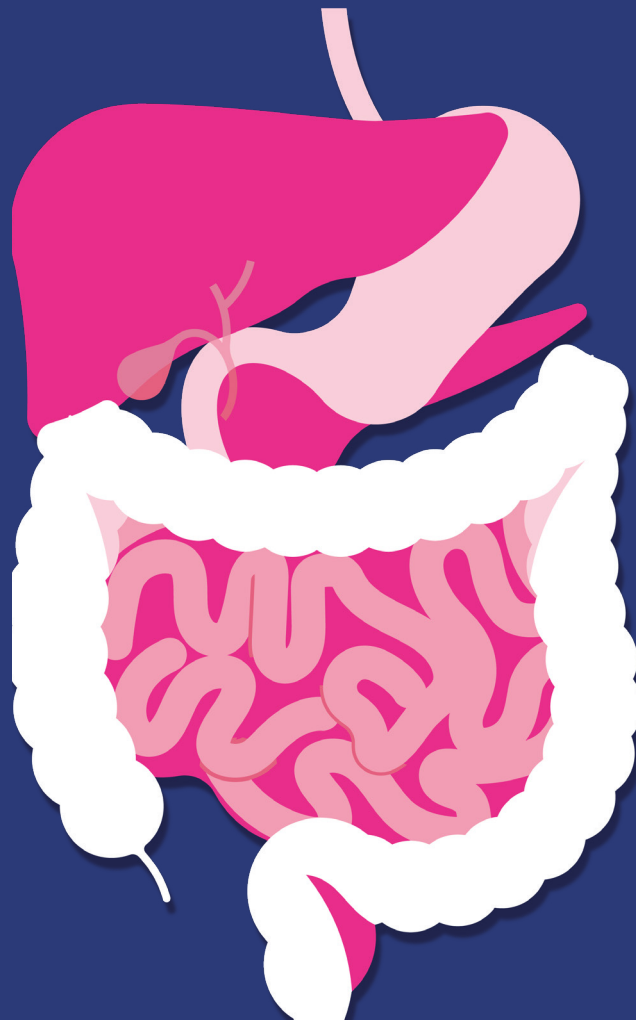


# The paediatric gastroenterology, hepatology and nutrition UK national census 2021

PGHAN national quality standards audit



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## **PGHAN national quality standards audit**

The PGHAN audit was funded jointly by

British Society of Paediatric Gastroenterology, Hepatology and Nutrition

[www.bspghan.org.uk](http://www.bspghan.org.uk)

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# Foreword

Paediatric Gastroenterology, Hepatology and Nutrition services support infants, children and young people with a wide range of conditions. Care is delivered both in local centres and by multidisciplinary teams in specialised centres. Specialised care needs to be delivered around the clock to ensure ongoing care, timely access for emergencies and to support to local centres.

Prioritising the physical and mental health of our children and young people has never been more important. The pandemic has been a reminder of the importance of planning, working collaboratively and creatively to rethink priorities and shape future care.

National and regional planning is evolving over the next few years. The integrating care agenda set out in the NHS Long Term Plan is driving systems to take greater responsibility for delivering services.

The British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and the Royal College of Paediatrics and Child Health (RCPCH) and the RCPCH have successfully conducted the first national audit of both services and workforce as well as implementation of the BSPGHAN Quality Standards (QS) covering the year 2019.

Our recommendations will offer professionals and providers expert guidance to drive improvement where needed. The journey starts with understanding the current landscape. Our data is comprehensive, characterising current networks, workforce and services in the UK and innovations that have been adopted during the pandemic. In describing what a patient may receive from our services, we have shown clinical variation and inequitable access to services in the UK. The 2017 Quality Standards are not being met in all areas and pathways of care within networks are not well described with networks being informal and unsupported.

Formal networks need to develop to address variation, focus on agreed pathways of care, service improvement, excellence and workforce resilience. The creation of effective partnerships with commissioners with accountability for children are required to prioritise children and young people in the face of competing demands. Formalising relationships between units should help networks to develop.

BSPGHAN and the RCPCH are committed to improving the health of our patients. BSPGHAN's strategic intentions are to continue annual online data collection to benchmark and support implementation of outcome-based Quality Standards with the aim of improving the care we offer to achieve better health, well-being and quality of life for our patients.



**Dr Sue Protheroe,**  
BSPGHAN President and Consultant Paediatric Gastroenterologist,  
Birmingham Women's and Children's Hospital

# Executive summary

## A call for change: developing robust specialist paediatric care networks

Following the 2010 publication<sup>i</sup> of 'Facing the Future: Standards for Acute General Paediatric Services,' the Royal College of Paediatrics and Child Health (RCPCH) set out standards for high quality, safe and sustainable acute general paediatric services. The British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) responded to this report, by developing its own Quality Standards for Paediatric Gastroenterology, Hepatology & Nutrition in 2017<sup>ii</sup> – providing guidance with a focus around the interaction between non-specialised and Specialist tertiary services, and provision of care.

The RCPCH and BSPGHAN in 2020 undertook a National Audit of Paediatric Gastroenterology, Hepatology and Nutrition (PGHAN), benchmarking services and national provision against the 2017 Quality Standards. The aim of this report is to allow a better understanding of the provision of PGHAN provision and services across the UK and to highlight unwarranted variation. Our dataset will help to provide the basis of improving health outcomes and the quality of life for children and young people receiving care for gastroenterology, liver, or nutritional conditions throughout the UK.

107 centres providing paediatric PGHAN care (27 Specialised Gastroenterology and Nutrition Centres, 3 Hepatology Centres and 77 Non-Specialised Centres) submitted data, providing the most comprehensive census of specialist PGHAN services to date.

***“The findings of the report make a compelling case to formalise networks for the provision of PGHAN services. This is essential for the equitable delivery of high quality care across the UK.”*** PGHAN Audit Steering Group

PGHAN provision in the UK first developed based on individual clinician expertise and existing clinical academic departments, with a gradual development of centres of excellence. Hepatology services across the UK are centrally commissioned to provide specialist care through 3 highly specialised Centres; whereas Gastroenterology and Nutrition networks have evolved on an ad-hoc basis with more than 20<sup>iii</sup> specialist centres linked with over 70<sup>iv</sup> non-specialised network centres. Formal networks between these centres have not been actively developed in Wales, Northern Ireland, and England. These informal networks and uneven geographic distribution of Specialist Centres with the UK may contribute to the observed variation in access to care. Our report documents how these informal networks, may contribute to variation in access and equity of provision of specialist advice and care within the UK.

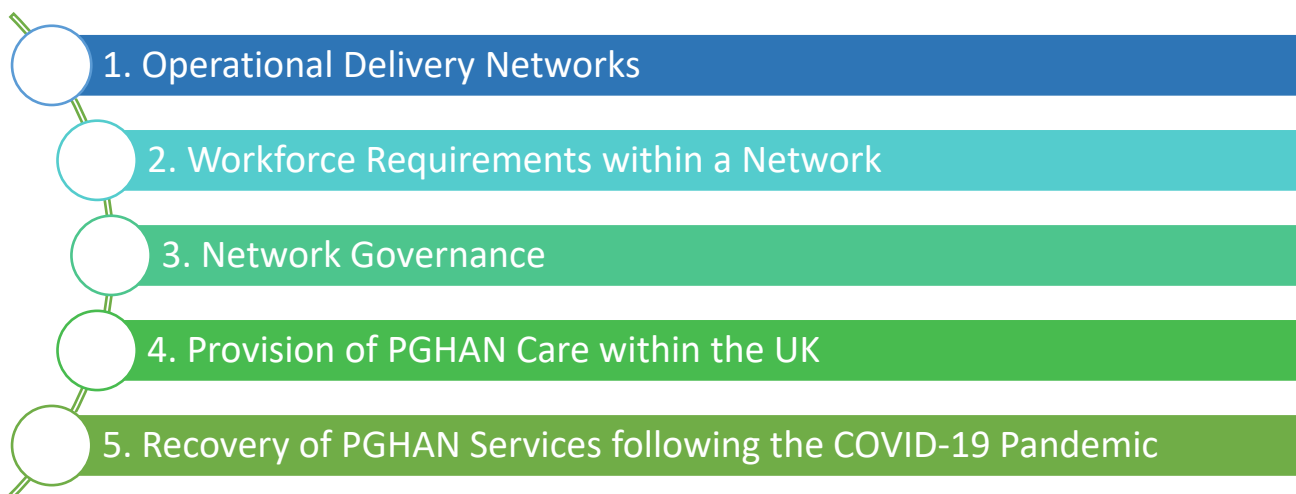
Our audit data demonstrates considerable variation in the level of provision by specialist centres with respect to on-call arrangements for specialist care or advice, paediatric endoscopy services, network governance arrangements, and staffing levels between centres, and regions, within the UK.

Dr Edward Gaynor and Dr John Fell,  
Consultant Paediatric Gastroenterologists  
PGHAN Audit Clinical leads

# Key report findings and recommendations

The following key findings and recommendations were agreed by members of the PGHAN Audit Steering Group.

