) = 100-120 million children under 16 years of age<sup>4</sup>.

### 1.3 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering specialised PGHAN services for children aged up to 16 years and resident in Wales.

The objectives of this service specification are to:

- detail the specifications required to deliver specialised PGHAN services for children aged up to 16 years who are resident in Wales
- ensure equitable access to specialised paediatric gastroenterology
- identify network centres that are able to provide PGHAN outreach services for Welsh patients as close to home as possible.
- improve outcomes for people accessing specialised PGHAN services.

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<sup>1</sup> [B \(england.nhs.uk\)](http://B.england.nhs.uk)

<sup>2</sup> Local data provided by Clinical Team at the Children's Hospital for Wales.

<sup>3</sup> [www.chimat.org.uk/tools/atlasof\\_variation](http://www.chimat.org.uk/tools/atlasof_variation)

<sup>4</sup> [B \(england.nhs.uk\)](http://B.england.nhs.uk)

## **1.4 Population Covered**

The Specialised PGHAN service is for children and young people aged up to 16 years with suspected and confirmed gastroenterology conditions.

## **1.5 Current Service**

Many conditions require specialist multi-disciplinary care, and close liaison with the 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 specialist PGHAN 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 –4 clinics a year
- Ysbyty Glan Clwyd – 4 clinics a year
- Wrexham Maelor Hospital– 4 clinics a year.

### **South Wales**

The specialised PGHAN service is based at the Children's Hospital for Wales with outreach clinics delivered by the specialist team in each University Health Board:

- Cwm Taf University Health Board
- Swansea Bay University Health Board
- Hywel Dda University Health Board.

### **Powys**

Children from Powys access specialised PGHAN services from 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).
  - [All Wales Gastroenterology, Hepatology and Nutrition Standards for Children and Young People's Specialised Healthcare Services 2009](#). Welsh Government.

- **National Institute of Health and Care Excellence (NICE) guidance**
  - [Coeliac disease: recognition, assessment and management](#). NICE guideline (NG20) September 2015.
  - [Coeliac disease](#). NICE Quality standard (QS134) October 2016.
  - [Ulcerative colitis: management](#). NICE guideline (NG130) May 2019.
  - [Crohn's disease: management](#). NICE guideline (NG129) May 2019.
  - [Pancreatitis](#). NICE guideline (NG104) September 2018, updated December 2020
  - [Constipation in children and young people: diagnosis and management](#). NICE Clinical guideline (CG99) May 2010, updated July 2017.
  
- **Other published documents**
  - British Society of Paediatric Gastroenterology, Hepatology and Nutrition
  - JAG accreditation standards June 2016 (<http://thejag.org.uk/CMS/Page.aspx?pageId=123>)
  - ESPGHAN/ESPEN/ESPR/CSPEN guidelines on paediatric parenteral nutrition; organisational aspects February 2018 (Clinical Nutrition) [http://www.clinicalnutritionjournal.com/article/S0261-5614\(18\)31172-5/pdf](http://www.clinicalnutritionjournal.com/article/S0261-5614(18)31172-5/pdf)
  - IBD UK, IBD standards, 2019 <http://ibduk.org/ibd-standards>
  - Standards for paediatric gastroenterology, hepatology and nutrition, Jan 2017 [Quality standards for specialist paediatric gastroenterology, hepatology and nutrition | RCPCH](#)
  - BSG and BSPGHAN joint consensus guidelines on management of eosinophilic oesophagitis <http://www.bsg.org.uk/clinical-resource/bsg-and-bspghan-joint-consensus-guidelines-on-the-diagnosis-and-management-of-eosinophilic-oesophagitis-in-children-and-adults>

## **2. Service Delivery**

The Welsh Health Specialised Services Committee will commission the service of Specialised PGHAN services for children aged up to 16 years in Wales, in-line with the criteria identified in this specification.

Specialised PGHAN services are provided in 20 centres in England, 3 in Scotland and 1 in Wales by expert multi-disciplinary teams (MDTs).

