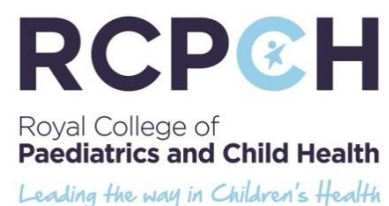


ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH
BRITISH SOCIETY OF PAEDIATRIC GASTROENTEROLOGY, HEPATOLOGY AND NUTRITION

Quality Standards for Paediatric Gastroenterology, Hepatology & Nutrition

FINAL

JANUARY 2017



Foreword

During the revision of the Facing the Future: Standards for Acute General Paediatric Services² the interaction between secondary and tertiary services was highlighted by paediatric clinical directors as an area of concern where they would welcome further guidance. The RCPCH and BSPGHAN particularly recognise that areas of improvement are required in gastroenterology, hepatology and nutrition to ensure children are receiving timely, high quality services as close to home as possible.

It is clear that there is heterogeneity in the way that services are being provided to children across the UK. These standards have been developed alongside the principles laid out by the RCPCH 'Bringing Networks to Life' publication that underpins the direction of travel for all paediatric services to be planned and provided through funded managed clinical networks.

These standards have been developed using the experience and authority of the RCPCH with the specialist expertise and knowledge of BSPGHAN throughout 2016. Extensive consultation with children and their families together with input from key stakeholders has helped to influence and steer the process of producing a key set of definitive standards.

We are committed towards supporting the membership of RCPCH and BSPGHAN by asking commissioners and service planners across the UK to ensure that these standards are being met so that high quality and consistent care is provided to all children with these conditions.

Dr Carol Ewing
Vice President for Health Policy, RCPCH

Dr Nick Croft
President, BSPGHAN

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Executive summary

The Royal College of Paediatrics and Child Health and the British Society of Paediatric Gastroenterology, Hepatology and Nutrition have worked together to develop these new standards. The standards apply to children receiving gastroenterology, hepatology and nutrition care in the secondary and tertiary care settings across the UK.

The standards are built around the requirement for specialist paediatric gastroenterology, hepatology and nutrition services to provide the full portfolio of services within a network. Networks allow for centres to join up their resources and expertise by supporting a stronger workforce that promotes standardised care spanning political and geographical boundaries. Investment made towards establishing managed clinical networks will enable high-quality services to children and their families as close to home as possible.

The standards will ensure that expertise in gastroenterology, hepatology and nutrition is available through networks that are operational to provide rapid access on all aspects of nursing and medical care 24 hours a day, seven days a week for children with suspected acute illness.

Clinical networks are highly reliant upon collaboration and standard two and three focus on supporting improvements to patient experience using the mechanisms of the network; ensuring equitable access to specialist care and smooth transition processes for children moving into adult services. Standards four to nine focus on endoscopy, inflammatory bowel disease, specialist nutrition care and hepatology.

We hope that commissioners and service planners will use these standards to enable all children across the UK to access high-quality rapid treatment. Implementation of these standards will be reliant upon health professionals adopting them on the ground. We hope that in doing so, health outcomes for children with gastroenterology, hepatology and specialist nutrition needs will be improved.

Dr John Fell
Chair of the Quality Standards Working Group BSPGHAN

Melissa Ashe
Project Officer RCPCH

Case for change

Public Health England's NHS Diagnostic Service Atlas¹ provided powerful evidence of variability in healthcare across the country at a time when services for infants, children and young people (ICYP) with gastrointestinal, liver or nutritional disorders are under significant pressure. Changes to the range of commissioning arrangements for the NHS in England and pressure on services across the UK risk the specialty networks and pathways of care becoming fragmented and disjointed, with a lack of clarity over funding arrangements and responsibilities.

Findings from standard nine of Facing the Future: Standards for Acute General Paediatric Services² ranked gastroenterology, hepatology and nutrition at the bottom for paediatricians in inpatient and paediatric assessment units being able to access specialist opinion for children with complex and specialist needs. A survey sent to all paediatric clinical directors in the UK to understand how services are providing gastroenterology and hepatology services to children demonstrated great heterogeneity in the way services are currently being provided.

Patient engagement activities undertaken by the RCPCH has shown mixed management of children undergoing transition from paediatric to adult services³. Ensuring smooth transition for children can help to promote self-management and independence that can work towards improving health outcomes and increased patient satisfaction⁴.

Whilst the 2015 RCPCH Workforce Census⁵ reports that while 75% of gastroenterology, hepatology and nutrition services are part of a formal or informal network for emergencies, it is unlikely that many of these networks are organised and mature enough to ensure that all services are able to acquire expert opinion 24 hours per day. Funding sought from the National Delivery Plans in Scotland supported the development and setting up of managed clinical networks for gastroenterology, hepatology and nutrition and has already shown marked improvement in children receiving more specialist care closer to home⁶.

England, Wales and Northern Ireland deliver gastroenterology and nutrition services without formal networks which can serve populations of between 2 and 4 million⁷. Services in Scotland operate within three funded regional networks to ensure multi-disciplinary teams across the networks are able to deliver specialist care as close to home as possible.

Hepatology services are established within networks in England, Northern Ireland, Scotland and Wales. Three National Specialist Liver Services for Children are funded in England and deliver specialised hepatology care through network arrangements and outreach clinics providing support to children across the UK with complex liver disease.

To ensure all children throughout the UK receive high quality care, at the right time and in the right place, services must pull together and organise themselves into clinical networks. Networks that establish clear, agreed and shared protocols will enhance the quality and efficiency of care being delivered across large geographical areas.

Aims and scope

The Royal College of Paediatrics and Child Health and the British Society of Paediatric Gastroenterology, Hepatology and Nutrition have collaborated to produce a new set of standards to respond to evidence in the variation of care provided to children and to the changes in commissioning arrangements for specialist services^{1,7}. A working group was convened to review available guidelines and standards for paediatric gastroenterology, hepatology and nutrition and to identify areas of deficiency and fragmentation in how services are being provided to paediatric populations.