Following our census of both Specialist and non-specialised PGHAN centres within the UK, this report highlights key findings and makes **10 Key Recommendations for patients, commissioners, NHS hospital Health Boards and Trusts**, to improve the provision and quality of care provided to those with gastro-intestinal, liver, and nutritional conditions and disorders. Recommendations have been made in the following five domains of care:

- 
1. Operational Delivery Networks
  2. Workforce Requirements within a Network
  3. Network Governance
  4. Provision of PGHAN Care within the UK
  5. Recovery of PGHAN Services following the COVID-19 Pandemic

## The voice of children and young people

RCPCH &Us is the voice of children, young people, parents and carers, created to actively seek and share their views to influence and shape policy and practice. Quotes from RCPCH &Us engagement activities, including those collated from interviews with patients and families within two gastroenterology services as part of the Children and Young People's Roadshow and Long Term Conditions Consultation in 2016, are included in the blue boxes alongside the key report recommendations presented below. .

The #Voice Matters section of this report raises the views of children, young people and their families which can be used to inform practice, discussions within clinical teams and Multidisciplinary team (MDT) colleagues, as well as improving understanding and awareness of patient and family experiences.

# 1. Recommendations for the establishment of operational delivery networks



To provide effective, efficient, and equitable PGHAN care, services are best arranged in formal designated networks with adequate staffing and skills reflecting the needs of the local populations:

## Recommendation 1.1:

- **Commissioning organisations** should ensure that all centres providing Paediatric Gastroenterology, Hepatology and Nutrition services work as part of an Operational Delivery Network (ODN) or formally designated network.
- **Patients and families** should expect that their local provider is part of network of services, with formal pathways for care and advice, and that they are consulted on the future development of these formal designated networks.

*"My gastro service is good at solving the problem"*  
RCPCH &Us

### Key Findings:

- **24%** (18/75) of UK non-specialised centres declared that they did not work in a clinical network, and were therefore providing PGHAN care without formal referral pathways for care or advice.
- Only **7%** (5/75) of non-specialised centres and 20% (6/30) of specialist centres were part of a formally designated and funded clinical network.

## Recommendation 1.2:

- **Health Board and Trust managers** should ensure that Specialist centres and non-specialised Network centres must provide services that are appropriately skilled and staffed in all hospital settings to meet their population needs.
- **Patients and families** should expect high quality and safe care, no matter where they live, through the access to formally designated networks.

*"There are not enough specialist doctors, here and at another big hospital. My GP doesn't understand about the gastro condition, so I had to research and give information to the GP"*  
RCPCH &Us

### Key Finding:

- There was a wide variation of staffing (medical, nursing and allied health professionals such as dietitians, psychologist and pharmacists) between centres and geographic locations.



## 2. Recommendations for workforce within a network



To meet the requirements to provide high quality and equitable services for those with gastroenterology, liver, or intestinal disorders, several workforce recommendations have been made:

### Recommendation 2.1:

- **Health Board and Trust managers** should ensure that a non-specialised Network centres have a minimum of 1 full-time consultant paediatrician with special interest in gastroenterology and hepatology (SPIN) with at least 20% of their working time formally allocated towards providing and developing paediatric gastroenterology and nutrition care.
- **Patients and families** should expect enhanced shared-care decisions through active local involvement of specialists.

#### Key Findings

- **18%** (14/77) of Non-specialised centres reported no consultant paediatrician with special interest in gastroenterology provision at their centres.
- **4%** (3/77) of those Non-specialised centres with some consultant paediatrician with special interest in gastroenterology provision had less than 0.2 whole time equivalent (WTE).

### Recommendation 2.2:

- **Health Board and Trust managers** should ensure that Specialist Gastroenterology and Nutrition centres offers a 24/7 consultant-led on call service with out of hours emergency endoscopy, employing at least 4 working-time equivalent (WTE) Paediatric gastroenterologists\* to provide consistent specialist care.
- **Patients and families** should expect timely specialist on-call advice to local providers or emergency procedures, such as endoscopy, are not delayed by insufficient PGHAN consultant workforce.

\*Based on workforce modelling to allow the provision of services expected from a Specialised Centre

#### Key Findings

- **37%** (10/27) of Specialist Centres in Paediatric Gastroenterology and Nutrition employ less than 3 WTE paediatric gastroenterologists. This limits the ability to provide a full provision of services, and limits the ability to provide around the clock care and advice to hospitals within their network.
- 24/7 availability for specialised PGHAN advice is not provided in all geographical areas in the UK.
- **81%** (22/27) of Specialist Gastroenterology and Nutrition centres perform out of hours endoscopy for children and of these, **41%** (9/22) had formally rostered out of hour emergency endoscopy. **67%** (2/3) of Specialist Hepatology Centres had formally rostered out of hour emergency endoscopy provision.

## Recommendation 2.3:

- **Health Board and Trust managers** should ensure that children and young people have access to the full multi-disciplinary team, trained to provide high quality PGHAN Care.
- **Patients and families** should expect that multi-disciplinary care is provided within Specialist centres and appropriately supported by local non-specialised centres and community services.
- **Specialist Centres in Gastroenterology, Nutrition and Hepatology** require access to: **specialist dietitians, pharmacy, speech & language (SALT), psychology and clinical nurse specialists** to be provided to achieve high-quality multi-disciplinary care.
- **Non-specialised centres** looking after children with gastroenterology, hepatology and nutrition problems must have timely local access to a core set of support services to provide integrated local, community and mental health care: **paediatric dietitians, speech & language (SALT), paediatric psychology and specialist children's mental health services (CAMHS).**

### Key Findings

- Whereas specialist centres all employed at least one nurse specialist and a paediatric dietitian, this was not the case in non-specialised centres where **17%** (13/76) had at least one nurse specialist and **47%** (36/77) employed a paediatric dietitian.
- Paediatric psychology was only available in **78%** (21/27) of Specialist Gastroenterology and Nutrition centres and in **32%** (34/106) of Non-specialised centres. Similarly, SALT provision was generally \*low, being available in **31%** (33/106) of all types of centre overall.

## Recommendation 2.4:

- **Health Board and Trust managers** should ensure that there is adequate specialist paediatric nurse provision for those children and young people, with highly specialised or complex PGHAN conditions.
- **Patients and families** should expect that those children with complex medical needs, are supported by a trained clinical nurse specialist.
- **Specialist Nurse Recommendations:**
  - A Specialist Gastroenterology and Nutrition centre providing care to children with inflammatory bowel disease (IBD) **should have adequate specialist nurse provision (at least 1 WTE IBD nurse specialist per 200 paediatric IBD patients)**<sup>v</sup>
  - A Specialist Gastroenterology and Nutrition centre providing care to children requiring parenteral nutrition (PN) for children **should have adequate specialist nurse provision (at least 1 WTE nutrition nurse specialist per 10 patients requiring home PN)**
- Dedicated clinical nurse specialist support should be provided for other PGHAN conditions, such as liver disease or complex gastrointestinal disorders, where clinical guidance suggests this support would be beneficial to patient care.

### Key Finding

- In each Specialist Centre a mean of **60** children a year are diagnosed with IBD.
- **81%** (22/27) of Specialist Gastroenterology and Nutrition centres had some IBD nurse specialist availability, with an average of 1.1 WTE per centre, however **23%** (5/22) of these had less than 1 WTE IBD nurse specialist.
- **70%** (19/27) of Specialist Gastroenterology and Nutrition centres had some nutrition nurse specialist available, although almost a third of these **32%** (6/19) had less than 1 WTE nurse specialist in nutrition.

### 3. Network governance recommendations

For formal clinical networks to provide high quality care, systems need to be in place to provide strong governance, consistency in clinical care and to ensure learning is shared across all network centres.



#### Recommendation 3.1:

- **Commissioning organisations** should ensure that their Clinical Networks have a robust system of communication and information sharing, to allow the development of agreed shared-care protocols, pathways of care, outreach, and telehealth appropriate for population needs. They should have an annual meeting and an identified network lead with dedicated time allocated to manage the network within their job plan. Administrative support should be provided.
- **Patients and families** should expect standardised guidelines for care across their region, and that best practice is shared across their clinical network.

*"They forward you on to alternative clinics and follow up quickly and they even send my meds straight to my house, and involve children and parents well"*  
RCPCH &Us

#### Key Findings

- **38%** (40/101) of all centres reported that an annual meeting was held within their network in 2019.
- **35%** (36/103) of all centres had shared PCHAN care protocols and guidelines for centres within their clinical network.

## 4. Recommendations for the provision of PGHAN care in the UK



The UK has a strong reputation for providing high quality and world leading PGHAN care. There is unwarranted variation noted in this census of provision within the UK. To improve access and provide for long-term sustainability of services, longer term funding and commissioning arrangements are required.

### Recommendation 4.1:

- **Health Board and Trust managers** should ensure that there should be sufficient resources provided to allow for effective and high-quality transition of children with long-term condition transferring to adult gastroenterology or hepatology care.
- **Patients and families** should expect a personalised care plan<sup>vi</sup> and for this to have been discussed and agreed with a named transition coordinator. They should expect to be transferred to an adult service or primary care professional with adequate resources and expertise to manage their condition. Primary care an important aspect of transition, however training nationally for the transition of PGHAN conditions is limited.

*"Someone who was two years older told me about transitioning. I'd been introduced to another patient so that when I went to clinic, I saw a familiar face and could ask questions" RCPCH &Us*

### Key Findings

- **78%** (58/74) of non-specialised centres and **37%** (11/30) of specialist centres did not have an allocated transition worker, to coordinate the transfer of a young person into specialised adult care.
- **35%** (26/74) of non-specialised centres and **53%** (16/30) of specialist centres had annual review of individual transition plans for adolescents under their care.

