E03/S/c

2013/14 NHS STANDARD CONTRACT
PAEDIATRIC MEDICINE: GASTOENTEROLOGY, HEPATOLOGY AND NUTRITION

SECTION B PART 1 - SERVICE SPECIFICATIONS

Service Specification No.	E03/S/c
Service	Paediatric Medicine: Gastroenterology, Hepatology and Nutrition
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

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: paediatric hepatology (liver diseases) and nutritional care (complex); 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 multi-disciplinary teams which 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,Royal College of Paediatrics and Child Health (RCPCH) ; examples include:

- Inflammatory bowel disease (www.ibdstandards.org.uk, http://bspghan.org.uk/working_groups/documents/IBDGuidelines, http://journals.lww.com/jpgn/Fulltext/2010/02001/Guidelines for_the_Management_of_Inflammatory.1.aspx)
- Coeliac Disease (NICE 2009, http://www.nice.org.uk/CG86)
- Constipation ((http://www.nice.org.uk/nicemedia/live/12993/48741/48741.pdf)
- Nutritional Support (Agostino C, Axelson I, Colomb V et al. The need for
- nutrition support
- Teams in paediatric units: a commentary by the European Society of Gastroenterology, Hepatology and nutrition (ESPGHAN)Committee on Nutrition. J Pediatr Gastroenterol Nutr 2005; 41: 8-11.)
- http://www.bapen.org.uk/pdfs/toolkit-for-commissioners.pdf Transition to adult services (Department of Health: Transition: Getting it right for young people. National Service Framework for Children, Young People and Maternity
- Services. (2006). Crohn's and Colitis UK (NACC), Crohn's in Children's Research (CICRA): Inflammatory Bowel Disease - Transition to adult health care: guidance for health professionals. (2008). www.ibdtransition.org.uk

2. 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

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 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
- ensuring that relevant psychological, emotional, educational and social care needs are addressed
- participating in local and national audit, quality improvement programmes and scientific and clinical research that lead to improvements 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:

- conditions needing specialist care from presentation - specialist gastroenterology and nutrition care is led by a specialist team which provides 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.
- 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, arrangement of regular disease review and provision of 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 are 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-specialities. 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, paediatric intensive care, 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 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 inpatient 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 outpatient 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
- 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 British Society of Gastroenterology, Hepatology and Nutrition (BSPGHAN)

(Adapted from British Society of Gastroenterology, Hepatology and Nutrition: Guide for purchasers of Paediatric Gastroenterology, Hepatology and Nutrition Services. (2003) http://www.bspghan.org.uk/;
Department of Health: National Service Framework for Children, Young People and Maternity Services (2004))

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 dietician 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 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 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 district general hospital 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

Specialist Nutritional 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 (enter nutrition (EN), parenteral nutrition (PN) for intestinal failure, and home PN (HPN). This must be delivered by a multidisciplinary team (MDT) (senior clinician, nurse specialist, dietician and pharmacist, 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 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 GPs). 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, Department of Health (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 a specialist environment.

The provider must send written confirmation to the patient’s 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 intolerances (actual and perceived) part of a network including

General Paediatric care

When treating children, the service will additionally follow the standards and criteria outlined in the Specification for Children’s Services (attached as Annex 1 to this specification)

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

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

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.

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 Interdependencies)*

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 highly specialised paediatric hepatology services.

3. Applicable Service Standards

3.1 Applicable national standards e.g. National Institute of Health and Care Excellence (NICE), Royal Colleges

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 Inflammatory Bowel Standards Group

- IBD Standards Group (2009) '\Service standards for the healthcare of patients who have inflammatory bowel disease http://www.ibdstandards.org.uk; http://bspghan.org.uk/working_groups/documents/IBDGuidelines which includes time to diagnosis, annual review, rate of emergency admission).

Available from the National Institute of Health and Care Excellence - www.nice.org.uk

- NICE (2006) Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children, NICE Clinical Guideline, CG43
- NICE. Upper GI endoscopy service commissioning guide (2007).http://www.nice.org.uk/usingguidance/commissioningguides/uppergiendoscopyservcies/.jspNICE (2009) The recognition and diagnosis of coeliac disease, NICE Clinical Guideline (revised 2012).
- 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

http://www.evidence.nhs.uk/nhs-evidence-content/evidence-updates

Improving practice and reducing risk in the provision of parenteral nutrition for neonates & children: a report from the Paediatric Chief Pharmacists Group November 2011. www.rpharms.com/support-pdfs/minimising-risk-pn-children- (6).pdf

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/WhatisGRS.aspx

Joint Advisory Group (JAG) for GI endoscopy.http://www.thejag.org.uk/

Joint Advisory Group (JAG) for GI endoscopy.http://www.thejag.org.uk/

Available from the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) – www.bspghan.org.uk

- BSPGHAN (2005) Guidelines for the diagnosis and management of coeliac disease in children
- BSPGHAN (2008) Guidelines for the management of inflammatory bowel disease in Children
- BSPGHAN (2012) Guidelines for the diagnosis and management of coeliac disease
- 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.DO C
- BSPGHAN Guide for Purchasers of PGHAN Services. http://bspghan.org.uk/inforamtion/guides.shtml

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

IBD working group consensus paper: Inflammatory bowel disease in children and adolescents: recommendations for diagnosis - the Porto criteria, J Pediatr. Gastroenterol. Nutr. 2005 Jul;41(1):1-7

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

- Bringing networks to life - RCPCH Guide to Implementing Clinical Networks, 2012).