These standards apply to infants, children and young people between the age of 0 – 18 years old requiring care from specialist paediatric gastroenterology, hepatology and nutrition services in a secondary and/or tertiary setting that supports the investigation and management of the following conditions: disorders of the gastrointestinal tract including conditions requiring paediatric endoscopy, inflammatory bowel disease (IBD), motility disorders, (including complex gastro-oesophageal reflux and constipation), functional disorders and conditions leading to intestinal failure, chronic diarrhoea of over three weeks durations, coeliac disease and other disorders associated with malabsorption^{7,8}.

It also encompasses two related specialities: paediatric hepatology (acute and chronic liver disorders) 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.

A large volume of gastroenterology is non-specialised and can be managed by secondary paediatric services, for example uncomplicated constipation and functional abdominal pain.

The standards will reduce variation in care; ensuring equitable services are available for all infants, children and young people. Ultimately, they will promote the best health outcomes and quality of life for children and their families.

The Royal College of Paediatrics and Child Health together with the British Society of Paediatric Gastroenterology, Hepatology and Nutrition play key roles in promoting standards of clinical practice for children. The standards are intended to be a tool and resource for healthcare professionals, commissioners, planners, providers, managers, regulators and inspectorates to help plan, deliver and quality assure children's healthcare services. This is the first time quality standards have been published for paediatric gastroenterology, hepatology and nutrition and plans to update and refine them will be made in three years' time if required.

Development of the standards

The development of the standards has been overseen by a Quality Standards Working Group in consultation with a wide range of stakeholders.

Stage one: analysis

Systematic literature review

As part of the evidence base for the standards a systematic literature review was carried out. The review looked at 'What interventions by paediatricians/child health specialists improve outcomes for infants, children and young people with gastro, liver or intestinal disorders presenting in [secondary and tertiary care pathways]?'

Key databases including Medline and Embase were searched in July 2016, returning 4,399 papers. Following a title screen this was reduced to 58 papers. An abstract screen was carried out independently by two reviewers using the inclusion and exclusion criteria and 14 papers were identified for inclusion.

Call for evidence

A call for evidence was issued and a hand search of relevant websites carried out, identifying another 8 papers for inclusion. Each of these papers was appraised and included in the evidence tables.

BSPGHAN working groups for endoscopy, hepatology, motility, IBD and nutrition were invited to nominate three key service recommendations that would be most helpful in promoting high quality services. These recommendations were appraised by the Quality Standards Working Group and included in evidence tables with 6 papers identified for inclusion.

Views of children and parents and carers

The Quality Standards Working Group recognises that key service standards are crucial towards improving health outcomes and quality of life for children with gastroenterology, liver and nutritional disorders. A representative from a children's charity joined the Working Group and the RCPCH worked strategically throughout the project to ensure the experience of children receiving gastroenterology, nutrition and liver care were included.

Three SurveyMonkey questionnaires were sent to a variety of patient groups, charities and through social media networks that resulted in 10 responses. Similarly, engagement postcards were disseminated to gastro clinics through the Working Group returning 12 responses. A clinic visit was organised at Birmingham Children's Hospital to explore how children and their families feel about their experience, wishes and ideas for standards of care. Twelve families took part and responses were included in evidence tables and presented to the Working Group.

Workforce survey of current practice

A SurveyMonkey questionnaire was sent to 138 organisations in the UK who provide acute children's services to understand the current structures for delivery of care across the UK. The survey was sent to clinical directors in June 2016 and the RCPCH received 84 responses.

RCPCH Medical Workforce Census 2015

Data from the RCPCH Medical Workforce Census 2015⁵ has been used to underpin workforce recommendations for guidance to implementing the standards. The census provides a snapshot of how trained and trainee paediatricians were working on 30 September 2015. All organisations in the UK who provide child health services (195) were invited to complete the census with 131 organisations returning completed information in addition to 40 organisations providing partial responses.

Stage two: formulation of standards

The evidence from the literature search and workforce survey, together with the views of children and young people with standards nominations submitted by other BSPGHAN working groups was evaluated by the Quality Standards Working Group. Drawing on the best evidence available, draft standards were developed.

Stage three: consultation

The draft standards were circulated to BSPGHAN Council and key RCPCH committees and to external stakeholders to ensure they are: relevant and achievable; specific and measurable; clear and consistent; to identify any gaps and suggestions for additional standards; and to engage users and key stakeholders.

Key RCPCH committees included:

- British Association for Community Child Health
- British Association of General Paediatrics
- Child Protection Standing Committee
- Paediatricians in Medical Management Committee
- Remote and Rural Special Interest Group and the Young People's Health Special Interest Group

Key stakeholders included:

- British Association of Parenteral and Enteral Nutrition
- British Society of Gastroenterology
- NHS Scotland, NHS England
- The Welsh NHS Confederation
- Royal College of Physicians
- Royal College of Nursing
- European Society for Paediatric Gastroenterology
- Hepatology and Nutrition
- National Institute for Health and Care Excellence

Standards were additionally sent to BSPGHAN and RCPCH membership, children's service commissioners, and individual gastroenterologists, hepatologists and nutrition experts.

Key patient and carers groups included: Children's Liver Disease Foundation, Crohn's in Childhood Research Association, Coeliac UK, Crohn's & Colitis UK, NSPCC, RCPCH & Us®.

Site visit

In order to further explore the efficacy of standards, a site visit was organised to University Hospital Southampton NHS Foundation Trust (Southampton General Hospital) in November 2016. The

purpose of this visit was to ‘road test’ the standards on the ground to ensure their viability whilst providing an opportunity to highlight examples of good practice or where challenges may be foreseen towards implementing them.

Feedback from consultation was considered by the Quality Standards Working Group and standards were refined prior to endorsement by the RCPCH and BSPGHAN.