### **2.1 Access Criteria**

The service will accept referrals from secondary or tertiary care clinicians for children aged up to 16 year who require specialist investigation or management within agreed protocols<sup>5</sup>.

The commissioned provider is responsible for ensuring that any referral meets national evidence-based clinical guidelines<sup>6</sup> and that the correct referral route has been followed and managed in accordance with agreed response times.

Children requiring paediatric gastroenterology expertise will be referred to specialist care as:

- Suspected chronic gastrointestinal conditions
- Suspected Inflammatory Bowel Disease (IBD), Eosinophilic Oesophagitis (EOE), Coeliac disease, motility or malabsorption disorders
- Suspected chronic liver conditions
- Intestinal failure requiring post-pyloric feeding or parenteral nutrition.

For patients between the age of 16 and 18 years, new referrals should be made to adult services. Adult clinicians can liaise with Paediatricians if required depending on the nature of the young adult's presentation. The arrangements for transitional care are noted in section 2.3.

### **2.2 Service description**

Specialised PGHAN services provide the full portfolio of gastroenterology and nutrition investigations, treatment and support services including: paediatric endoscopy, IBD, motility disorders, intestinal failure, coeliac disease and other disorders associated with malabsorption for children up to 16 years old.

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<sup>5</sup> In rare instances with prior approval from the Consultant Team, referrals from primary care will be accepted.

<sup>6</sup> [BSPGHAN | The British Society of Paediatric Hepatology, Gastroenterology and Nutrition](#)

This includes:

- Conditions needing care from the PGHAN MDT, who will provide treatment and follow up whilst working alongside primary and secondary care until the child is transitioned to adult services.
- Conditions that can be managed in a local hospital but then require temporary referral to specialist care with local follow up or ongoing shared care.
- Secondary care referrals requiring further investigation only available at the specialist centre. Specialist MDTs manage children with chronic PGHAN conditions, undertake investigations, provide treatment, monitor care and enable rapid access assessments as required.
- Care should be delivered in a defined clinical network with clear mechanisms for communication and access to specialist advice.
- Supporting other specialties in the management of patients requiring PGHAN expertise; such as, neonatology, paediatric surgery, oncology and paediatric intensive care.

### **Care pathway**

The service should offer the following care pathways and components:

- Capacity to accept emergency inpatient transfers at short notice, and admit children directly for specialist investigations.
- Rapid access for the assessment and management of new referrals – inpatient, outpatient and day case.
- Rapid access to specialist advice as well as inpatient, outpatient and day case assessment of children managed by the specialist service.
- Outpatient follow-up for chronic conditions requiring tertiary level PGHAN review.
- Prompt access to inpatient beds for the management of acutely ill children.
- Access to support services including paediatric surgery, histopathology and radiology and intensive care.
- Children’s wards and children’s nurses for all inpatient, outpatient and day case stays.
- A full range of diagnostic investigations including emergency access to endoscopy services.
- Endoscopy procedures in a fully child-friendly unit with appropriate anaesthetic sessions and facilities with accredited paediatric anaesthetists.
- Treatment includes medical and surgical management of gastroenterological disease, nutritional and psychological support for the child and their family, liaison with and support of education, and counselling on treatment and prognosis.
- Management is supported by a multi-disciplinary team (MDT).

- Discharge processes must ensure timely and appropriate communications with services that are expected to provide other parts of the patient's pathway in compliance with national guidance.