4. Key Service Outcomes

- To minimise mortality and morbidity by providing the most appropriate care for children with gastrointestinal, nutritional and liver disease
- To ensure that there is a sufficient, skilled and competent multi-disciplinary workforce to manage children with gastrointestinal, nutritional and liver disease
- To ensure that children are treated in line with national guidelines and agreed local pathways
- To ensure shared care and clinical networks deliver good specialist care close to home through integrated pathways of care
- To ensure that children have their healthcare and any social care plans coordinated.
- 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
- A written transition process with a transition lead
    - Speed of access to care
    - Outcomes measures in terms of mortality and morbidity/ complication rates for specific conditions (e.g. IBD standards)
    - Adherence to national guidelines with performance measured according to regional and national audit
    - 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.

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

This specification annex applies to all children's services and outlines generic standards and outcomes that would fundamental to all services

The generic aspects of care: The Care of Children in Hospital (Health Service Circular (HSC) 1998/238) requires that:

- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimise complications and mortality.
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child. Accommodation is provided for them to remain with their children overnight if they so wish.

Service description/care pathway

All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

Services should therefore be organised and delivered through 'integrated pathways of care (National Service Framework for children, young people and maternity services (Department of Health & Department for Education and Skills, London 2004)

Interdependencies with other services

All services will comply with Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies – Department of Health

Imaging

All services will be supported by a three tier imaging network (Delivering quality imaging services for children, Department of Health 13732 March 2010). Within the network:

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

Specialist Paediatric Anaesthesia

Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training.1 All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training2 and should maintain the competencies so acquired3 *. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example magnetic resonance imaging (MRI) scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.

Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

*The Safe and Sustainable reviews of paediatric cardiac and neuro- sciences in England have noted the need for additional training and maintenance of competencies by specialist anaesthetists in both fields of practice.

References

1. Guidance for Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists.(RCoA) 2010 www.rcoa.ac.uk
2. Certificate of Competion of Training (CCT) in Anaesthesia 2010
3. CPD matrix level 3

Specialised Child and Adolescent Mental Health Services (CAMHS)

The age profile of children and young people admitted to specialised CAMHS day/in-patient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS in-patient settings, including over-16s. The average length of stay is longer for admissions to mental health units. Children and young people in specialised CAMHS day/in-patient settings generally participate in a structured programme of education and therapeutic activities during their admission.

Taking account of the differences in patient profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following:

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply (http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx)
- Staffing profiles and training - essential QNIC standards should apply.
- The child/ young person's family is allowed to visit at any time of day taking account of the child / young persons need to participate in therapeutic activities and education as well as any safeguarding concerns.
- Children and young people are offered appropriate education from the point of admission.
- Parents/carers are involved in the child/young person's care except where this is not in the best interests of the child / young person, and in the case of young people who have the capacity to make their own decisions, is subject to their consent.
- Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child/ young person.

Applicable national standards e.g. NICE, Royal College

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.

- There must be an Registered Children’s Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of two RCNs in total).

Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes HBN 23 Hospital Accommodation for Children and Young People NHS Estates, The Stationary Office 2004.

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children’s Workforce Development Council Induction standards (Outcome 14b Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Each hospital which admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies (National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002).Facing the Future Standards, Royal College of Paediatrics and Child Health.

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a Essential Standards of Quality and Safety, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (Seeking consent: working with children Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 Essential Standards of Quality and Safety, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- ensuring that staff and people who use services understand the aspects of the
- safeguarding processes that are relevant to them.
- ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- ensuring that people who use services are aware of how to raise concerns of

abuse

- having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern
- having effective means of receiving and acting upon feedback from people who use services and any other person.
- taking action immediately to ensure that any abuse identified is stopped
- and suspected abuse is addressed by:
    - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
    - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
    - reporting the alleged abuse to the appropriate authority
    - reviewing the person's plan of care to ensure that they are properly supported following the alleged abuse incident.
- using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- participating in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- ensuring that those working with children must wait for a full CRB disclosure before starting work.
- training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010

All children and young people who use services must be

- Fully informed of their care, treatment and support.
- Able to take part in decision making to the fullest extent that is possible.
- Asked if they agree for their parents or guardians to be involved in decisions they need to make.

(Outcome 4I *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010)

Key Service Outcomes

Evidence is increasing that implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) have the potential to greatly improve patient experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS. Implementation is also expected to contribute to improvements in health inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transition for those with long term conditions), these should be organised so that:

- all those involved in care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

The National Minimum Standards for Providers of Independent Healthcare, (Department of Health, London 2002) require the following standards:

- **A16.1** Children are seen in a separate outpatient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- **A16.3** Toys and/or books suitable to the child's age are provided.
- **A16.8** There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult patients; the segregated areas contain all necessary equipment for the care of children.
- **A16.9** A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by
- **A16.10** The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified hospital play specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control
- All hospital settings should meet the Standards for the Care of Critically Ill Children (Paediatric Intensive Care Society, London 2010).

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

- a choice of suitable and nutritious food and hydration, in sufficient
- quantities to meet service users' needs;
- food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background
- support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs.
- for the purposes of this regulation, 'food and hydration' includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
- providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.

All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate

All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 Essential Standards of Quality and Safety, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

- ensure the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- ensure that staff handling medicines have the competency and skills needed for children and young people's medicines management
- ensure that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, and including information about the use of unlicensed medicine in paediatrics.

Many children with long term illnesses have a learning or physical disability. Providers should ensure that:

- they are supported to have a health action plan
- facilities meet the appropriate requirements of the Disability Discrimination
- Act 1995
- they meet the standards set out in Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health, 2006, London

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 and 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; maintenance of patient registries; and opportunities for patients, together with their families and carers. To access 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 Test's (LFTs) 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).