Key terms and definitions

Children	Infants, children and young people under the age of 18 across the UK.
Lead Specialist Centre for Gastroenterology and Nutrition	Provides the full portfolio of gastroenterology and nutrition investigation, treatment and support services including: paediatric endoscopy, inflammatory bowel disease (IBD), motility disorders, (including complex gastro-oesophageal reflux and constipation), functional disorders and conditions leading to intestinal failure, chronic diarrhoea of over three weeks durations, coeliac disease and other disorders associated with malabsorption.
Lead Specialist Centre for Hepatology	Three centres that provide investigations and treatment for children with neonatal liver disease, chronic liver disease, acute liver failure and liver transplantation care. These centres are: Birmingham Children’s Hospital; King’s College Hospital Paediatric Liver Centre, London; and Leeds General Infirmary Children’s Liver Unit.
Network Centre	Centres that have at least one consultant paediatrician with special interest in paediatric gastroenterology.
Managed Clinical Network	Networks that are funded and have defined objectives and structure, a clear governance framework and an identified network lead to ensure shared protocols and effective communication.
Clinical Network	Services brought together to strategically provide high quality, specialist care to the local population.

Using the standards

Each standard is first listed and then presented alongside:

- The rationale and evidence base
- Guidance notes to support the implementation of the standards
- Metrics to both monitor progress towards meeting the standard and by the Royal College and BSPGHAN in future audits to assess whether the standards are being met.

The metrics are based on information that is currently collected or can be made readily available. Any additional data which might be collected by services is suggested under activity data.

For more information contact health.policy@rcpch.ac.uk

Summary of the standards

- 1. Trusts and health boards that provide paediatric gastroenterology and nutrition services work within a clinical network. Trusts and health boards that provide paediatric hepatology services work within a clinical network.**
- 2. All hospitals have access to specialist gastroenterology, hepatology and nutrition advice by telephone with adequate capacity for transfer to the tertiary centre 24 hours a day 7 days a week to ensure access to services are equitable and designed across geographical, political and NHS/health board boundaries through the network.**
- 3. Transition planning is documented and agreed by the child, the paediatric team and adult services. Transition policies and pathways are published on trust and health board websites.**
- 4. Paediatric endoscopies must be undertaken in a child-friendly environment with appropriate facilities. For children presenting in an emergency, timely access to endoscopy must be available through clear and agreed pathways within the network.**
- 5. Children with suspected inflammatory bowel disease are seen by a specialist service within four weeks in an age appropriate facility by a multi-disciplinary team and reviewed regularly as required within the network.**
- 6. Children who require specialist dietary treatment have a named paediatrician and access to a specialist paediatric dietitian as part of a multi-disciplinary team to ensure their nutritional requirements are met.**
- 7. Children receiving inpatient parenteral nutrition are reviewed at least once a week by a multidisciplinary nutritional care team to include a paediatrician with experience in parenteral nutrition, paediatric dietitian, parenteral nutrition pharmacist and children's clinical nurse specialist with knowledge and experience in nutrition support.**
- 8. Children receiving home parenteral nutrition (HPN) are cared for by an intestinal failure or designated HPN unit with a multidisciplinary nutrition team.**
- 9. The gastroenterology network is linked to a lead specialist centre for hepatology with agreed patient pathways, access to specialist hepatology advice through their on-call rota, outreach clinics and shared care arrangements.**

Standard one

Trusts and health boards that provide paediatric gastroenterology and nutrition services work within a clinical network.

Trusts and health boards that provide paediatric hepatology services work within a clinical network.

Rationale and evidence

Clinical networks are increasingly seen as a way of providing high quality care to a population across a large geographical area ensuring patients have access to specialist care regardless of where they live. Successful clinical networks ensure that clear mechanisms for communication across the network offers 24/7 access to specialist advice by telephone. A successful network is highly reliant on collaboration with agreed shared care protocols and robust systems of communication and information sharing. Networks include the capability for medical, surgical and allied health professional multi-disciplinary team meetings, audit and other measures of quality improvement, data management, shared IT protocols and research.

Guidance

Within each gastroenterology and nutrition network there is one or more lead specialist centre which provides the full range of paediatric gastroenterology and nutrition investigation, treatment and support services in addition to one or more network centres that provides a limited range of services depending on geography, local expertise and funding. Network centres will have at least one consultant paediatrician with special interest in paediatric gastroenterology (SPIN doctor), and some may provide a tertiary referral service to smaller units within the network⁸.

Hepatology networks are organised by three lead specialist centres that provide specialised assessment and management of complex liver disease in an appropriate care environment for children⁹. Network centres that provide a limited range of services refer to one of the lead specialist centres for hepatology for advice 24 hours a day, 7 days a week.

The network lead is responsible for ensuring protocols and guidelines are shared across the network including a clear and agreed pathway of care for acute gastrointestinal bleeding and child protection protocols.

When specialist services are being provided locally, all centres must have a designated paediatric gastroenterology consultant with appropriate multidisciplinary support responsible for linking expertise between the network centre and lead specialist centre.

For networks that do not provide the full portfolio of gastroenterology, hepatology and nutrition, an agreement must be made with neighbouring networks to ensure equity of access to specialist services.

Minimising transfers for children helps to promote stability and avoids complications during transit. Optimally, lead specialist centres that provide gastroenterology and nutrition services are located with paediatric surgery, specialist anaesthetic services and pain management, neonatology expertise, paediatric interventional radiology, clinical biochemistry, histopathology and critical care.

In addition to these services, specialised hepatology services require hepatobiliary surgery, paediatric interventional radiology, transplant immunology, microbiology, virology and intensive care. Network centres that provide specialist services locally must be located with the appropriate multi-disciplinary support.

Strong relationships between paediatric and adult colleagues for gastroenterology, hepatology and nutrition services will ensure transitional care is appropriately managed. Similarly, the network provides access to services to support patients with complex care needs to ensure the mental health and psychological needs of patients are addressed.