### **Paediatric gastroenterology, hepatology and nutritional care service (PGHAN) MDT**

The PGHAN service MDT should include the following key components<sup>7</sup>:

- Sufficient consultant appointments to provide consultant continuity with cross-cover and access to expert opinion by telephone (24 hours/day) with capacity to attend the tertiary centre if required.
- Sufficient PGHAN clinical nurse specialists to support inpatient care (including MDT meetings), discharge planning and re-admission avoidance, to cover specialist clinics, ensure regional liaison, as well as perform service evaluation and development.
- Sufficient specialist PGHAN dietitians for inpatients (including MDT meetings), for local and outreach outpatient clinics plus regional liaison, service evaluation and development.
- Paediatric radiologists with appropriate experience and sufficient time to support the assessment, investigation and continued management of children referred to the unit.
- Endoscopy performed by endoscopists with training and/or extensive experience in endoscopy and ileo colonoscopy in children.
- Endoscopy procedures carried out in a fully child-friendly unit with appropriate anaesthetic sessions and facilities with accredited paediatric anaesthetists.
- Histopathologist with expertise in paediatric gastrointestinal histopathology
- Surgeons with expertise in gastrointestinal surgery, including paediatric intestinal failure and IBD
- Clinical psychologist with experience in managing children with chronic conditions.
- Sufficient specialist prescribing pharmacists with expertise in paediatric parenteral nutrition, and pharmaceutical treatments used in chronic GI conditions.
- Clinical biochemistry staff with experience in PGHAN, including paediatric parenteral nutrition.
- Dedicated social care support for children who have complex care needs for discharge planning and continuing support.
- A lead paediatrician, link dietician and link nurse in each network centre with an interest in gastroenterology, with allocated clinical sessions to facilitate shared care.

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<sup>7</sup> British Society of Gastroenterology, Hepatology and Nutrition (BSPGHAN)

- Sufficient administrative and clerical support for the PGHAN MDT including support for outreach services, regional, and national audit, data management and research.

### **Specialist Nutritional Support Services**

Specialist Nutritional Support Services should be provided for the investigation and/or management of intestinal failure.

The wider remit includes post-pyloric enteral nutrition (EN), parenteral nutrition (PN) and home PN (HPN). This should be delivered by an MDT (including a senior clinician, nurse specialist, dietitian, nutritionist, pharmacist, biochemist and surgeon).

The specialist nutrition support team is commissioned to deliver the following services:

- Provide individualised, multidisciplinary nutrition support for patients with intestinal failure and their families
- Provide training and education for staff and families
- Minimise the risk from potential complications of nutrition interventions
- Discharge planning, long term care of children and young people with intestinal failure on home parenteral nutrition, and deliver joint clinics with local providers to facilitate shared care.

### **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 service<sup>8</sup>:

#### **Co-located services**

As specialist gastroenterology and nutrition services are an essential support to other paediatric sub-specialities, the specialist service should be co-located with other specialised services e.g. paediatric surgery, paediatric anaesthesia and pain management, neonatology, paediatric radiology, clinical biochemistry, histopathology, paediatric high dependency care and intensive care services.

Interdependent services include genetics, paediatric immunology and infectious disease, paediatric non-malignant haematology, paediatric rheumatology, paediatric nephrology, paediatric metabolic disease, paediatric respiratory, paediatric dermatology, paediatric oncology, paediatric cardiology and cardiothoracic, paediatric neurosciences including

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<sup>8</sup> Department of Health Report 2008 *Commissioning a Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Interdependencies*

neurodevelopment, CAMHS/psychosocial support, paediatric orthopaedics, palliative care.

Paediatric specialist centres should have access to and support from:

- a paediatric gastroenterologist working alongside members of a nutritional support team.
- interdependent services include neonatology, intensive care, surgery, cardiology, neurology who regularly refer complex cases to paediatric gastroenterology.
- related services are social care and family support, and patient and family support groups.

There should be strong links with adult gastroenterology service colleagues to improve transitional care and eventual handover to adult services, primary care services, secondary provider clinicians and specialist nurses.

There should also be strong links with highly specialised paediatric hepatology services.

## **2.4 Transition care arrangements**

All children and young people with a gastroenterology disease need a coordinated transitional care programme leading to transfer of care to an adult gastroenterologist and gastroenterology MDT services at an appropriate age, under a shared care arrangement.

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 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 with the support of the third sector where relevant.