### Recommendation 4.2:

- **Health Board and Trust managers** should ensure that complex PGHAN care and paediatric endoscopic services should be primarily provided within a specialised centre, co-located with appropriate specialised services such as paediatric intensive care units and paediatric surgery. Where this is not present, clear and timely pathways of referral should exist.
- **Patients and families** should expect that these services should be provided in a child and young-person friendly environment, and that equity of access to these services is maintained nationally. Children and families should be consulted in the future co-design these facilities and pathways of care.

## Key Findings

- **97%** (38/39) of centres providing endoscopy services, do so in an age appropriate & child-friendly environment.
- Only **63%** (17/27) of specialist gastroenterology and nutrition centres and **67%** (2/3) of specialist hepatology centres co-locate on the same site with the full range of specialised paediatric service as outlined in the 2017 quality standards.



**Figure 1 - Co-location of PGHAN centres with other specialised services**

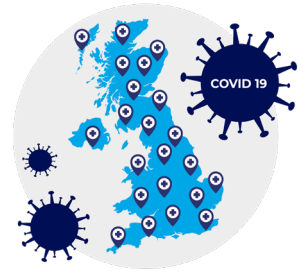
## Recommendation 4.3:

- **Commissioning organisations** should ensure that Telehealth and Video Clinic consultations are evaluated and organised to provide high quality and responsive health care, alongside traditional methods of assessment.
- **Patients and families** should expect to be involved in the development and design of future PGHAN services, including in areas such as virtual consultation models.

## Key Finding

- **100%** (30/30) of all specialised centres reported that they had seen an increase in their provision of telehealth since the first wave of COVID-19 with **74%** (20/27) of specialist gastroenterology and nutrition centres and **67%** (2/3) specialist centres in hepatology now providing more than half of their clinics through telehealth or video clinics.

## 5. Recommendations for the recovery of PGHAN services following the COVID-19 pandemic



During the COVID-19 pandemic reconfiguration of paediatric services were seen throughout the UK, to provide additional capacity for the management of adults adversely affected by coronavirus (SARS-CoV-2). In much of the UK, this led to reduction in capacity or changes in traditional pathways of care, for those with gastro-intestinal, liver, and nutritional conditions and disorders. The following recommendations have been made in regards to the prioritisation of full restoration of PGHAN services following the pandemic.

### COVID-19 Recommendation:

- **Health Board and Trust managers** should ensure that the full restoration of specialist PGHAN services following the COVID-19 pandemic is prioritised.
- **Patients and families** should expect that care for children with gastrointestinal, liver and nutritional disease or disorders are prioritised by providers and regional commissioning bodies.

### Key Findings

- **19%** (14/74) of non-specialised centres and **40%** (12/30) of specialist centres reported changes in endoscopy referral pathways following the COVID-19 pandemic.
- **20%** (15/74) of non-specialised centres and **47%** (14/30) of specialist centres reported that non-emergency endoscopy services had not been restored due to the pandemic.
- **18%** (13/74) of non-specialised centres and **19%** (5/27) of specialist gastroenterology and nutrition centres reported that emergency endoscopy services had not been restored due to the pandemic.

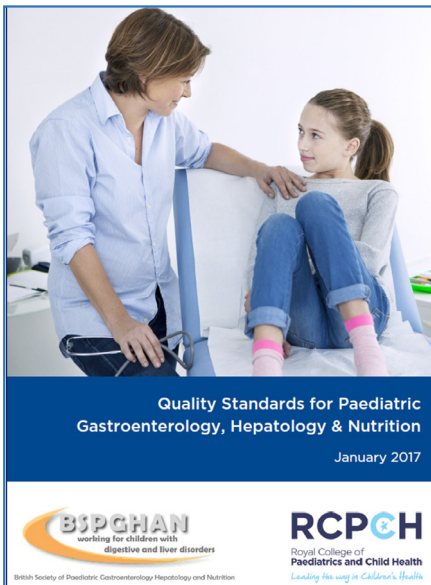
*"We've been looking at what services need to look at for children and young people as part of their COVID recovery plans. There are three priorities to work on: 1) Have child and youth accessible, friendly and relevant information about accessing health services and staying safe through the pandemic. 2) Increase access to mental health services to support children and young people impacted by the pandemic, 3) Create the best virtual health experience possible thinking about access, confidentiality, rapport and holistic care." RCPCH & Us*

# Introduction

## Development of national PGHAN quality standards

During the revision of the 'Facing the Future: Standards for Acute General Paediatric Services' 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 British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and the Royal College of Paediatrics and Child Health (RCPCH) particularly recognised that areas of improvement were required in gastroenterology, hepatology and nutrition to ensure that children and young people receive timely, high quality services as close to home as possible.

BSPGHAN and the RCPCH 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. 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.



The Royal College of Paediatrics and Child Health and the British Society of Paediatric Gastroenterology, Hepatology and Nutrition subsequently worked together to develop and publish the Quality Standards for Paediatric Gastroenterology, Hepatology and Nutrition in 2017. These new standards were built around the requirement for specialist paediatric gastroenterology, hepatology and nutrition services to provide the full portfolio of services within a network.

The full 2017 Quality Standards for Paediatric Gastroenterology, Hepatology and Nutrition can be viewed at: [www.rcpch.ac.uk/resources/quality-standards-specialist-paediatric-gastroenterology-hepatology-nutrition](http://www.rcpch.ac.uk/resources/quality-standards-specialist-paediatric-gastroenterology-hepatology-nutrition)

## Scope of the 2020/2021 national audit of quality standards

Following the publication of the 2017 Quality Standards for Paediatric Gastroenterology, Hepatology and Nutrition (PGHAN), the intention was to formally assess provision of PGHAN services across the UK. A proposition to undertake a census of all UK centres providing these services was agreed between the RCPCH and BSPGHAN.

The purpose of this national census was to provide a comprehensive understanding of PGHAN



services and provision in order that recommendations could be made to:

- **To improve health outcomes** and the quality of life for all infants, children and young people receiving care for gastroenterology, liver or intestinal disorders throughout the UK.
- **To identify any unwarranted variation in care** and ensure that equitable services are available for all infants, children and young people in the provision of gastroenterology, hepatology and nutrition services across the UK.
- **To audit paediatric centres against measures** which align with nine standards focusing on providing specialist gastroenterology, hepatology and nutrition services in the UK.
- **To understand how paediatric services are providing care** to local populations and whether system leaders are planning and commissioning services effectively in networks.
- **To inform the RCPCH, its members and healthcare professionals** of future work that is needed to improve the quality of care provided to infants, children and young people with PGHAN needs.

The intention from this national audit was to share key findings with all stakeholders and provide a basis for the support and production of new outcome-based Quality Standards in the UK.

# Methodology

## Audit methodology

The project team wrote to the clinical leads for paediatric services in Health Boards and Trusts across the UK to invite them to participate in the audit and to identify an appropriate clinician to act as the PGHAN Audit lead within the Health Board/Trust who would have the overall responsibility for the submission of data to the audit.

The project team ultimately identified 138 Health Boards and Trusts across the UK that were felt to be eligible for the inclusion in the audit by virtue of providing paediatric gastroenterology, hepatology and nutrition services.

Identified centres were encouraged to complete a structured submission of all PGHAN services provided, through an online platform (Case Capture™, Netsolving Ltd). Audit questions were based on the 2017 Quality Standards, alongside a census of PGHAN provision and service users. Additional questions were added following the start of the COVID-19 pandemic, to illustrate the impact of services and their subsequent restoration.

## Audit participation

The census received 107 data submissions by the audit data entry deadline of 28th February 2021. The composition of centres who contributed is as follows:

- 27 Self-Declared Gastroenterology and Nutrition Specialised Centres
- 3 Self-Declared Hepatology Specialised Centres
- 77 Non-specialist Centres

It should be noted that a 78% return rate is very positive for a non-mandatory audit. These data submissions equate to an accurate census sampling exercise, representative of UK provision. Although it is not a full and comprehensive capture of the entire UK PGHAN landscape covering all centres.

A limitation of our methodology allowed a limited number of instances where two separate hospital services within the same Health Board/Trust legitimately entered separate data submissions for each service. Furthermore, all three of the self-declared Hepatology Specialised Centres in the UK co-locate with paediatric gastroenterology services.