Centres which do not offer paediatric gastroenterology and hepatology services must have a clear and agreed pathway and protocol in place in order to refer children out or to access specialist advice.

Metrics

Metrics
<ul style="list-style-type: none">• Evidence of shared care protocols and guidelines• Evidence of protocol for referral of acute liver failure to lead specialist centre for hepatology• Evidence of annual meeting for network• An identified network lead with dedicated time within their job plan to ensure clear and effective communication across the network• Evidence of multi-disciplinary team, audit, data management and benchmarking within network• Evidence of agreed protocols for gastrointestinal bleed within network• Evidence of clinical letters sent out within ten working days

Standard two

All hospitals have access to specialist gastroenterology, hepatology and nutrition advice by telephone with adequate capacity for transfer to the tertiary centre 24 hours a day 7 days a week to ensure access to services are equitable and designed across geographical, political and NHS/health board boundaries through the network.

Rationale and evidence

We know through engaging with children and young people that providing services as close to home as possible is important for providing high quality and tailored care for patients and families¹⁰. Clinical networks enable equitable care to patients and ensure resources are shared and targeted where there is a greater need for investment. This is a notable benefit for services delivered outside of the tertiary setting to meet the essential needs of the child as well as supporting patients who may be subject to postcode prescribing¹¹.

Standard nine in Facing the Future: Standards for Acute General Paediatric Services² states that centres must have access to appropriate specialist advice in a timely manner. An audit of this standard undertaken in 2013¹² ranked gastroenterology, hepatology and nutrition joint bottom when units were asked about availability for immediate telephone advice. Providing specialist advice through agreed networks will ensure that specialist paediatric gastroenterology consultant opinion is easily accessed when caring for children with acute and complex needs.

Guidance

The network provides a pathway for timely review and rapid access for the assessment and management of urgent referrals. Centres within the network are responsible for ensuring referral times meet clinical guidelines and are in accordance with agreed response times. Networks are encouraged to collaborate and link in with other networks in order to provide 24 hour advice 7 days a week. Advice must be documented to support clinical governance. All children admitted for specialist gastroenterology, hepatology and nutrition care must be seen by a suitably trained paediatric consultant within the maximum of 24 hours².

Metrics

Metrics	Activity Data
<ul style="list-style-type: none">• Evidence of 24/7 telephone advice arrangements• Audit of referral times meeting national and clinical guidelines• Audit of time to decision for transfer / time to receive in accordance to national clinical guidelines• Evidence that specialist advice given and received is clearly documented	<ul style="list-style-type: none">• Number of telephone calls received for specialist advice• Number of outreach clinics held• Number of patients received in outreach clinics

Standard three

Transition planning is documented and agreed by the child, the paediatric team and adult services. Transition policies and pathways are published on trust and health board websites.

Rationale and evidence

The RCPCH & Us[®] Roadshow reported that children from as young as 8 years old are concerned over the arrangements made to plan their transition into adult services³. Transition care arrangements must be an integral part of any service, preferably with joint clinics held between adult and paediatric gastroenterology teams which young people can attend for as long as is appropriate and agreed.

Guidance on transition is widely available yet only 50% of young people and their parents surveyed by the CQC in 2014 said they had received support from a lead professional during the lead up to transitioning to adult services¹³. Planning this change is integral to ensuring a smooth exchange of information between patients, their families and services involved in providing continuity of care.

Patients transitioning into adult gastroenterology services from the age of 16 years old will be expected to become more independent in managing their condition, and so it is crucial that planning for this change is made in advance to ensure relapses are prevented. For patients with complex care needs or for those whose health needs are better met in a paediatric environment, planning should consider this and the age in which the point of transition happens should not be based on a rigid threshold¹⁴.

Guidance

Planning transition for young people into adult services must involve the young person and where possible their parents and carers in a way that the young person feels included and understands. Clinicians must ensure that transition planning is appropriate to the child's development, maturity and healthcare needs and that it includes the child's preference.

NICE quality standards¹⁴ recommends that transition planning for children begins by school year 9 (aged 13 to 14 years) or immediately if they are referred to children's services at this age. A 'transition worker' is allocated to the young person who will ensure coordination of services and support for the young person during the transition period, with the exact length of support agreed by the child¹⁴ (this person may or may not already be involved in the child's care). Transition plans must be reviewed annually with the child and their parents/carers. Adult gastroenterology and hepatology colleagues must be included within the network to ensure involvement for young people's transition planning. Transition planning must be person-centred, ensuring the young person's social and psychological needs are accounted for, with a psychologist and access to mental health services being available to the young person through the network.

For new referrals of patients between 15 and 18 years old the most appropriate clinical setting to begin treatment is agreed between the child, parent/carer, paediatric team and adult services.

Metrics

Metrics	Activity Data
<ul style="list-style-type: none">• Evidence of adult gastroenterology and hepatology colleague in network or gastroenterologist / hepatologist with an interest in transition• Identification of the transition worker for each patient• Evidence of transition information given to patients in preparation of transition• Evidence that child and parent / carer understanding of the information is checked• Transition policy and pathway available on trust and health board websites• Annual meeting to review plans for children transitioning to adult services	<ul style="list-style-type: none">• Number of patients over 16 years old seen in paediatric clinics• Number of agreed transition plans

Standard four

Paediatric endoscopies must be undertaken in a child-friendly environment with appropriate facilities. For children presenting in an emergency, timely access to endoscopy must be available through clear and agreed pathways within the network.

Rationale and evidence

For children who require internal examination, timely access to endoscopy must be available through defined local or regional pathways. This is particularly important for children who require endoscopy before treatment can be commenced or delivered, for example for children with oesophageal varices, inflammatory bowel disease or coeliac disease, where national guidance should be followed where available. The UK IBD Audit¹⁵ shows that 99% of all services have a process in place to ensure endoscopy is accessed within 72 hours.

