Service Specification No. | 23.7
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Service | Paediatric Gastroenterology, Hepatology and Nutrition
Commissioner Lead | Barbara Howe
Provider Lead | 
Period | 12 months
Date of Review | 

1. Population Needs

1.1 National/local context and evidence base

Paediatric gastroenterology is a clinical speciality comprising the investigation and management of disorders of the gastrointestinal tract including diagnostic endoscopy, inflammatory bowel disease (IBD), motility disorders, (including complex gastro oesophageal reflux and constipation), functional disorders and conditions leading to intestinal failure. It also encompasses two related specialities: first, paediatric hepatology (liver diseases) and second, nutritional care (complex); which includes the nutritional management of children with gastrointestinal and other complex diseases including enteral and parenteral nutrition (intravenous feeding) and the provision of home parenteral nutrition. Specialised gastroenterology, hepatology and nutrition services are provided in around 20 specialist centres in England by expert multidisciplinary teams who treat sufficient numbers of patients to develop and maintain the appropriate expertise. Gastroenterology units generally serve populations of 2-4 million, the vast majority in established network arrangements with referral from 6 to 12 local district hospitals, where there should be at least one general paediatrician with a special interest in paediatric gastroenterology, hepatology and nutrition. There is close liaison with supra regional paediatric hepatology services for the assessment and management of complex liver disease.

Prevalence
Prevalence/incidence varies by condition. Examples include:
- Coeliac disease; prevalence is 1 in 100
- Inflammatory Bowel Disease has a prevalence of 20 cases per 100,000 children under age 16 years, with an incidence of 5 new cases per 100,000 children per year.
- Diagnostic endoscopy rates vary around 100 per 100,000 population under age 17 years (www.chimat.org.uk/tools/atlasof variation)
- Intestinal failure (parenteral nutrition (intravenous feeding) > 28 days) = 100-120 /million children under 16 years of age

Evidence base
Care pathways are based on national standards (http://www.doh.gov.uk/nsf/children.htm, Bringing Networks to Life, RCPCH) ; examples include
- Constipation (http://www.nice.org.uk/nicemedia/live/12993/48741/48741.pdf)
- Transition to adult services (Department of Health: Transition: Getting it right for young people.
2.0 Scope
The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

* - Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.

2.1 Aims and objectives of service
Aim
The aim of the service is to provide optimal patient and family-centred specialist care for infants, children and young people with gastrointestinal, liver and nutritional disorders and promote optimal outcomes, future physical and psychological development and quality of life. The service aims to manage these defined disorders to standards agreed by the British Society of Paediatric Gastroenterology, Hepatology & Nutrition, including International Consensus guidelines.

Objectives
The service aims to improve the outcome and quality of life of children with gastrointestinal, liver and nutritional disorders by:-
- Identifying children with a Gastroenterology, Hepatology and Nutritional health care needs
- Providing evidence based treatment (or internationally accepted best practice for rare disorders where the evidence base is limited) and care with appropriate monitoring arrangements
- Providing services which are high quality, safe, clinically effective, appropriate, accessible and acceptable to patients and families/carers.
- Optimising the nutritional management of children with complex nutritional diseases or children with chronic disease in whom the nutritional management is a major component
- Ensuring effective and seamless transition from children's to adult care and to ensure that the young person understands their condition and is developing autonomy to manage their own healthcare
- Providing care as close to home as possible. Providing a patient-centred service for each child/young person within a managed clinical network, achieving effective communication between local and specialist care, as well as between allied health professionals and families.
- Providing rapid telephone advice to health professionals ensuring a personal service for each child/young person and their family with effective communication between local and specialist care and also between professionals, children, young people and their families
- Ensure that relevant psychological, emotional, educational and social care needs are addressed
- Participating in local and national audit, quality improvement programs and scientific and clinical research that lead to improvement in patient care

2.2 Service description/care pathway
- Paediatric specialised gastroenterology, hepatology and nutritional support services focus on the investigation and management of rare disorders and of complex or atypical cases of more common disorders.
- This includes:
  - A] Conditions needing specialist care from presentation - specialist gastroenterology and nutrition care is led by a Specialist team who provide treatment and follow up for children with complex and life-long conditions such as inflammatory bowel disease and Intestinal Failure until care is transitioned to adult services. All management changes are made in the specialist centre with appropriate liaison and information sharing with secondary and primary care, and in some cases shared management with secondary care (including out-reach clinics). The specialist service is commissioned to provide direct access for these patients.
  - B] Conditions that can be managed mostly in a local hospital (secondary care) - but then
require temporary referral to specialist care with the vast majority subsequently discharged to local follow up

- Conditions requiring referral from secondary care for further investigation only available at the specialist centre.