## **2.5 Exclusion Criteria**

The service will not accept new referrals for people over 16 years of age or for conditions not outlined in section 2.1

## **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**

### **North Wales**

Children resident in North Wales will access specialist gastroenterology services at Alder Hey Children's Hospital.

Shared care arrangements are in place with:

- Betsi Cadwaladr University Health Board (BCUHB).

Ongoing outpatient treatment where possible will be provided as close to the patients home as possible in the three main acute hospitals in North Wales:

- Glan Clwyd Hospital  
Rhuddlan Rd  
Bodelwyddan  
Rhyl  
LL18 5UJ
- 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 specialist gastroenterology services at the Children's Hospital for Wales. Diagnostic endoscopy services are provided in the Children's Hospital for Wales and Morriston Hospital, Swansea.

Shared Care arrangements are in place with:

- Cwm Taf Morgannwg University Health Board (CTMUHB)
- Aneurin Bevan University Health Board (ABUHB)
- Swansea Bay University Health Board (SBUHB)
- Hywel Dda University Health Board (HTHB)

Ongoing outpatient treatment where possible will be provided as close to the patients home as possible in each of the following Health Boards:

- Aneurin Bevan UHB
- Cwm Taf 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 specialist gastroenterology 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

## **Highly Specialised Services**

Highly specialised paediatric hepatology services for children in South Wales and Powys are provided by

- **Alder Hey Children's Hospital**  
East Prescott Road  
Liverpool  
L14 5AB
- **Birmingham Children's Hospital**  
Steelhouse Lane  
Birmingham  
B4 6NH
- **King's College Hospital**  
Denmark Hill  
Brixton  
London  
SE5 9RS

### **3. Quality and Patient Safety**

The provider should work to a set of agreed quality standards and provide monitoring information to the lead commissioner. The quality management systems must be externally audited and accredited.

Patient Reported Outcome Measures (PROMS) and/or Patient Reported Experience Measures (PREMS) should be reported to WHSSC quarterly through the contract monitoring process.

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 PGHAN service should aim to deliver the following:

##### **Inflammatory Bowel Disease**

- **Diagnosis:**
  - Follow defined diagnostic pathways from primary/secondary care through to specialist review (Target 90%).
  - Patients are reviewed by a member of the IBD team within 2 weeks of referral for suspected IBD (Target 90%).
  - Diagnostic ileocolonoscopy is carried out within 4 weeks of referral (Target 90%).
  - Patients undergo MR Enterogram (or other small bowel imaging if MRE not tolerated) as part of diagnostic workup (Target 90%).
  - Patients with perianal lesions undergo MRI pelvis (Target 90%).
  - Patients are introduced to IBD specialist nurse at diagnosis (Target 90%).
  - Patients have nutrition assessment by specialist dietitian at diagnosis (Target 90%).
  
- **Personalised treatment:**
  - Patients with mild/moderate Crohn's disease are commenced on exclusive enteral nutrition under guidance of specialist dietitian (Target 80%).
  - Steroid therapy is used in accordance with local protocols (Target 90%).
  - Patients with deep ulcers, perianal or stricturing/penetrating disease are commenced on biological treatment at diagnosis (Target 90%).

- Appropriate screening tests are carried out before commencing immune modulating treatments without delaying treatment (Target 90%).
- Biological treatments are used in accordance with local protocols (Target 90%).
- Monitoring:
  - Patients are reviewed by a member of the IBD team at least 3 monthly (Target 90%).
  - Complicated cases are discussed in regular IBD MDTs (Target 90%).
  - Patients with persistent extraintestinal manifestations are referred to the appropriate specialist team (Target 90%).
  - Patients have access to specialist dietetic support for symptom control (Target 90%).
  - Patients have access to psychological support (Target 90%).
- Patient outcomes:
  - Patients achieve deep remission at 3 months from diagnosis (Target 90%).
  - Patients are in steroid free deep remission at 1 year from diagnosis (Target 80%).
  - Surgical rates for ulcerative colitis are maintained below UK average (Target <10%).
  - Surgical rates for Crohn's disease are maintained below UK average (Target <25%).
  - Maintain acceptable unplanned admission rates (Target <20%).