The Joint Advisory Group on gastrointestinal endoscopy (JAG) created the Global Rating Scale quality improvement web-based assessment tool in 2004 for the adult gastrointestinal endoscopy service to enable units to assess how well they provide a patient-centred service and to drive up standards. The paediatric Global Rating Scale* is expected to be published in 2017 and will strongly support the provision of high-quality, integrated and patient-focused endoscopy for children.

Guidance

General anaesthesia for paediatric endoscopy is provided by paediatric anaesthetists. When sedation is used for endoscopy, clinicians must follow NICE Guidelines on Sedation in Under 19s¹⁶. Professionals training in endoscopy have access to the JAG Electronic Training System e-portfolio before arranging summative assessment. Units have policies and systems in place to ensure a properly trained and competent workforce allows staff to meet the requirements of professional revalidation.

Paediatric endoscopies must be undertaken in a child-friendly environment with appropriate and adequate facilities, including the testing and validation of decontamination equipment, where national guidance should be followed¹⁷.

Sending information to the child and their family of what is to be expected during endoscopy can help the child to prepare for the level of discomfort during the procedure (if under sedation). Units should provide service contact information and after care information to children and parents with a 24 hour contact number in case children have questions or experience problems.

The network ensures there is a clear and agreed pathway of care in place for acute gastrointestinal bleeding in the emergency care setting and for other acute procedures such as foreign body retrieval.

Metrics

Metrics	Activity Data
<ul style="list-style-type: none">Evidence of agreed pathway of care for management of gastrointestinal bleed	<ul style="list-style-type: none">Unplanned admission <8 days, 30-day mortality, duodenal haematoma and

* For more information regarding the paediatric Global Rating Scale contact askjag@rcplondon.ac.uk

<ul style="list-style-type: none"> • Evidence of agreed pathway of care for management of foreign body / battery retrieval • Quality improvement measures applicable to national programme • Audit of adverse events at least every 3 months • Annual patient feedback survey 	<p>perforation rates collated for diagnostic procedures</p> <ul style="list-style-type: none"> • Patient/carer surveyed for unit feedback annually, with evidence of action on negative comment or complaint • Completion rates for colonoscopy
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Standard five

Children with suspected inflammatory bowel disease are seen by a specialist service within four weeks in an age appropriate facility by a multi-disciplinary team and reviewed regularly as required within the network.

Rationale and evidence

Children with suspected inflammatory bowel disease (IBD) require prompt referral into specialist services in order to treat and manage their diagnosis or relapse. Children and young people have told us that improving wait times to diagnosis and specialist care would significantly improve their patient experience¹⁸.

Up to a quarter of all patients diagnosed with IBD are under 16 years old and will typically experience relapse and remissions as part of their chronic condition through to adulthood. Children with IBD are most appropriately cared for by paediatric multidisciplinary IBD teams in order to deliver person-centred care effectively.

Transitioning IBD patients from paediatric care to adult services is important to ensure a continuum of care is delivered but also to begin to encourage self-management and independent living. Refer to standard three for more guidance on transition.

Guidance

Care for children with IBD is most appropriately provided by paediatric gastroenterologists with specialist children's nursing and dietetic support. British Society of Gastroenterology IBD Standards¹⁹ advise for teams to operate in a managed clinical network in order to provide access to care for children as close to home as possible, through local shared-care arrangements with adult gastroenterology teams.

The IBD service must have defined access to the clinical network and include the following with an interest in IBD: children's nursing expertise; paediatric dietetics; mental health support professionals; clinical psychologists and counsellors; rheumatologist; ophthalmologist; dermatologist; radiologists; endocrinologist; adult gastrointestinal physician interested in adolescent IBD; gastrointestinal pharmacist; and a nutrition support team.

The network must agree a communication pathway for referral of possible IBD patients and follow national guidance where available²⁰. Children with suspected IBD must be contacted with an appointment within two weeks of referral and seen by a specialist within four weeks, or more rapidly if clinically necessary, with endoscopy offered within six weeks of initial referral if required. Children with a suspected relapse should wait no longer than 72 hours to be reviewed by the IBD service¹⁹.

Children with IBD require regular clinical review. Monitoring of immunosuppressants and biologics is undertaken in accordance with BSPGHAN²¹ and NICE²² guidelines. In order for units to manage their service effectively, teams must perform regular audits and engage with research and quality improvement programmes, including audit data collected for patients on biologics.

Metrics

Metrics
<ul style="list-style-type: none">• Documented wait times• Evidence of audit data collected for patients on biologics• Evidence of submission to national audit and quality improvement programme

Standard six

Children who require specialist dietary treatment have a named paediatrician and access to a specialist paediatric dietitian as part of a multi-disciplinary team to ensure their nutritional requirements are met.

Rationale and evidence

Enteral nutrition support consists of specialised oral nutrition support and the application of specialised liquid formulations via an enteral feeding device. The evidence for this standard is based on the 2010 position statement by the European Society of Paediatric Gastroenterology, Hepatology and Nutrition Committee on Nutrition²³.

Children receiving specialised nutritional therapy are more at risk of malnutrition and require close monitoring by multidisciplinary teams with expertise in nutrition. More specialised dietary treatments include jejunal feeding, multiple food allergies with complex exclusion diets, severe malnutrition with risk of refeeding syndrome, exclusive enteral nutrition for Crohn's disease and modular feeds. Whilst this list is not exhaustive it is not intended within this standard to include dietary management for which there is standardised treatment and national guidance.

Guidance

Children who require specialist dietary treatment must have a named paediatrician and access to an appropriate specialist paediatric dietitian. Those who are enterally tube fed must additionally have access to children's nursing expertise and speech and language therapists when appropriate. Professionals caring for these children will meet regularly to facilitate and coordinate care for these children either through nutrition meetings or in a multi-disciplinary team meeting.

The multidisciplinary nutrition care team is staffed with a paediatrician experienced in nutrition, a specialised paediatric dietitian, a children's clinical nurse specialist experienced with enteral feeding devices and a medical practitioner (paediatric surgeon, interventional radiologist or paediatric gastroenterologist) experienced in the insertion of long term enteral feeding devices.