- Specialist teams determine the overall management of children with more complex disease i.e. investigation and treatment, arranging regular disease review and provide rapid access to members of the specialist team for advice/review and continuing care

- Care is delivered in a well-defined clinical network with clear mechanisms for communication across the network which offers 24/7 access to specialist advice, shared care guidelines based on evidence and national guidance

- Many conditions do not have a definitive diagnostic test so that accurate and timely diagnosis relies on the clinical skills and experience of the assessing clinician with support from of associated sub-specialties. Hence co-location with other specialities is essential.

- As specialist gastroenterology, hepatology and nutrition services are also essential to support other paediatric sub-specialities e.g. neonatology, paediatric surgery, oncology, PICU, co-location with relevant specialities is again essential.

Conditions are generally referred to specialist care as :-

- they are rarely seen in general paediatric practice or are very severe / extreme presentations of the a more common condition (e.g. severe constipation or severe gastro oesophageal reflux),
- they require complex long-term management
- specific difficulties are encountered in very young children
- children with certain chronic disease require longer-term nutritional support

The service will offer the following care pathways and components :

- Capacity to accept emergency in-patient transfers at short notice, and admit children directly for specialist investigations without prior clinical assessment
- 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
- Longer term monitoring of cases through out-patient assessment (including outreach) - this may be throughout childhood and adolescence for complex-life long conditions, such as IBD and intestinal failure
- Prompt access to inpatient beds for the management of acutely ill children
- Access to support services including paediatric surgery, radiology, intensive care
- Access for planned assessment and investigation as inpatient or day case, with clearly defined referral/management pathways, scheduled treatment and follow up with well-defined care pathways
- 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,
- The main diagnostic methods include endoscopy with biopsy samples for histological investigation, imaging (including ultrasound scanning, CT/MRI scans and less commonly diagnostic interventional radiology procedures).
- 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.
- Many children with gastroenterological diseases have a life-long chronic disease and contact with the paediatric gastroenterology service can be prolonged and intense. The service must ensure continuity of care at a senior level to achieve consistent management.
- Management is supported by a multi-disciplinary team, (MDT) – see below
- 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.
The following are the standards for staffing and facilities are based on the requirements of the National Service Framework for Children and Young People in England and recommendations of BSPGHAN


The components of a Paediatric Gastroenterology, Hepatology and Nutrition Service are:-

- Sufficient consultant numbers to provide consultant continuity with cross-cover and access to expert opinion by telephone 24 hours/day
- Sufficient Paediatric Gastroenterology/Nutrition nurse specialists to support inpatient care (including multidisciplinary team meetings), discharge planning and re-admission avoidance, to cover specialist clinics, ensure regional liaison as well as perform service evaluation and development
- Paediatric Dietitian support for inpatients (including multidisciplinary team meetings), for 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 colonooscopy 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 children with complex gastrointestinal disease (e.g. adolescent IBD) with allocated time for joint assessment of complex patients including multidisciplinary meetings and clinics
- Clinical Psychologist and/or age-appropriate mental health support.
- Pharmacist and clinical biochemistry staff with experience in paediatric parenteral nutrition.
- Dedicated Social Care support for children who have complex care needs for discharge planning and continuing support
- Time available in the job plans of clinicians and support staff (e.g. dieticians, nurses) to support the care of children with complex needs across the network – this includes provision for multidisciplinary team meetings (for example case conferences, nutrition meetings, radiology meetings, clinico-pathological conferences), joint clinics (e.g. with paediatric surgery, adult physicians as part of transitional care and local clinicians in order to facilitate care close to home through outreach)
- A lead paediatrician in each network DGH with expertise and interest in gastroenterology with allocated clinical sessions to facilitate shared care
- Sufficient administrative and clerical support for the clinical and support staff to facilitate rapid access to assessment and management with clear and effective communication lines across the network - including administrative support for outreach services, as well as capability for regional and national audit, data management and research