**List of 27 self-declared paediatric gastroenterology and nutrition specialised centres that submitted data to the PGHAN audit:**

**NHS Health Board or NHS Hospital Trust:**

1. Alder Hey Children's NHS Foundation Trust
2. Barts Health NHS Trust
3. Belfast Health & Social Care Trust
4. Birmingham Women's and Children's NHS Foundation Trust
5. Brighton and Sussex University Hospitals NHS Trust
6. Cambridge University Hospitals NHS Foundation Trust
7. Central Manchester University Hospitals NHS Foundation Trust
8. Chelsea and Westminster Hospital NHS Foundation Trust
9. Evelina London Children's Hospital
10. Great Ormond Street Hospital for Children NHS Foundation Trust
11. King's College Hospital NHS Foundation Trust
12. Leeds Teaching Hospitals NHS Trust
13. Noah's Ark Children's Hospital for Wales
14. Norfolk and Norwich University Hospitals NHS Foundation Trust
15. Nottingham University Hospitals NHS Trust
16. Oxford University Hospitals NHS Foundation Trust
17. Royal Aberdeen Children's Hospital, NHS Grampian
18. Royal Children's Hospital, Glasgow
19. Royal Free London NHS Foundation Trust
20. Royal Hospital for Children and Young People, Edinburgh, NHS Lothian
21. Sheffield Children's NHS Foundation Trust
22. St George's University Hospitals NHS Foundation Trust
23. The Newcastle Upon Tyne Hospitals NHS Foundation Trust
24. University Hospital Southampton NHS Foundation Trust
25. University Hospitals Bristol NHS Foundation Trust
26. University Hospitals of Leicester NHS Trust
27. University Hospitals of North Midlands NHS Trust

**List of 3 self-declared paediatric hepatology specialised centres that submitted data to the PGHAN audit:**

**NHS Health Board or NHS Hospital Trust :**

1. Birmingham Women's and Children's NHS Foundation Trust
2. King's College Hospital NHS Foundation Trust
3. Leeds Teaching Hospitals NHS Trust

**List of 77 non-specialised centres that submitted data to the PGHAN audit:**

**NHS Health Board or NHS Hospital Trust:**

1. Airedale NHS Foundation Trust
2. Aneurin Bevan University LHB
3. Barking, Havering and Redbridge University Hospitals NHS Trust

4. Birmingham Women's and Children's NHS Foundation Trust
5. Bradford Teaching Hospitals NHS Foundation Trust
6. Calderdale and Huddersfield NHS Foundation Trust
7. Chelsea and Westminster Hospital NHS Foundation Trust
8. Chesterfield Royal Hospital NHS Foundation Trust
9. County Durham and Darlington NHS Foundation Trust
10. County Durham and Darlington NHS Foundation Trust
11. Cwm Taf Morgannwg University Local Health Board
12. Dartford and Gravesham NHS Trust
13. Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust
14. Dorset County Hospital NHS Foundation Trust
15. East and North Hertfordshire NHS Trust
16. East Cheshire NHS Trust
17. East Kent Hospitals University NHS Foundation Trust
18. East Suffolk and North Essex NHS Foundation Trust
19. Epsom and St Helier University Hospitals NHS Trust
20. Frimley Health NHS Foundation Trust
21. Gateshead Health NHS Foundation Trust
22. Great Western Hospitals NHS Foundation Trust
23. Hampshire Hospitals NHS Foundation Trust
24. Homerton University Hospital NHS Foundation Trust
25. Hywel Dda University LHB
26. Imperial College Healthcare NHS Trust
27. Ipswich Hospital NHS Trust
28. James Paget University Hospitals NHS Foundation Trust
29. Lewisham and Greenwich NHS Trust
30. Lincoln County Hospital
31. Luton and Dunstable University Hospital NHS Foundation Trust
32. Maidstone and Tunbridge Wells NHS Trust
33. Mid Essex Hospital Services NHS Trust
34. Mid Yorkshire Hospitals NHS Trust
35. Milton Keynes University Hospital NHS Foundation Trust
36. NHS Borders
37. North Bristol NHS Trust
38. North West London Hospitals NHS Trust
39. Northern Lincolnshire and Goole NHS Foundation Trust
40. Northumbria Healthcare NHS Foundation Trust
41. Pennine Acute Hospitals NHS Trust
42. Poole Hospital NHS Foundation Trust
43. Portsmouth Hospitals NHS Trust
44. Powys Teaching LHB
45. Royal Berkshire NHS Foundation Trust
46. Royal Cornwall Hospital (trillick)
47. Royal Devon and Exeter NHS Foundation Trust
48. Royal Surrey County Hospital NHS Foundation Trust
49. Royal United Hospitals Bath NHS Foundation Trust
50. Sandwell and West Birmingham Hospitals NHS Trust
51. Sherwood Forest Hospitals NHS Foundation Trust

52. Solent NHS Trust
53. South Tees Hospitals NHS Foundation Trust
54. South Tyneside and Sunderland NHS Foundation Trust
55. South Warwickshire NHS Foundation Trust
56. South West Acute Hospital Enniskillen
57. Southend University Hospital NHS Foundation Trust
58. Surrey and Sussex Healthcare NHS Trust
59. Swansea Bay University Local Health Board
60. the Dudley Group NHS Foundation Trust
61. the Hillingdon Hospitals NHS Foundation Trust
62. the Royal Wolverhampton NHS Trust
63. Torbay and Southern Devon Health and Care NHS Trust
64. University Hospitals Birmingham NHS Foundation Trust
65. University Hospitals Coventry and Warwickshire NHS Trust
66. University Hospitals of Derby and Burton NHS Foundation Trust
67. University Hospitals of Derby and Burton NHS Foundation Trust
68. University Hospitals Plymouth NHS Trust
69. Walsall Healthcare NHS Trust
70. Warrington and Halton Hospitals NHS Foundation Trust
71. West Suffolk NHS Foundation Trust
72. Western Sussex Hospitals NHS Foundation Trust
73. Worcestershire Health and Care NHS Trust
74. Wrightington, Wigan and Leigh NHS Foundation Trust
75. Wye Valley NHS Trust
76. Yeovil District Hospital NHS Foundation Trust
77. York Teaching Hospital NHS Foundation Trust

# What we found and actions required

## Further full audit findings and recommendations for action

Full details of the tables of results and analyses which inform the key findings and recommendations set out within this report can be found on the PGHAN Audit pages of the RCPCH website at:

[www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/pghan-audit](http://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/pghan-audit)

## 1. Networks and pathways of care

### PGHAN networks and characterising current networks

The joint BSPGHAN/RCPCH Quality Standards for Paediatric Gastroenterology, Hepatology and Nutrition (2017) stated the following:

*“Improving clinical outcomes and reducing variation in care will be best progressed and facilitated by services being commissioned, planned, delivered and evaluated through funded clinical networks. All centres should work in a network to facilitate the co-location of other subspecialties in order to manage the complex needs of patients with gastroenterology, liver and complex nutrition needs”*

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. A successful network is highly reliant on collaboration & 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. Successful clinical networks **should have formal funding arrangements** and clear mechanisms for communication across the network with 24/7 access to specialist advice.

#### Required actions

- Appropriate skilled and staffed services should be provided in inpatient and outpatient settings appropriate for the population needs to reduce variation in care and improve safety.
- Neighbouring centres, including those across regional boundaries, should work together to agree and map referral pathways for best patient care.
- BSPGHAN should encourage centres to work together to formalise arrangements to ensure that services are planned, delivered, and evaluated through clinical networks.
- BSPGHAN should develop an online audit for annual audit of key data benchmarking and annual returns to address areas where there are gaps to ensure quality improvements.
- Networks should ensure a robust system of communication and information sharing to agree shared care protocols, pathways of care, outreach, and telehealth appropriate for population needs.
- An annual meeting and identified network lead with dedicated time within their job plan.

- Non-specialised network centres will have at least one consultant paediatrician with special interest in paediatric gastroenterology (SPIN doctor) who is designated to link with the lead specialist centre, and has dedicated time within their job-plan to achieve this.
- Specialised centres should offer 24/7 on call access to specialist advice by telephone and an on-call service where there are 4 or more WTE consultants.

## **Findings**

- While the majority of Gastroenterology and Nutrition Specialised Centres and Hepatology Specialised Centres and non-specialist centres declared that they worked in a clinical network, 7% and 33% and 24% Non-specialist centres respectively did not.
- There are no Gastroenterology and Nutrition Specialised Centres outside of Scotland in a funded clinical network (there are 4 centres in Scotland of which 5 Network Centres and 2 hepatology centres indicate that they are part of a funded clinical network. 67% of funded clinical networks (6/9) have funds for clinical lead role .
- 38% of all centres reported that an annual meeting was held within their network in 2019. An annual meeting was only held in 41% Gastroenterology and Nutrition Specialised Centres (11/27). 36% of these were held virtually.
- A good proportion of units offer outreach clinic in line with NHS principles of care closer to home.
- Only a third of all centres have shared PGHAN care protocols and guidelines for all centres within their clinical network. Although guidelines exist across centres and lead centres feel these are shared, but Non-specialist centres do not feel they have access to these guidelines.
- 24% centres submitted data to any PGHAN national audit programs for children in 2019.
- Telehealth was not well developed in England in 2019 - 88% of Gastroenterology and Nutrition Specialised Centres delivered no telehealth in 2019.

## **Transition to adult care**

Transition is an essential part of the health care journey for a young person. Many initiatives in Children's service support this such as the ready steady go. While the focus has tended to be on disease areas (such as IBD, liver disease) the need is true of all patients including those moving to specialised adult services, secondary care adult services or primary care follow up.

### **Required actions**

- Transition pathways for all conditions should be developed based on local expertise and involve adult nursing teams and patient care co-ordinators with clearly laid out roles and responsibilities.
- The network must ensure strong relationships with adult colleagues to ensure transitional care is appropriately managed and delivered.
- While IBD on the whole have reasonable transition plans in place, other conditions do not and should be focussed on including those moving to primary and secondary care.
- Children's Services should coordinate transition processes better for children on enteral feeding who are often not under paediatric gastroenterology (such as community based clinicians, neurology, surgery). Agreed protocols to regularly review this provision could improve the outcome for this cohort.

- Networks 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.