Written protocols for jejunal feeding and refeeding syndrome must be documented and agreed within the network.

Metrics

Metrics	Activity Data
<ul style="list-style-type: none">Evidence of multidisciplinary nutrition care team in networkEvidence of written and agreed protocols for specialised nutrition interventions and the management of complicationsDocumented shared care arrangementsDocumented clinical governance meetings	<ul style="list-style-type: none">Number of children on specialised diet/enteral feeds with a named PaediatricianPercentage of children having height and weight plotted on growth chart and/or use of malnutrition screening toolNumber of children on exclusive enteral nutrition for inflammatory bowel disease such as Crohn's disease requiring a nasogastric tube

<ul style="list-style-type: none">• Evidence of MDT decision to initiate and manage enteral tube feeding nutritional support	<ul style="list-style-type: none">• Incidence of refeeding syndrome
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Standard seven

Children receiving inpatient parenteral nutrition are reviewed at least once a week by a multidisciplinary nutritional care team to include a paediatrician with experience in parenteral nutrition, paediatric dietitian, parenteral nutrition pharmacist and children’s clinical nurse specialist with knowledge and experience in nutrition support.

Rationale and evidence

Providing sufficient nutrients to children and young people with intestinal failure is crucial towards supporting their nutrition needs but is particularly important during infancy and adolescence when growth occurs more rapidly²⁴.

Children and infants cared for in hospital will require parenteral nutrition (PN) when no other method of feeding is feasible, often when there are problems with the gastrointestinal tract. Parenteral nutrition is invasive and children who require long term PN are more likely to suffer with intestinal failure-associated liver disease, requiring careful consideration when assessing patients for PN support²⁵.

This standard is based on 2005 guidelines on Paediatric Parenteral Nutrition²⁴ and the 2005 position statement of the ESPGHAN committee on nutrition²⁶. This standard should be applied to children and young people, and for neonates guidance should be sought from the British Association of Perinatal Medicine²⁷.

Guidance

Children receiving inpatient parenteral nutrition are reviewed at least once a week by a multidisciplinary nutritional care team staffed with a paediatrician with experience in parenteral nutrition, paediatric dietitian, parenteral nutrition pharmacist and a children’s clinical nurse specialist with experience in nutrition to decrease the inappropriate use of parenteral nutrition and minimise the rate of metabolic and catheter related complications^{24,26}. More regular review is undertaken by a dietician and pharmacist.

Effective networking with local units is essential in order to provide monitoring of patients with, for example, sepsis or central venous catheter occlusion, based on shared care guidelines to local hospitals²⁸.

Nutritional support algorithms should be followed for the ordering and monitoring of parenteral nutrition. The team must conduct regular audits and provide clear evidence of participation in audits and clinical governance to ensure compliance with the algorithm.

Metrics

Metrics	Activity Data
<ul style="list-style-type: none">• Documented shared care arrangements• Documented clinical governance meetings• Evidence of weekly MDT nutritional care team ward round• Evidence of MDT decision to initiate and manage parenteral nutritional support	<ul style="list-style-type: none">• Number of patients with intestinal failure associated liver disease• Documentation of critical incident reviews• Audit of complications secondary to parenteral nutrition

Standard eight

Children receiving home parenteral nutrition (HPN) are cared for by an intestinal failure or designated HPN unit with a multidisciplinary nutrition team.

Rationale and evidence

The number of children receiving home parenteral nutrition (HPN) has increased by 200% in the last five years and is key to preventing and treating undernutrition and dehydration²⁸. It is considered for patients where enteral feeding is not possible due to intestinal failure.

The 2016 position statement from the British Intestinal Failure Alliance (BIFA) on Home Parenteral Nutrition²⁸ was developed to help nutrition support teams set up intestinal failure and Home Parenteral Nutrition centres to address key practicalities, whereby this standard bases its guidance.

Guidance

Patients receiving home parenteral nutrition are cared for by an intestinal failure or HPN designated unit with a multidisciplinary nutrition support team. Children's teams include a paediatrician with expertise in parenteral nutrition, children's clinical nurse specialist with experience in nutrition, a dietitian and pharmacist. The network provides arrangements for cross cover with skilled staff of appropriate expertise when any member of the team is away. 24 hour emergency specialist advice is available through the network with access to critical care or high dependency unit when required. There should be on site expertise in stoma care/tissue viability that includes managing a dehiscence abdominal wound and when appropriate giving distal enteral feeding.

Patients are reviewed in age appropriate adequate facilities in a dedicated outpatient department, or sometimes by telephone or video link. The frequency is determined by the patient's underlying medical problems, their nutritional/fluid status and complexity of the regimen/medical treatments /psychosocial issues. The clinic appointment should involve the paediatrician with expertise in parenteral nutrition, a children's clinical nurse specialist with experience in nutrition and a paediatric dietitian.

Home parenteral nutrition teams should be well linked with an onsite interventional radiology service, microbiology service and have good relationships and links with an aseptic unit. The unit should ideally have at least 10 paediatric patients receiving HPN and new units may develop under the guidance of an established unit meeting the criteria in this document. Patients receiving HPN must have access to children and adolescent mental health services which should have experience in managing patients with intestinal failure.

Metrics

Metrics	Activity Data
<ul style="list-style-type: none">Evidence of weekly multi-disciplinary team meetings	<ul style="list-style-type: none">Evidence of annual review of intestinal failure patientsAudit of complications secondary to home parenteral nutrition

	<ul style="list-style-type: none">• Number of patients with intestinal failure associated liver disease
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Standard nine

The gastroenterology network is linked to a lead specialist centre for hepatology with agreed patient pathways, access to specialist hepatology advice through their on-call rota, outreach clinics and shared care arrangements.