### **Eosinophilic Oesophagitis**

- Follow defined diagnostic pathways from primary/secondary care through to specialist review (Target 90%).
- Diagnostic endoscopy is carried out within 6 weeks of referral (Target 90%).
- Achieve clinical remission within 3-6 months of diagnosis (Target 80%).
- Weaning of steroids within 6-12 months of diagnosis (Target 80%).

### **Paediatric Endoscopy**

- Preparation
  - Patients are listed for endoscopic procedures with vetting from a consultant paediatric endoscopist (Target 100%).

- Consent for procedures is confirmed by a paediatric endoscopist or someone trained in taking consent for endoscopy (Target 100%).
- Pre-endoscopy assessments are carried out in designated clinics (Target 90%).
- Patients are provided with age appropriate information regarding their procedure (Target 90%).
- Procedure
  - WHO checklists are used before and after procedures (Target 100%).
  - Procedures are carried out under general anaesthetic or anaesthetist given sedation (Target 90%).
  - Patients admitted with acute upper gastrointestinal bleeding who are haemodynamically stable receive endoscopy, if appropriate with 24 hours of decision (Target 75%).
  - Diagnostic ileocolonoscopy for suspected inflammatory bowel disease is undertaken within 4 weeks of referral (Target 90%).
  - Diagnostic endoscopy for suspected coeliac disease is undertaken within 6 weeks of referral (Target 90%).
  - Diagnostic endoscopy for all indications is undertaken within 8 weeks of referral (Target 90%).
  - Intubate the caecum when performing colonoscopy (Target 90%).
  - Intubate the terminal ileum when undertaking procedures for IBD patients (Target 80%).
- Post-procedure
  - Contemporaneous electronic endoscopy reports are completed on the day of the procedure (Target 90%).
  - Complications are recording and presented at regular morbidity and mortality meetings (Target 90%).
  - Histology outcomes and management plans are communicated to patient families within 4 weeks of the procedure (Target 90%).

## **Nutrition Support Team**

- Inpatients
  - Requests for inpatient parenteral nutrition are made to the Nutrition Support Team using an electronic referral form with clearly defined indications (Target 90%).

- Baseline nutrition blood tests are carried out and results documented before commencing parenteral nutrition (Target 90%).
- Dietetic assessment is carried out before commencing parenteral nutrition with documented refeeding risk and predicted target weight or calorie intake (Target 90%).
- Parenteral nutrition is prescribed in accordance with ESPGHAN guidelines (Target 90%).
- Patients on parenteral nutrition are reviewed daily by a member of the NST (Target 90%).
- Patients are reviewed in a weekly consultant led NST ward round (Target 90%).
- Parenteral nutrition is administered via a central venous catheter (Target 100%).
- Central venous catheters are cared for in accordance with locally defined protocols (Target 90%).
- Catheter related bloodstream infection rates are maintained below the national average (Target <3/1000 catheter days).
- Outpatients
  - A thorough MDT and home assessment is completed as part of discharge planning for patients going home on parenteral nutrition (HPN) (Target 90%).
  - Caregivers receive HPN training and have locally agreed competencies signed off prior to discharge (100%).
  - Multiagency referral form is completed for patients prior to discharge (Target 100%).
  - Patients are reviewed 3 monthly in NST MDT clinics (Target 90%).
  - Catheter related bloodstream infection rates are maintained below the national average (Target <1/1000 catheter days).
  - Patients on HPN undergo routine anthropometry and nutrition screening tests as per clearly defined local protocols (Target 90%).
  - Patients have a named specialist dietitian (Target 100%).
  - Families have access to psychological and social support (Target 90%).