## **Findings**

- 34% (35 out of 104) of centres allocate a 'transition worker' to a young person to assist their coordination to (highly) specialised adult care (16 Gastroenterology & Nutrition Specialised Centres, 3 Hepatology Specialised Centre and 16 Non-specialist Centres).
- 54% (56 out of 104) centres have a shared process with adult services to ensure that the patient has been given adequate written information about their transition to adult services in their clinical network (23 Gastroenterology & Nutrition Specialised Centres, 3 Hepatology Specialised Centre and 30 Non-specialist Centres).
- 40% (42 out of 104) centres have an annual review of individual plans for children transitioning to adult services in their centre (13 Gastroenterology & Nutrition Specialised Centres, 3 Hepatology Specialised Centre and 26 Non-specialist Centres).
- Apart from IBD (93% in specialist Gastroenterology & Nutrition Specialised Centres) and Liver diseases in the 3 hepatology centres, most conditions do not have written operation protocols for transition. This was particularly true of enteral nutrition in Non-specialist Centres.

## **Summary**

It is evident that transition pathways need improvement to facilitate care closer to home as possible and appropriate. Children dependant on enteral feeding were least likely to have an agreed transition pathway.

# **2. Workforce within networks**

To provide the best evidenced and delivered care a trained worked consultant workforces is needed. They should be supported within the network by a fully equipped multi-disciplinary team including specialist nurses, dietitians, psychologists and other services such as speech and language and mental health specialists (CAMHS).

## **Consultant workforce**

A functioning network requires adequate staffing with consultant gastroenterologists and consultants with a special interest in gastroenterology at all sites where children with gastroenterology, hepatology and nutrition needs are cared for.

## **Special interest consultants in a network non-specialist centre**

Optimal local care, and proper functioning of a PGMAN network, requires at least one consultant paediatrician with a special interest in gastroenterology (SPIN doctor) in each network centre as recommended by Standard 1 of the PGMAN Quality Standards (2017). These quality standards also indicated that, to work effectively, a SPIN doctor required a minimum of two of their Programmed Activities (PAs) dedicated paediatric gastroenterology provision 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.



## **Required actions**

- All (100%) Non-specialist centres should have a minimum of one consultant paediatrician with special interest in gastroenterology (SPIN) with at least 0.2 working time equivalent (WTE) allocated towards paediatric gastroenterology and nutrition in their agreed job plan.

## **Findings**

- 18% of non-specialist centres reported no consultant paediatrician with special interest in gastroenterology (SPIN) at their centres with an additional 4% of non-specialist centres having < 0.2 Working time equivalent (WTE) consultant paediatrician with special interest in gastroenterology.

## **Paediatric gastroenterology or hepatology consultants in a Specialised Centre**

Adequate number of paediatric gastroenterology consultants is essential for complex case management, peer support, to provide prospective cover during colleague's absence and for continuity of care. It is also essential for providing 24/7 on-call cover, provision of emergency endoscopy and the availability of specialist advice by telephone and to comply with all the standards laid out in the PGHAN Quality Standards (2017).

## **Required actions**

- A specialist centre requires at least 4 WTE paediatric gastroenterologists at each specialist paediatric gastroenterology and nutrition centre to provide specialist services as outlined in the PGHAN Quality Standards (2017).

## **Findings**

- 96% of Gastroenterology and Nutrition Specialised Centres have at least 2 or more WTE paediatric gastroenterologists (range = 0.8-8.4 WTE) while 63% of Gastroenterology and Nutrition Specialised Centres employ 3 or more WTE paediatric gastroenterologists. Mean and median WTE for all Gastroenterology and Nutrition Specialised Centres was 3.71 (SD = 1.8) and 3 respectively.
- 5 non-specialist centres also had 1 WTE paediatric gastroenterologist at their centre.

## **Nurse specialists and allied health professionals**

Caring for children with gastroenterology hepatology and nutrition needs often requires multidisciplinary support. All the elements an MDT need to be available within a network, located where they can be most effectively utilised.

## **Nurse specialists and allied health professionals (AHPs)**

Caring for children with specialist gastroenterology, hepatology and nutrition needs involvement of MDT's as recommended in standards 6, 7 and 8 of PGHAN Quality Standards (2017). Key participants in

these teams include paediatric gastroenterologists, hepatologists dieticians, clinical nurse specialists, paediatric psychologists, paediatric pharmacists and speech and language therapists ( SALT). Some members are required for more specialist work, such as pharmacists in specialist centres that provide parenteral nutrition (mainly in specialised centres). Others such as dieticians and nurse specialistS are of value for any service managing children with gastroenterology and nutritional needs, although the 2017 Quality Standards concentrated on their necessity for MDT work in specialist centres.

### Required actions

- Gastroenterology and Hepatology Specialised Centres all require dietetic, pharmacy, SALT, psychology and clinical nurse specialists to be available for their MDT work.
- Non-specialist network centres looking after children with gastroenterology, hepatology and nutrition problems should have local access to a core set of support services: paediatric dietitian, SALT and paediatric psychology, with nurse specialist support where more complex cases are being managed in the non-specialist centre setting.

### Findings

- When all types of centre providing specialised or non-specialist care were reviewed as a whole, a clinical nurse specialist was available in only 41%, with just 17% available in non-specialist centres.
- 62% of all centres combined had access to a paediatric dietician aligned to gastroenterology, with less than half (47%) in non-specialist centres.
- Paediatric psychology services were available in 32% of all centres, with just 13% in non-specialist centres. Whereas in specialised centres provision was better but not universal (78% in specialised Gastroenterology and Nutrition centres and in all 3 Hepatology centres)
- Access to speech and language therapy (SALT) was universally low with 33% Gastroenterology and Nutrition Specialised Centres and 67% Hepatology Specialised Centres having SALT available at their centres.
- 81% Specialised Gastroenterology and Nutrition Centres had a paediatric pharmacist aligned with their service.

### Nurse specialists in specialist centres

Caring for children with specialist gastroenterology, hepatology and nutrition needs requires involvement of MDT's as recommended in standards 6, 7 and 8 of PGHAN Quality Standards report (2017). Specialist centres in particular undertaking complex care (parenteral nutrition, neuro-gastroenterology/motility and liver/bowel transplant) thus require a full range of highly skilled nurse specialists adequately trained in the management of IBD, liver diseases, parenteral nutrition and looking after pre/post-transplant children.

### Required actions

- A Specialist Gastroenterology and Nutrition centre providing care to children with inflammatory bowel disease (IBD) **should have adequate specialist nurse provision (at least 1 WTE IBD nurse specialist per 200 paediatric IBD patients).**<sup>vii</sup>
- A Specialist Gastroenterology and Nutrition centre providing care to children requiring parenteral nutrition (PN) for children **should have adequate specialist nurse provision (at least 1 WTE nutrition nurse specialist per 10 patients requiring home PN).**

## **Findings**

- 81% of Gastroenterology and Nutrition Specialised Centres had some IBD nurse specialist availability (23% of these with < 1 WTE nurse specialist in IBD).
- 70% of Gastroenterology and Nutrition Specialised Centres had provision for nutrition nurse specialist availability (32% of these with < 1 WTE).
- Only 5 Gastroenterology and Nutrition Specialised Centres (19%) had any specialist nurse provision in motility/neuro-gastroenterology.
- All 3 paediatric hepatology centres (100%) had nurse specialists for liver diseases and transplant. No non-specialist centres in the UK have nurse specialists for liver diseases and transplant.

## **Workforce aiding transition from adolescent to adult services**

As endorsed by standard 6 of RCPCH “Facing the Future-standards for ongoing health needs” (March 2018), NICE guideline (NG43) on “Transition from children’s to adults’ services for young people using health or social care services” (February 2016) and Standard 3 of the PGHAN Quality Standards (2017), transition care arrangements should be a key element of paediatric gastroenterology services with sharing/ updating transition policies and co-ordination of transition with joint clinics held between paediatric and adult gastroenterology teams.

## **Required actions**

- All centres managing children with gastroenterology nutrition and hepatology needs should have a transition lead or a transition worker to assist co-ordination of transition to specialised adult care.

## **Findings**

- 59% Gastroenterology and Nutrition Specialised Centres, 100% of Hepatology Specialised Centres, and 22% Non-specialist centres allocated a transition worker to a young person to assist co-ordination of transition to adult services.

### 3. Provision of PGHAN care within the UK

The Quality Standards for Paediatric Gastroenterology, Hepatology and Nutrition (January 2017, BSPGHAN & RCPCH) make the case for a comprehensive national provision of services for children within the UK. Furthermore, they were developed to promote the requirement that access to these specialist paediatric gastroenterology, hepatology and nutrition (PGHAN) services should be within a network of secondary (non-specialised services) and tertiary providers (specialised services).

Access and provision of these services are essential to providing optimal care to children with gastrointestinal and hepatic conditions.

#### Provision of PGHAN care in specialised centre

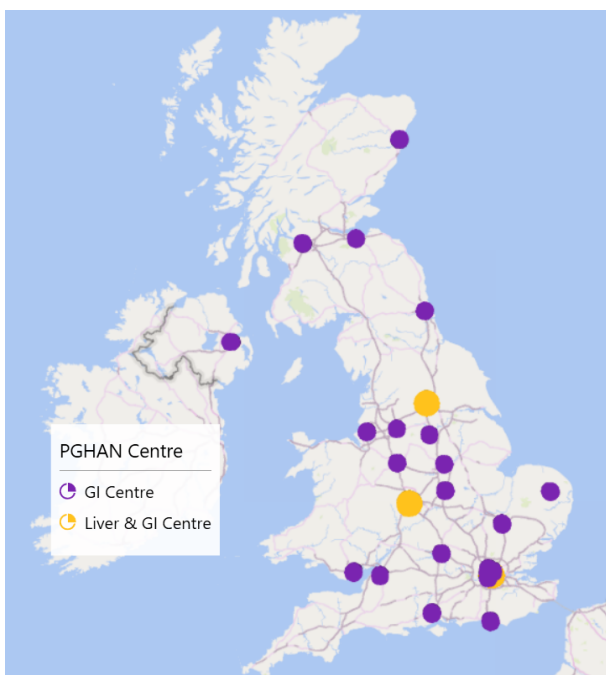
From the 138 eligible health boards and trusts across the UK providing paediatric care, we had a 78% response rate (107/138). The distribution of specialist centres is focused on pre-existing children's hospitals, with some non-specialist centres providing some PGHAN services.