Rationale and evidence

Specialist hepatology services are provided by three lead specialist centres in Leeds, Birmingham, and London. They provide investigations and treatments for children with neonatal liver disease, chronic liver disease, acute liver failure and liver transplantation care. These services are accessed by direct referral from primary or secondary services, or by referral from the specialist gastroenterology service. Shared care is provided through network arrangements, including outreach clinics.

Guidance

Specialist hepatology services are provided in three lead specialist centres who coordinate care with multiple hepatology network centres. In order for hepatology services to deliver care as close to home as possible, outreach clinics are organised that rely on close collaborations with the local and specialist paediatric consultant providing joint consultations and agreed local investigations and treatment.

The network must agree to the persons who are allocated responsibility for liver biopsy. This individual has responsibility for performing the liver biopsy, interpreting and disseminating the results and is responsible for risk governance around this procedure.

Shared care coordination of immunosuppression for patients with liver transplantation and auto immune liver disease must be organised via telephone through the network. Agreed communication pathways within the network ensures that dose changes are communicated rapidly, using telephone clinics, and that all changes are documented to shared care leads.

Metrics

Metrics	Activity Data
<ul style="list-style-type: none">Evidence and audit of shared care protocolsEvidence of responsible person within network that has responsibility designated for guidelines, audit and risk governanceEvidence of on-call rota or dedicated phone lines for 24/7 advice	<ul style="list-style-type: none">Number of patients with neonatal cholestasisNumber of telehealth clinics provided

Practice example

The management of neonatal cholestasis within the hepatology network

All newborn infants who develop prolonged jaundice beyond two weeks of age where conjugated bilirubin is elevated (>25 micromol/litre) should be investigated for a possible underlying liver disorder. Where a diagnosis of biliary atresia is subsequently made, children should be referred to a

lead specialist centre for hepatology early enough in order for surgery to be performed before eight weeks of age²⁹.

Network centres must have the protocols in place for the preliminary investigation into the cause of jaundice in order to exclude liver failure. National guidance for neonatal jaundice must be followed²⁹.

Implementation of the standards

Workforce

The RCPCH Paediatric Workforce Census 2015 tells us there are 155 hospitals with inpatient services in England, 14 in Scotland, 8 in Northern Ireland and 12 in Wales. There are specialist paediatric gastroenterology, hepatology and nutrition (PGHaN) services at 27 hospitals in the UK; 21 in England, 3 in Scotland, 1 in Northern Ireland and 2 in Wales. Sixteen of these services provided information about networking arrangements.

For planned work, 6 services (37.5%) are part of a funded/managed clinical network, 8 (50.0%) are part of an informal clinical network and 2 (12.5%) are not part of a clinical network. For emergency work, 6 services (37.5%) are part of a funded/managed clinical network, 6 (37.5%) are part of an informal clinical network and 4 (25.0%) are not part of a network.

There are 108 consultant PGHaN specialists in the UK (estimated 101.9 WTE), and 2 specialty and associate specialist doctor PGHaN specialists. The census records special interest of general paediatricians and community child health paediatricians indicating that there are 85 consultants with a special interest in gastroenterology, 15 with a special interest in nutrition and 2 with a special interest in hepatology.

It is optimal that every network centre providing paediatric services will have a consultant paediatrician with a special interest in gastroenterology, hepatology and nutrition (SPIN doctor). The network will need to jointly decide and document the role and scope of practice for consultants depending on their experience, expertise and surrounding care provided by lead specialist centres.

The BSPGHAN Commissioning Specification⁸ document recommends a minimum of two Consultant Programmed Activities for SPIN doctors in network centres to account for outpatient clinics, ward reviews, multi-disciplinary and network activity in addition to at least a one hour monthly multi-disciplinary team meeting.

The standards will have a range of impacts on the paediatric medical workforce, particularly from standard two, where staffing levels required across the UK will depend on local circumstance. As an example, to ensure access to specialist advice is available 24 hours a day, seven days a week through the network, the investment of approximately 3.375 WTE will be required to provide resident consultant time during 9-5 Monday to Friday with access to consultant at home for the rest of the week (7 days). Additional resources will be required for weekend review and after hours (overnight) on-call.

The network lead will require one programmed activities per week to manage portfolios and protocols of the network and shared-care arrangements.

Training

Special Interest (SPIN) modules in paediatric gastroenterology, hepatology and nutrition (PGHaN) have been developed by the RCPCH to standardise the special interest curricula being used for paediatric trainees and general paediatricians wanting to gain specialist expertise in PGHaN. The RCPCH provides training via the National Training Number Grid with curricula for both PGHaN³⁰

subspecialty and paediatric endoscopy³¹ training offered. Once specialty training is completed, doctors are awarded with a Certificate of Completion of Training allowing them to apply to the General Medical Council specialist register.

Subspecialty training in PGHaN is also provided by the European Society for Paediatric Gastroenterology, Hepatology and Nutrition with an aim to standardise the quality of care across Europe³².

The Joint Advisory Group on GI Endoscopy (JAG) provides certification for endoscopy professionals in the UK to ensure quality and parity in service. JAG recommends that trainees register with the Endoscopy Training System (JETS) e-portfolio to book courses and support the development and assessment of training processes, enabling trainees to record their endoscopic experience and competence and to apply for JAG certification.

Paediatricians are required to keep their knowledge and skills up during their working life and to improve their performance. Continuing Professional development³³ helps to plan and manage the learning activities required to get through appraisal and revalidation, where core guidance from the General Medical Council should be followed³⁴.

Networks will facilitate more opportunities for comprehensive training and Continuing Professional Development in this specialty. Consideration should be given to ensuring that recruitment into specialty training and special interest modules for paediatric gastroenterology, hepatology and nutrition are commensurate with future demand generated for consultants in order to comply with these standards.

Research

Research is key to achieving better outcomes for our patients through improved care and engagement in research should be a core element within each clinical network. The RCPCH Research Charter³⁵ outlines the guiding principles for working with children and their families in research.