Specialised Nutrition Support Services are for the investigation and/or management of the complex nutritional needs for patients whose primary care is often provided by another team - the wider remit includes (enteral nutrition (EN), parenteral nutrition (PN) for intestinal failure, and home PN (HPN)). This must be delivered by an MDT (senior clinician, nurse specialist, dietician, pharmacist, clinical psychologist, speech and language therapist, biochemist, surgeon).

The specialist nutrition support Team is commissioned to deliver the following services

- Consult service for children and young people with nutritional needs
- Clinical support (assessment, prescribing and monitoring of children and young people on parenteral nutrition, multidisciplinary ward rounds, discharge planning, long term care of children and young people with intestinal failure/on Home parenteral nutrition)

Referral processes and sources
The service is commissioned to provide:
A) Conditions needing specialist care from presentation,
B) Conditions that can be managed by a local hospital or by a local hospital initially as secondary care and then referred to specialist care
C) Interventions provided by a specialist centre.
Referral criteria and sources are determined according to pathways of care

- Referral processes are largely from secondary care and determined according to pathways depending on the rarity and complexity of the condition and the age of the child.
- The service will accept referral from primary and secondary care clinicians for patients who require specialist investigation or management within agreed protocols.
- The provider will be responsible for ensuring that any referral meets clinical guidelines and that the correct referral route has been followed in line with any relevant national or local guidelines or recommendations and in accordance with agreed response times.
- GP referrals will be screened for their suitability for specialist care (e.g. Choose and Book Criteria should be agreed and shared with GP’s). Rapid referral from a GP from within or outside the local catchment area is necessary due to urgency of need for specialist investigation such as endoscopy (in cases of gastrointestinal bleeding, and suspected IBD). The percentage of referrals from primary care will vary between units dependent on the regional referral base (patient and provider preference).
- Patients may also be referred for the assessment and management of nutritional problems where the input of the nutrition support team is required. This is an important aspect of the specialised service but is not well described in “Commissioning Safe and Sustainable Specialised Paediatric Services- a Framework of Critical Interdependencies” DoH (2008); http://www.doh.gov.uk/prod_consum_dh/groups/dh which recognises interdependencies to support safe practice rather than provision of expert support.

Discharge from the Specialised Service

- Discharge from the provider will occur when the patient no longer needs to be managed within specialist environment.
- The provider must send written confirmation to the patients’ GP/local hospital detailing the reasons for discharge and recommendation the reason for re-referral if necessary.
- For the following conditions, the majority will be discharged from the specialist service to receive local follow up with input from the specialist centre when required:-
  - Coeliac disease /disorders associated with malabsorption
  - Peptic ulcer disease including H. pylori gastritis
  - Factitious induced illness presenting with gut symptoms
  - Multiple food intolerances (actual and perceived) part of a network including allergist and local paediatrician.

2.3 Population covered

Equity of access to services

Specifically, this service is for infants and children, with disorders of the gastrointestinal tract and nutritional conditions requiring specialised intervention and management, as outlined within this specification.

Equity of access is ensured by a common admission policy for all children to the specialist service (criteria will be defined), and common guidelines. Tertiary paediatric gastroenterology units and District General Hospitals collaborate to ensure provision of a full portfolio of tertiary services across the regional network. Children should not be managed outside of existing networks and pathways because inequity to specialist access will result in delay in diagnosis and treatment with worse clinical outcomes.

2.4 Any acceptance and exclusion criteria

2.4.1 Acceptance criteria

The service will accept inward referrals from secondary care clinicians.

The service will also accept referrals from other providers of Specialised services, particularly when the referring service is not accredited to undertake the clinical role that the patient requires; or when the patient’s condition has stabilised and on-going care could effectively be undertaken at a designated provider closer to the patient’s home.

