

Key recommendations from the PGHAN National Quality Standards Audit – UK National Census 2021

Improving the Paediatric Gastroenterology, Hepatology and Nutrition Services for children and young people in the UK

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Key Recommendation 1:

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.

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.

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.

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Key Recommendation 2:

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.

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.

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

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.

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).

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.

Key Findings:

- Whereas specialist centres all employed at least one nurse specialist and a paediatric dietician, 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 dietician.
- 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.

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).

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 Findings:

- 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 availability, although almost a third of these (6/19) had less than 1 WTE nurse specialist in nutrition.

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Key Recommendation 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.

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 PGHAN care protocols and guidelines for centres within their clinical network.

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Key Recommendation 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 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.

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.

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 Findings:

- **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.

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Key Recommendation 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 recommendation has been made in regards to the prioritisation of full restoration of PGHAN services following the pandemic.

Recommendation 5.1

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.

Find out more

You can find out more information or read the full PGHAN National Quality Standards Audit - UK National Census 2021, here:

www.rcpch.ac.uk/pghan-census

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