#### Required actions

- Access to specialist paediatric gastroenterology, hepatology and nutrition care should be equitable across the UK.
- Where this cannot be provided locally, there should be formalised clinical networks to facilitate timely assessment, evaluation and management.

#### Findings

- 27 Self-Declared Gastroenterology and Nutrition Specialised Centres in the UK.
- 3 Self-Declared Hepatology Specialised Centres in the UK.
- 77 Non-specialist Centres / Network Centres in the UK.



**Figure 2 - Distribution of UK Centres providing Specialised PGHAN Care**

**(London includes 7 Paediatric Gastroenterology and Nutrition Specialised Centres and one Paediatric Hepatology Specialised Centre)**

## Provision of PGHAN Care in non-specialist centres

Providing care closer to home for children with complex medical conditions is desirable. This care should be provided with those with specific training or expertise. Access to services should be equitable and designed across geographical boundaries as outlined in Standard 2 of PGHAN Quality Standards (2017). The network model of delivering care through specialised centres working closely with local providers (Non-specialist centres), or some hepatology services being provided in gastroenterology centres, is utilised in the UK.

### Required actions

- Commissioners should ensure that Specialist centres and non-specialised Network centres must provide services that are appropriately skilled and staffed in all hospital settings to meet their population needs.
- Commissioning should support models of networked care across geographical boundaries, so that care can be delivered closer to home, where appropriate.
- Specialised Gastroenterology networks should be 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.

### Findings

- A third of Network or Local Providers within the UK report to provide some specialised paediatric services in Gastroenterology or Nutrition, with a good geographic distribution of Specialised Centres in Gastroenterology and Nutrition within the UK. They often provide these services within an informal network with specialised centres.
- Most specialised hepatology (liver) services are provided through the three Specialised Hepatology Centres based in Birmingham, Leeds and London (King's College Hospital).
- There is provision of limited hepatology services provided in 63% of Specialised Centres in Gastroenterology and Nutrition.

## Co-location of specialised paediatric services

Minimising transfers for children helps to promote stability and avoids complications during transit. Optimally, lead specialised centres that provide gastroenterology and nutrition, or hepatology services, should be located with paediatric surgery, specialist anaesthetic services and pain management, neonatology expertise, paediatric interventional radiology, clinical biochemistry, histopathology, and paediatric intensive care. In addition to these services, specialised hepatology services require hepatobiliary surgery, paediatric interventional radiology, transplant immunology, microbiology, virology, and intensive care. Standard 1 of PGHAN Quality Standards (2017) sets out that specialised centres that provide specialist services locally must be located with the appropriate multi-disciplinary support.

### Required actions

- Health Board and Trust managers should ensure that complex PGHAN care and paediatric

endoscopic services should be primarily provided within a specialised centre, co-located with appropriate specialised services such as paediatric intensive care units and paediatric surgery.

## **Findings**

- Only 63% of specialist gastroenterology centres and 67% of specialist hepatology centres co-locate on the same site, with the full range of specialised paediatric service as outlined in the 2017 quality standards.
- Where possible, Specialised PGHAN services should be co-located with other specialised paediatric services.

## **Provision of elective endoscopy**

Access to high quality endoscopy is a vital part of paediatric gastroenterology care in children. Standard 4 of PGHAN Quality Standards (2017) sets out how this should be performed in a child friendly environment and that timely access to endoscopy must be available through clear and agreed pathways within the network.

### **Required actions**

- Services should ensure suitably funded 24/7 on call rotas and skill mix (which may include adult endoscopists for rare interventions) to manage the emergency procedures required.
- BSPGHAN should work with the Joint advisory Group on GI endoscopy (JAG) to define clear standards for endoscopy in children (retraining and environment).
- Networks should ensure that all paediatric endoscopy is undertaken in a suitable environment by people trained to undertake the procedure.

## **Findings**

- All Specialist Centres in Gastroenterology & Nutrition, and Hepatology centres within the UK provide elective diagnostic endoscopy. Interestingly 12% (9/72) network centres also provided elective diagnostic endoscopy. More specialised endoscopy techniques, such as insertion of feeding devices (e.g. gastrostomy insertion) was limited to fewer centres – 93% of Specialist Centres in PGHAN care, as well as 11% (8/75) Network Centres.
- 97% of centres providing endoscopy services, do so in an age appropriate & child-friendly environment.
- Most elective procedures are undertaken by paediatricians (paediatric gastroenterologist/ hepatologists or paediatricians with a special interest with additional training - SPIN) or paediatric surgeons. Only small numbers are undertaken by adult endoscopists or surgeons.

## **Access to out-of-hours emergency interventions**

Pathways for emergency endoscopies are often not clear however severe gastro-intestinal (GI) bleeds requiring skilled interventions are rare. A national audit has been undertaken and data presented in abstract form (EMERGENCi), this shows most foreign body management is undertaken by paediatric

surgeons (with rapid intra-hospital transfer) and that severe GI bleeds needing interventions are rare and most Gastroenterology & Nutrition Specialised Centres see very few per year.

### **Required actions**

- Management guidelines and pathways of referrals for GI bleeds and foreign bodies and pathways of referrals should be defined by all members of the networks.
- BSPGHAN should ensure that agreed national protocols, & guidance are produced, updated regularly and shared with all network, including guidance on emergencies including GI bleeding with support by surgeons & adult colleagues.

### **Findings**

- 81% (22/27) of Gastroenterology & Nutrition Specialised Centres and 4% (3/75) of Non-specialist centres perform out of hours endoscopy for children, while available these out of hours rotas are not fully funded.
- Disappointingly in those centres with these emergency endoscopy services, only 41% of Gastroenterology and Nutrition Specialised Centres, and 67% of Hepatology Specialised Centres had formally-rostered provision.
- 64% (48/75) of Non-specialist centres have a preferred referral pathway for emergency endoscopy services.
- 46% (48 out of 105) of centres have neither local criteria for access to diagnostic endoscopy and for children presenting in an emergency nor timely access to endoscopy through clear and agreed pathways, breaking down as 74% [20/27] of Gastroenterology & Nutrition Specialised Centres, 100% [3/3] of Hepatology Specialised Centres and 33% [25/75] Non-specialist Centres).
- Only 10-30% of Gastroenterology & Nutrition Specialised Centres and Non-specialist centres have management guidelines for GI bleeding and foreign bodies.

## **Access to specialists in complex or chronic PGMAN conditions**

Access to healthcare professionals who are specialists in Paediatric Gastroenterology, Nutrition or hepatology is essential for those with complex or chronic conditions. The PGMAN Quality Standards (2017) outlined the importance of an expert multidisciplinary team and for access to these teams to be timely with agreed pathways. For example, Standard 5, outlines the need for a specialist review within 4 weeks of referral for suspected inflammatory Bowel Disease (IBD), and standards 7 and 8 make specific recommendations about children on parental nutrition (PN). Other conditions such as Coeliac disease require a workforce committed to new developments in diagnostics and management.

### **Required actions**

- The diagnosis of paediatric IBD should be facilitated with a recommendation that they are seen by a specialist paediatrician within 4 weeks of referral, and resources are provided to achieve this.
- Children receiving inpatient parenteral nutrition should be reviewed at least once a week by a multi-disciplinary 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.

- Children receiving home parenteral nutrition (HPN) are cared for by an intestinal failure or designated HPN unit with a multi-disciplinary nutrition team.
- Children with suspected coeliac disease, should be offered a no-biopsy/endoscopy pathway, where eligible with current UK best practice.

## **Findings**

- 80% of children with a suspected diagnosis of IBD will be seen within 4 weeks, when referred to a Gastroenterology and Nutrition specialised centre. However non-specialist Centres reported that only 43% of patients are seen by a specialist consultant within 4 weeks of referral.
- 81% of Paediatric Gastroenterology and Nutrition Specialist Centres and all Hepatology Specialist Centres have hospital based enteral nutrition care teams. Encouragingly, 21% of Non-specialist centres report provision to support complex enteral nutrition therapies.
- All Specialist centres for Hepatology, and 85% (23/27) Specialised Gastroenterology & Nutrition Centres have nutritional multi-disciplinary teams to help initiate and manage inpatient/hospital parenteral nutrition. Although most centres will review weekly patients on parenteral nutrition PN, this is not the case in all reporting centres, and is required for optimal and safe provision of inpatient PN.
- All Specialist Centres, and most Network Centres (91%) are familiar with the no-biopsy/endoscopy pathway for the diagnosis of Coeliac Disease.

## **Provision of telehealth and virtual services**

Providing telehealth and virtual services for patients and families will enable regular monitoring of patients who have long-term health needs and will improve access to care for patients who live in geographically remote locations. Rapid developments during the COVID-19 pandemic should be evaluated and adopted where the delivery or access to care is improved. A principle of equity of access to specialist paediatrics services, should be promoted.