The service will accept referrals for patients up until their 19th birthday and those with chronic conditions in transition to adult service by local negotiation with adult service and patient choice. The service will accept referrals for those conditions listed in this specification, either suspected or with the diagnosis established. New patients presenting at any age ≤16 years will be accepted, and in
general no referrals to adult services should be made for those ≤16 years of age. For those aged 16 to <19 years of age, referral to paediatric or adult gastroenterology services may be appropriate –

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

2.4.2 Exclusions
The service will not accept new referrals ≥19 years of age. However between 16 to <19 years of age, new referrals should be made to the centre with the appropriate best expertise to deal with the presenting problem. Liaison between paediatric and adult units may be required to ensure optimal management arrangements. In this age range, discussion between the referring clinician and the specialist centre is advised.

Conditions specifically funded by NCG paediatric Hepatology services are excluded. Common conditions, such as functional constipation, gastro-oesophageal reflux and abdominal pain, do not usually need to be seen by the specialist service. However there may be circumstances where an opinion is requested (by phone, letter or face-to-face consultation) prior to on-going secondary or primary care.

2.5 Interdependencies with other services
The provider will work directly with, but not limited to, the following professionals to ensure a seamless service: (ref. Department of Health Report 2008 “Commissioning a Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies)

Co-located services –
- As specialist gastroenterology and nutrition services are an essential support to other paediatric sub-specialities, the specialist service must be co-located with other specialised services e.g. paediatric surgery, paediatric anaesthesia & 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 neurodevelopment, CAMHS/Psychosocial support, paediatric orthopaedics, palliative care,
- Paediatric specialist centres should have access to and support from a paediatric gastroenterologist working in 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 be strong links with NCG funded paediatric Hepatology services

3. Applicable Service Standards

3.1 Applicable national standards e.g.: NICE, Royal College

The specialist service will ensure implementation of national guidelines and development of agreed quality standards where national guidelines do not exist to standardise care across local and regional networks.

Standards of Care

Available from the National Institute of Health and Clinical Excellence -
Nice Clinical guideline 99 ‘Diagnosis and management of idiopathic childhood constipation in primary and secondary care (2010)

Constipation in children and young people :Evidence and Update June 2012

Improving Practice And Reducing Risk In The Provision Of Parenteral Nutrition For Neonates & Children
A Report From The Paediatric Chief Pharmacists Group November 2011
Malnutrition Matters Meeting Quality Standards in Nutritional Care.
www.bapen.org.BAPEN 2010uk/pdfs/toolkit-for-commissioners.pdf

Endoscopy Global Rating Scale (GRS) http://www.grs.nhs.uk/WhatsGRS.aspx

Available from the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) - www.bspghan.org.uk
BSPGHAN Report of the BSPGHAN working group to develop criteria for DGH Gastroenterology, hepatology and Nutrition Services.
http://www.BSPGHAN.org.uk/document/DGH_SERVICES_BSPGHAN.DOC

Available from the European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) – www.espgahan.med.up.pt/joomla/

Inflammatory Bowel Disease Quality Improvement Project
Clinical Standards Department - Clinical Effectiveness and Evaluation Unit
The Royal College of Physicians http://www.ibdqip.co.uk
http://www.doh.gov.uk/nsf/children.htm,

Available from the Royal college of Paediatrics and Child Health

Standards of care across local and regional networks
- Treatment will be offered in line with national policies and guidance, agreed care pathways and referral criteria.
- Care will be provided that promotes equity to access to services based on clinical need for the population served.
- The provider shall have sufficient clinical and support staff to ensure a multi-disciplinary approach to provision of services in respect of, and at all times, in accordance with, good clinical practice, good health care practice and recommendations of and in line with relevant guidelines from BSPGHAN and RCPCH.