A long-term aspiration is to ensure that all children under our care have the opportunity to contribute to research. This is particularly important for less common conditions such as inflammatory bowel disease where multicentre studies are required to generate the evidence base that informs care.

Clinicians and allied health professionals should be able to demonstrate how they keep up-to-date with latest research findings relevant to their practice and consider how they can lead or contribute to current research studies. Building the research enterprise will increase support for further funding and resource allocation to child health research in the specialty.

Child protection

Child protection is a part of safeguarding that works to protect children who are identified as suffering, or are likely to suffer harm, abuse or neglect. Every professional who comes into contact with children and families has a responsibility to promote the welfare of the child and to prevent them from harm³⁶. Children are best protected when professionals are clear about their roles and responsibilities³⁷.

Timely access to a paediatrician with the appropriate training and experience in child protection is essential in order that needs assessments can begin quickly when concerns arise. Consultant and career grade paediatricians should be competent to Level 3 in Safeguarding Children and Young People and should continue to acquire competencies throughout their professional development³⁸.

Key guidance available to professionals involved in a child's care:

- RCPCH *Child Protection Companion*³⁷
- RCPCH *Fabricated or Induced Illness by Carers: a Practical Guide for Paediatricians*³⁹
- NICE *Child maltreatment: when to suspect maltreatment in under 18's*⁴⁰
- GMC guidance *Protecting children and young people: the responsibility of all doctors*⁴¹
- HM Government's *What to do if you're worried a child is being abused*⁴²
- The Scottish Government *National Guidance for Child Protection in Scotland*⁴³
- The Welsh Government *Working Together Under the Children Act 2004*⁴⁴
- Northern Ireland *Co-operating to Safeguard Children*⁴⁵

Concerns about a child's safety or whether a child is in need of additional support, must be discussed with a senior colleague or the Trust's Named Doctor for child safeguarding without delay. Concerns must be documented alongside the consultation and any agreed actions in the child's health record, ensuring it is dated, timed and signed correctly. If there are immediate concerns, follow local interagency policies and refer to children's social services or, in an emergency, the police. If you feel that your concerns have not been taken seriously, escalate them in accordance with the Trust Escalation Policy. Do not rest until action has been taken and if necessary, discuss with the Designated Doctor for child safeguarding.

Concerns should also include children not brought to clinic or whose appointments are regularly cancelled where policy provided by the Trust or Health Board must be followed.

Clinicians must act according to the General Medical Council, Local Safeguarding Children's Board and Trust/Health Board policies on consent, confidentiality and information sharing. If concerns over a child's well-being occur during service week, ensure that the name of the lead consultant is clearly documented in the child's record.

Children can present with a wide range of perplexing symptoms, with a puzzling discrepancy between presentation and a recognised clinical picture. It is important to consider factitious illness when reported symptoms and signs are only observed in the presence of the parent/carer and when multiple opinions are sought and disputed by the parents or carer and the child continues to be presented for investigation⁴⁰. When factitious illness is suspected, referral must be made without consent, as obtaining consent might put the child at immediate risk³⁹.

Future vision for paediatric gastroenterology, hepatology and nutrition

These standards have been developed to improve equity of care for children in the UK. This section will lay out the aspirations and direction of travel for specialist paediatric gastroenterology, hepatology and nutrition (PGHaN) services that has not been possible to describe within the scope and purpose of the standards.

Managed clinical network

BSPGHAN and the RCPCH maintain that improving clinical outcomes and experience, and reducing variation in care will be best progressed and facilitated by services being commissioned (where applicable across the UK), planned, delivered and evaluated through funded managed clinical networks. The architecture and benefits towards progressing specialist PGHaN services to this optimal has been laid out by the College¹¹ and provides the criteria required to reach this optimum within the next three to five years:

- Appropriate skilled and staffed services are provided in inpatient and outpatient settings
- Clear governance and accountability that requires collaborative quality assurance frameworks
- Clear and accountable pathways of care and with shared and agreed protocols and standards for children presenting in an emergency
- Critical interdependencies of services are maintained
- IT services are linked and shared to support audit activities and data analysis
- Performance is monitored to reduce variation in care and improve safety
- Regular informal or formal meetings are organised to ensure services are planned, commissioned and shared appropriately
- Specialist advice is available 24 hours a day, seven days a week through telephone and/or on-call rotas*
- An identified network lead with dedicated time within their job plan to ensure clear and effective communication across the network
- Opportunities for research, training and shared learning that enhances the skills and practical development of the workforce

Successful development to this optimal will require operational and financial agreement between commissioners, service planners and those delivering gastroenterology and hepatology care.

Telehealth

The development and provision of telehealth services for patients and families helps to enable regular monitoring of patients who have long term health needs or are located in geographically isolated regions using technology in their home. The benefits to providing patients and families specialist assessment for the child without the associated cost in time and travel are considerable and significantly improves clinician and patient satisfaction⁴⁶.

* Whilst telephone advice rotas will be achievable in a short time frame, it is expected that operational on-call rotas will require more time to implement, especially for smaller centres, where maturity to this optimum should be achieved within three to five years when this document will require review.

Co-location

Specialist gastroenterology and hepatology services often rely on other subspecialties in order to manage the complex needs of its patient group.

Lead Specialist Centres that provide paediatric gastroenterology and nutrition services are co-located with paediatric surgery, nutrition services, specialist anaesthetic services and pain management, neonatology expertise, paediatric radiology, clinical biochemistry, histopathology and critical care.

Specialised hepatology services are co-located with the above specialities in addition to hepatobiliary surgery, paediatric interventional radiology, transplant immunology and microbiology, virology and intensive care.

Services interdependent with gastroenterology are 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 and palliative care.

The optimal mechanism for the network to fully provide equity of care for all children in the UK is for the services listed above to operate in a managed clinical network. The network must ensure strong relationships with adult colleagues to ensure transitional care is appropriately managed. Similarly, the network must provide access to services to support patients with complex care needs and to ensure the mental health and psychological needs of children are considered.

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