### **Required actions**

- Commissioning organisations should ensure that Telehealth and Video Clinic consultations are evaluated and organised to provide high quality and responsive health care, alongside traditional methods of assessment.

## **Findings**

- All centre respondents signified that they had seen an increase in their provision of telehealth and video clinics since the first wave of COVID-19 – with 75% of Specialised Centres in Gastroenterology/Nutrition and 66% Specialised Centres in Hepatology now providing more than half of their clinics through telehealth or video.
- Patient and Network Centre feedback has been positive about these consultations, as part of a mixed provision of care involving both face-to-face and virtually delivered care.



## #VoiceMatters

RCPCH &Us is a children, young people and family network, working with over 2,000 young patients, their families and friends across the UK each year. Through the work of RCPCH &Us we keep children and young people at the centre of everything we do, supporting their voice to inform, influence and shape the work of the RCPCH.

The RCPCH is guided by the United Nations Convention on the Rights of the Child, particularly article 12, which encourages children and young people's voice in decision making and article 24, providing them with the best health care possible. You can find out more about the rights of the child, how it relates to your practice and useful resources at [www.rcpch.ac.uk/rightsmatter](http://www.rcpch.ac.uk/rightsmatter).

Clinicians involved in supporting and delivering care for PGHAN are encouraged, as part of their professional development, to identify and visit children and young people's groups with relevant interests. Listening and learning from the experiences of children and young people, followed by reflecting on this with peers on how to improve clinical and service practice is central to creating patient focused services. The #VoiceMatters section raises the views of children, young people and their families which can be used to inform your practice, discussions with your teams and MDT colleagues, as well as improving understanding and awareness of patient and family experiences.

To support the development of these guidelines, we have reviewed the voice and views of children, young people and their families who have worked with RCPCH &Us. You can find out more about RCPCH &Us at [www.rcpch.ac.uk/and\\_us](http://www.rcpch.ac.uk/and_us).

## What children, young people and families said

*"The best doctor is someone who can change your feelings of health and can help you on the worst day possible" RCPCH &Us*

It can be hard for us and our families when we are ill. We can be scared, worried, nervous and trying to be strong for everyone else, including you. It helps us when people take time, when they are patient, kind and explain things in different ways for different people in our family, so that we can understand what is going on. Sometimes we need to have conversations and time with you separately from our family members so that we can talk to you about things that we might not want to mention in front of each other.

There can be lots for us to remember about what you have said or all the other people that are involved in helping us. Please make sure that you introduce us to everyone but also create a way for us all to remember what is going on, like a picture book or a notebook that has drawings in it, as it is already a lot to think about. It helps when just one person is in charge of explaining things in a clear and easy to understand way, so we get used to that person and feel comfortable to ask questions.

*"My gastro service is good at solving the problem, they forward you on to alternative clinics and follow up quickly" RCPCH &Us*

It can sometimes feel with these kinds of illnesses that there is lots of questions and problems to solve, and that from when you are first ill to when you get told what the problem is, can be a really long time. It is great when doctors think about getting us help from other people quickly, like help from a play specialist when we are scared of the blood tests or having the operation, or help from the dietician so that we know what to eat especially when we are on holiday or who give us a fast track card for A&E if we need it. It would be helpful if there was a way to help other people understand what is happening too, like our GP and schools, because sometimes they've never met anyone with the condition so don't really get it or get how to help us.

This might be something that we live with for our whole lives. It can be worrying thinking that the doctor, nurses, receptionists and everyone you have grown up with in your children's clinic will change when you move to adults. This could be when you are still at school so it doesn't always feel like it is time to go to another hospital and be helped by a different doctor or nurse in a new clinic. It would be good to find out different ways to help that move and transition, like lots of appointments with both sets of doctors (old and new), virtual tours, phone calls and visits so you get used to it, and that you start talking about it really early so a few years before you have to move. Sometimes it feels rushed and for some of us that can be too much, so we stop coming in for our appointments with the new doctors.

***"The best doctor is informed about national and local support services for children and young people, signposting and engaging with them" RCPCH &Us***

We like it when there is the chance to meet or learn from other patients and their families about their experiences, their tips and to be able to say "I am Beth and I have this condition" and someone else there already knows about it and is the same age and then it doesn't feel so lonely. It's important for parents to be able to have someone to talk to who is medical and someone who is not medical when things are difficult day to day between appointments. Having an illness or condition that people can't see can be hard for people to understand. It helps when doctors think about how to help make sure you have good mental health as well as looking after physical health. Sometimes mental health can be worse when you have got a medical condition. Having doctors who know how to talk to us about mental health as well as our physical health is important. Talking about how we are coping and feeling should be an everyday normal conversation, not just something that is mentioned or checked once.

***"Mental health is equally important; it might even be more important than physical health" RCPCH &Us***

We wish that we were told sooner about local support groups or services and national charities that can help us to understand things like benefits when you are ill or looking after someone who is ill, that knows about our conditions and has tips like diet sheets or recipes shared, or that you can talk to someone who isn't your doctor to get help understanding things.

It would be great if you find out about your local area or national charities and have this ready to explain to us or our families, and to remind us regularly when you see us as it is easy to forget or lose the information when there are lots of other things going on.

We also know that virtual appointments are going to be around for a while to help the NHS while it

isn't safe for everyone to come into clinics and hospitals at the same time.

*“Offering online appointments - the issue is that sometimes at home with the family there is no safe space to have confidential call and feel safe that no one is listening in.” RCPCH &Us*

There are a few things that can be done to help us have good appointments whether they are on the phone or using video.

1. Reassure us about how it will work
2. Give us choice of how to talk with you
3. Help us to keep it private when we are at home
4. Help us to prepare for our virtual appointment
5. Make it easy for people without good Wi-Fi access
6. Make it clear and simple about how we get help when we need it

*“Remember that for some young people it is becoming too much with everything happening in their bedroom: school, friend socials, mental health appointments/health consultations. You can't get away from it space wise” RCPCH &Us*

Thank you for reading these guidelines and working with others to be the best services possible for children and young people 😊

*“the best doctor is someone like you, kind, funny, happy and listens to me and my family” RCPCH &Us*

## Questions to think about:

1. How are you going to support children and young people to feel comfortable in opening up to you about their experiences? Are there tools and resources that could help?
2. Have you asked about other things in our house, where we live or at school that we might need help with that could be having an impact on our condition?
3. What ways will you use to help everyone (patient/family/carer) talk with you on their own, in the way that is right for them?
4. How will you help to make virtual health appointments safe, private and confidential for patients?
5. What local and national charities do you know that help families dealing with complex conditions?
6. What information could you share with non-specialists to help those outside of the MDT e.g. GPs and schools?
7. What transition tools and plans are in place and when do they start? (NICE guidance states from age 13).

**Thank you to children, young people and families from the RCPCH &Us network for sharing their ideas and views used in this section.**

## Useful RCPCH &Us resources

- **Hidden health - a parent-led card and toolkit** [www.rcpch.ac.uk/hiddenhealth](http://www.rcpch.ac.uk/hiddenhealth) toolkit designed by parents to support accessing support in paediatric services, with checklists for parents and for professionals.
- **Being me - supporting children and young people** [www.rcpch.ac.uk/resources/being-me-supporting-children-young-people-care](http://www.rcpch.ac.uk/resources/being-me-supporting-children-young-people-care) resources designed by children and young people to support conversations about mental health and emotional wellbeing.
- **Transition to adult services** [www.rcpch.ac.uk/resources/transition-adult-services](http://www.rcpch.ac.uk/resources/transition-adult-services) resources, case studies and examples of how to do transition well with young people.
- **The COVID-19 Book Club** [www.rcpch.ac.uk/resources/covid-19-summaries-key-findings-children-young-peoples-views#the-covid-19-book-club](http://www.rcpch.ac.uk/resources/covid-19-summaries-key-findings-children-young-peoples-views#the-covid-19-book-club) information from children and young people about priorities for recovery plans in paediatric services.
- **Epilepsy12 Youth Advocates** [www.rcpch.ac.uk/epilepsy12-youth-advocates](http://www.rcpch.ac.uk/epilepsy12-youth-advocates) guide created by young people about how to have a gold standard service to support patients with worries or anxieties about their condition (can be adapted to any condition).
- **COVID-19 &Us - views from RCPCH &Us** [www.rcpch.ac.uk/resources/covid-19-us-views-rcpch-us](http://www.rcpch.ac.uk/resources/covid-19-us-views-rcpch-us) ideas and views on virtual health appointments and service led mental health support through the pandemic.
- **State of Child Health - Voice matters** <https://stateofchildhealth.rcpch.ac.uk/voice-matters/> voices and views on how to stay healthy, happy and well, with recommendations and suggested actions from young people on mental health, rights, confidentiality and youth friendly services.
- **Paediatrics 2040 - Voice matters** <https://paediatrics2040.rcpch.ac.uk/voice-matters/> voices and views on how to develop the services of the future, with recommendations and suggested actions from young people on mental health, communication and improving services.