## **Other**

- Diagnostic Endoscopy for every child suspected of having Coeliac Disease within 6 weeks of referral.
- 24 / 7 consultant on call with ability to offer endoscopy and directly review patients.

- Rapid access out-patient service for urgent cases.
- Routine Outpatient waiting time of less than 8 weeks from receipt of referral.

### **3.2 National Standards**

- Quality Standards for Paediatric Gastroenterology, Hepatology and Nutrition, British Society of Paediatric Gastroenterology, Hepatology and Nutrition and the Royal College of Paediatrics and Child Health.<sup>9</sup>
- IBDUK IBD standards ([www.ibduk.org/ibd-standards](http://www.ibduk.org/ibd-standards))
- JAG Global Rating Scale (GRS): version for paediatric services, RCP. [https://www.thejag.org.uk/Downloads/JAG/Accreditation%20-%20Global%20Rating%20Scale%20\(GRS\)/Guidance%20-%20paediatric%20GRS%20measures%202.0.pdf](https://www.thejag.org.uk/Downloads/JAG/Accreditation%20-%20Global%20Rating%20Scale%20(GRS)/Guidance%20-%20paediatric%20GRS%20measures%202.0.pdf)
- ESPGHAN/ESPEN/ESPR/CSPEN guidelines on paediatric parenteral nutrition: Organisational aspects ([https://www.clinicalnutritionjournal.com/article/S0261-5614\(18\)31172-5/pdf](https://www.clinicalnutritionjournal.com/article/S0261-5614(18)31172-5/pdf))
- NCEPOD Report: A Mixed Bag (2010) [https://www.ncepod.org.uk/2010report1/downloads/PN\\_report.pdf](https://www.ncepod.org.uk/2010report1/downloads/PN_report.pdf)

### **3.3 Other quality requirements**

The provider should work to written quality standards to meet the requirements of the Health Board, Trust and Lead commissioners including:

- regular updates within SLA meetings
- reporting of any serious untoward incidents to the Delivery Unit/ Welsh Government and to WHSSC within 48 hours feedback of outcomes from any serious incidents and learning from these.
- service quality improvements and initiatives outcomes from audits against national standards
- Patient experience feedback and the development of PROMS and PREMS to demonstrate and reflect the service provided and the development of action plans to meet any concerns addressed within these
- The need to engage with the third sector to provide information, peer support and other service available from voluntary organisations to children and families.
- Annual Multi-Disciplinary Peer review with providers across the Network.

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<sup>9</sup> [https://www.rcpch.ac.uk/sites/default/files/2018-03/standards\\_for\\_paediatric\\_gastroenterology\\_hepatology\\_and\\_nutrition.pdf](https://www.rcpch.ac.uk/sites/default/files/2018-03/standards_for_paediatric_gastroenterology_hepatology_and_nutrition.pdf)

## **4. Performance monitoring and Information Requirement**

### **4.1 Performance Monitoring**

WHSSC will be responsible for commissioning services in line with this service specification. 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

WHSSC 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 2026 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 Welsh Health Specialised Services 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 WHSSC.

### **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: [Welsh Health Specialised Services Committee \(WHSSC\) | Individual Patient Funding Requests](#)

## **Annex i Abbreviations and Glossary**

### **Abbreviations**

<b>AWMSG</b>	All Wales Medicines Strategy Group
<b>IPFR</b>	Individual Patient Funding Request
<b>SMC</b>	Scottish Medicines Consortium
<b>WHSSC</b>	Welsh Health Specialised Services

### **Glossary**

#### **Individual Patient Funding Request (IPFR)**

An IPFR is a request to Welsh Health Specialised Services Committee (WHSSC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

#### **Welsh Health Specialised Services Committee (WHSSC)**

WHSSC is a joint committee of the seven local health boards in Wales. The purpose of WHSSC is to ensure that the population of Wales has fair and equitable access to the full range of Specialised Services and Tertiary Services. WHSSC ensures that specialised services 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.