3.2 Applicable local standards

Do not use
4. Key Service Outcomes

1. To minimise mortality and morbidity by providing the most appropriate care for children with gastrointestinal, nutritional and liver disease

2. To ensure that there is sufficient, skilled and competent multidisciplinary workforce to manage children with gastrointestinal, nutritional and liver disease

3. To ensure that children are treated in line with national guidelines and agreed local pathways

4. To ensure shared care and clinical networks deliver good specialist care close to home through integrated pathways of care

5. To ensure that children have their healthcare and any social care plans coordinated.

6. To ensure maintenance or improvement in children’s clinical condition (in conditions where this is measurable) to enable normal activities of daily living and optimal school attendance

9. A Written Transition process with a transition Lead

10. Speed of access to care

  E.g. 1] Outcomes measures in terms of mortality and morbidity/ complication rates for specific conditions (e.g. IBD standards)

  2] Adherence to national guidelines with performance measured according to regional and national audit

  3] Satisfaction from patients/parents and secondary providers seeking advice measured according to validated measure

Outcomes for specific conditions will be identified by BSPGHAN Working Groups and patient parent public representatives during a consultation period. Quality dashboards and Compliance with national standards and quality indicators to include specific outcomes.

5. Location of Provider Premises

The Provider’s Premises are located at:

[Name and address of the Provider’s Premises OR details of the Provider’s Premises OR state “Not Applicable”]

6. Individual Service User Placement

[Insert details including price where appropriate of Individual Service User Placement]
Appendix 1
Conditions Managed by Paediatric Gastroenterology, Hepatology and Nutrition

The diagnosis and management of the following conditions are included within the national paediatric gastroenterology and nutrition specialised service* :-

Inflammatory bowel disease (IBD) e.g. Crohn’s Disease, ulcerative colitis and indeterminate colitis) which includes diagnosis, continued management, in the specialist centre and shared care provided according to defined shared care pathways, major treatment decisions including monoclonal antibody therapy, surgery, reassurance that patients are able to obtain appropriate prescriptions and provision of the gateway to those specialised treatments or interventions/very high cost drugs that would not be offered by local clinicians, Specialist supervision and education for families of children receiving Biological therapy, Monitoring of children receiving immune suppression and maintenance of patient registries, opportunities for patients, together with their families and carers appropriate learning about their disease from members of the multi-professional team

Diagnosis and management of Coeliac disease and other disorders associated with malabsorption
Enteropathy / Chronic diarrhoea- >3 weeks duration for diagnostic evaluation and nutritional support
Gastrointestinal polyps and polyposis syndromes
Peptic ulcer disease including H. pylori gastritis (diagnosis); gastrointestinal polyps and polyposis syndromes
Eosinophilic disorders e.g. eosinophilic enterocolitis; eosinophilic oesophagitis
Gastrointestinal motility disorders: achalasia, oesophageal dysmotility, chronic intestinal pseudo obstruction
Gastrointestinal bleeding
Factitious induced illness presenting with gut symptoms
Multiple food intolerances (actual and perceived) part of a network including allergist and local paediatrician
Exocrine pancreatic insufficiency and pancreatic disorders including pancreatitis
Liver diseases (in collaboration with supra-regional liver units)
Conditions such as abnormal Liver Function tests (LFT’s) related to obesity (not persistent, progressive), abnormal LFT’s related to Intestinal Failure (not persistent, progressive, complex), abnormal LFT’s related to IBD (not persistent, progressive or antibody positive), abnormal LFT’s related to Cystic Fibrosis (not persistent, progressive) may be managed by a specialist paediatric gastroenterology unit in the first instance.
Hepatitis B and C should be treated in conjunction with a national liver centre according to agreed protocols.

Specialised gastrointestinal investigations and investigations provided by a specialist centre include
upper gastrointestinal endoscopy (diagnostic and therapeutic), ileo-colonoscopy (diagnostic and therapeutic),
video-capsule endoscopy, endoscopic ultrasonography (EUS), endoscopic retrograde cholangiopancreatography (ERCP) (diagnostic and therapeutic), oesophageal pH and impedance monitoring, diagnostic breath tests including hydrogen breath tests, pancreatic function intestinal intubation tests, gastrointestinal motility investigations (including oesophageal and gastrointestinal manometry, electrogastrography), enteroscopy, Liver Biopsy

Specialised Nutrition Support Services (see above)

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