# BSPGHAN and RCPCH information and resources

## Royal College of Paediatrics and Child Health information and resources

The Royal College of Paediatrics and Child Health (RCPCH) was founded in 1996. We play a major role in postgraduate medical education, professional standards, research and policy. The RCPCH has a number of useful resources, including:

- **British Paediatric Surveillance Unit** [rcpch.ac.uk/work-we-do/bpsu](http://rcpch.ac.uk/work-we-do/bpsu)  
The BPSU is a world leading centre for rare paediatric disease surveillance. It enables doctors and researchers to investigate how many children in the UK and Republic of Ireland are affected by particular rare diseases, conditions or treatments each year.
- **Courses and continuing professional development** [rcpch.ac.uk/education/courses](http://rcpch.ac.uk/education/courses) and [rcpch.ac.uk/education/continuing-professional-development](http://rcpch.ac.uk/education/continuing-professional-development)
- **Invited reviews** [rcpch.ac.uk/invitedreviews](http://rcpch.ac.uk/invitedreviews)  
We support healthcare organisations, commissioners and clinical teams to resolve concerns about paediatric service provision, safety, training, compliance with standards, and proposals for paediatric reconfiguration or service design. Our service is confidential, established and influential, and tailored to each organisation's needs.
- **Medicines for Children** [medicinesforchildren.org.uk](http://medicinesforchildren.org.uk)  
The Medicines for Children website provides parents and carers with information they can trust on over 200 medicines commonly prescribed to children. It offers free access to patient information leaflets and videos specifically developed to advice parents and carers how to give medicine to their child.
- **MedsIQ** [qicentral.rcpch.ac.uk/medsiq](http://qicentral.rcpch.ac.uk/medsiq)  
Medication errors are a significant but preventable cause of harm to children and young people.
- **Research activities** [rcpch.ac.uk/work-we-do/research-activities](http://rcpch.ac.uk/work-we-do/research-activities)  
We aim to improve children's health outcomes through supporting high quality and trusted research. Let's share our expertise, collaborate with others and promote the evidence to drive forward improvements in child health.
- **RCPCH Child Protection portal** [childprotection.rcpch.ac.uk/](http://childprotection.rcpch.ac.uk/)  
RCPCH Child Protection portal is an online resource to help inform clinical practice, child protection procedures, and professional and expert opinion in the legal system.
- **RCPCH QI Central** [qicentral.org.uk](http://qicentral.org.uk)  
QI Central is a free online resource open to all child health professionals to help embed QI projects in clinical practice and continually improve services and outcomes for infants, children and young people. As an online repository of peer-reviewed tools and projects, healthcare professionals are also able to submit their own projects and resources to share their experiences with others and propagate knowledge in quality improvement.
- **Workforce and service design** [rcpch.ac.uk/workforce](http://rcpch.ac.uk/workforce)  
We play a key role in workforce planning to ensure there is an appropriately trained paediatric medical workforce to deliver safe and sustainable services for children in the UK - in the present and in the future.

# **The British Society of Paediatric Gastroenterology, Hepatology and Nutrition information and resources**

The British Society of Paediatric Gastroenterology, Hepatology and Nutrition (known as BSPGHAN) is the national, professional and academic society which represents specialty colleagues working for infants, children and young people with digestive and liver disorders.

BSPGHAN is a society that brings together colleagues from a range of professional disciplines and is recognised by the Royal College of Paediatrics and Child Health (RCPCH) as the society responsible for this field of paediatric medicine.

BSPGHAN's membership is renowned for its friendliness and inclusivity. Membership stands at around 500 members, comprising consultants and specialist trainees in paediatric gastroenterology, hepatology and nutrition; affiliated health care professionals such as specialist dietitians, nurses, pharmacists, clinical psychologists and scientists. This breadth of membership is a great benefit to the society and the wide range of professionals serve to represent our models of care for families. BSPGHAN has Professional groups and Working Parties to advocate for the key issues that our patients face.

## **BSPGHAN's aims:**

BSPGHAN supports clinical research, training and education for all our members with the aim of promoting optimal care for our patients. BSPGHAN encourages collaboration and open dialogue. As BSPGHAN has grown, our ability to provide professional leadership and influence stakeholders such as healthcare commissioners, providers at local, regional and national levels, and national bodies such as the RCPCH and NICE, has increased. BSPGHAN links with partners including patients and families, children's charities and industry to deliver its agenda.

[www.bspghan.org.uk](http://www.bspghan.org.uk)

# Glossary of terms and abbreviations

<b>BSPGHAN</b>	British Society of Paediatric Gastroenterology, Hepatology and Nutrition.
<b>Children</b>	Infants, children and young people under the age of 18 across the UK.
<b>Clinical Network</b>	Services brought together to strategically provide high quality, specialist care to the local population.
<b>Coeliac disease</b>	An autoimmune disease caused by the gut's reaction to gluten. It is treated by omitting gluten from the diet. Gluten is found in wheat, barley, and rye.
<b>Gastroenterology</b>	Gastroenterology is the branch of medicine which deals with disorders of the digestive tracts (e.g. intestines), growth and nutrition.
<b>Gastroenterology and Nutrition Specialised Centre (GN)</b>	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.
<b>Hepatology</b>	Hepatology is the branch of medicine that incorporates the management of disorders of the liver, gallbladder, biliary tree, and pancreas.
<b>Hepatology Specialised Centre (H)</b>	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.
<b>IBD</b>	Inflammatory Bowel Disease (IBD) is a term mainly used to describe 3 conditions: ulcerative colitis, Crohn's disease and IBD-unclassified (IBD-U). These are long-term auto-immune conditions that involve inflammation of the gut.
<b>Managed Clinical Network</b>	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.
<b>MDT</b>	Multi-disciplinary team. This will often include doctors, specialist nurses,

dietitians and pharmacists. Other allied health professionals such as psychologists or other specialists (e.g. surgeons) maybe involved.

**Mean**

A measure of the 'average' of a set of numbers. Add up all the numbers, then divide by how many numbers there are in the sample.

**Median**

The median is the middle number of a list of numbers when they are sorted from the smallest to the largest number.

**Non-specialist**

**Network Centre (NC)**

A centre that provides PGHAN care, often a local centre providing general paediatric services. These centres should have at least one consultant paediatrician with special interest in paediatric gastroenterology.

**Operational Delivery**

**Networks (ODNs)**

Operational Delivery Networks (ODNs) are focused on coordinating patient pathways between providers over a wide area to ensure access to specialist resources and expertise. ODNs should ensure outcomes and quality standards are improved and evidence based, networked patient pathways are agreed between commissioning bodies.

**PGHAN**

Paediatric Gastroenterology, Hepatology and Nutrition.

**Parenteral Nutrition (PN)**

Parenteral nutrition (PN) refers to the provision of nutrients by the intravenous route. In general, PN is used when it is not possible to supply nutrition using the GI tract ie. when intestinal failure is present. Total Parenteral Nutrition (TPN) implies that all macronutrient (carbohydrate, nitrogen and lipid) and micronutrient (vitamins, trace elements and minerals) and fluid requirements are met by an intravenous nutrient solution and no significant nutrition is obtained from other sources.

**RCPCH**

Royal College of Paediatrics and Child Health.

**SALT**

Speech and Language Therapy.

**WTE**

Whole Time Equivalent. 1 WTE is equal to a full-time doctor, nurse, or allied health professional.



# Appendix 1:

## Summary of quality standards for paediatric gastroenterology, hepatology and nutrition, BSPGHAN and RCPCH, 2017

Nine standards were developed around the requirement for specialist gastroenterology, hepatology, and nutrition services to be provided within clinical networks.

1. Trusts and health boards that provide paediatric gastroenterology and nutrition 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 multi-disciplinary 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 multi-disciplinary 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.

## Appendix 2: Co-location of specialist services

In the development of the PGHAN Quality Standards (2017), several key supporting specialised services were identified, to provide the basis for high quality paediatric gastroenterology, hepatology and nutritional care. These should co-locate with PGHAN services or have clear and timely pathways of referral where co-location is not possible.

### **These include:**

- Paediatric surgery
- Specialist anaesthetic services and pain management
- Neonatology expertise
- Paediatric interventional radiology
- Clinical biochemistry
- Paediatric histopathology
- Paediatric intensive care
- Paediatric interventional radiology

### **In addition to these services, specialised hepatology services require:**

- Paediatrics hepatobiliary and transplant surgery
- Paediatric interventional radiology
- Transplant immunology, microbiology, virology, and intensive care

## References

<sup>1</sup> *Facing the Future - standards for acute general paediatric service*, RCPCH, 2010.

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<sup>2</sup> *Quality Standards for Paediatric Gastroenterology, Hepatology & Nutrition*, BSPGHAN & RCPCH, 2017.

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<sup>3</sup> 27 self identified as specialist gastroenterology and nutrition centres

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<sup>4</sup> 77 self identified as non-specialised network centres

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<sup>5</sup> British Society of Gastroenterology IBD Guidelines 2019 – “best practice identifies a minimum per 250 000 population of two gastroenterologists, two colorectal surgeons, 2.5 IBD nurses, 1.5 stoma nurses, 0.5 dietitian (allocated to Gastroenterology), 0.5 administrative support, one histopathologist, one radiologist and one pharmacist – all with arrangements for cover in the event of absence.”

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<sup>6</sup> Personalised Care Plans in the NHS - <https://www.england.nhs.uk/personalisedcare/>

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<sup>7</sup> British Society of Gastroenterology IBD Guidelines 2019 – “best practice identifies a minimum per 250 000 population of two gastroenterologists, two colorectal surgeons, 2.5 IBD nurses, 1.5 stoma nurses, 0.5 dietitian (allocated to Gastroenterology), 0.5 administrative support, one histopathologist, one radiologist and one pharmacist – all with arrangements for cover in the event of absence.”

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The paediatric gastroenterology, hepatology and nutrition  
UK national census 2021  
PGHAN national quality standards audit

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