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British Society of Paediatric Gastroenterology, Hepatology and Nutrition

40th Annual Meeting

25th – 27th March 2026

The Queens Hotel, Leeds

ABSTRACT BOOKLET

RCPCH has approved this activity for CPD in accordance with the current RCPCH CPD Guidelines

Registered Charity No: 299294

OC1

Mental health and wellbeing in children with inflammatory bowel disease: a prospective audit of experiences and service needs in a tertiary gastroenterology service in England

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LEICESTER ROYAL INFIRMARY

Children and young people (CYP) with inflammatory bowel disease (IBD) are at increased risk of developing psychological problems compared with the general population. However, local data on the prevalence of mental health disorders in CYP with IBD and their experience of accessing support remain limited. A prospective audit was undertaken to quantify the burden of mental health conditions, explore barriers to support, and identify opportunities for service improvement.

A questionnaire was distributed to all CYP under the age of 18 years with a confirmed diagnosis of IBD under follow-up in a tertiary gastroenterology service (n=247). The survey was conducted electronically using secure text message invitations with a one-month response period and weekly reminders. A total of 126 completed responses were received, representing a 51% response rate.

Of those responding, 13 children (10%) had early onset IBD before the age of 10 years. Fifty-three children (42%) were aged 16–18 years and therefore approaching transition to adult services. Sixty-seven children (53%) were receiving biologic therapy at the time of the audit, including infliximab in 47, adalimumab in 13, ustekinumab in 2, and vedolizumab in 1.

Nineteen children (15%) reported a diagnosed mental health condition prior to their IBD diagnosis. A further 32 (25%) developed a mental health condition after their diagnosis of IBD, meaning that overall 51 children (40% of responders) had experience of a mental health problem.

With respect to treatment burden, 48 children (38%) reported attending hospital monthly(4-6weekly) for infusions, and a further 33 (26%) attended (8-12weekly)a few times per year. Ninety-six children (76%) indicated that IBD had an impact on their daily life, which included disruption to school attendance and restriction of social activities.

CYP and families reported a number of barriers in accessing psychological support. The most frequently cited were long waiting times for specialist services, lack of support provided in school settings, and difficulty accessing help for those with pre-existing mental health problems. When rating the quality of care received, children and families indicated lower satisfaction with psychological support compared with satisfaction with medical treatment and dietary advice.

Participants also suggested several improvements as routine enquiry about mental health at the time of IBD diagnosis and during follow-up appointments, direct access to clinical psychology embedded within the IBD service, improved signposting to available resources, and stronger liaison between the IBD team and schools.

This audit of 126 children with IBD highlights that 40% had a mental health problem, either predating or following their diagnosis, and more importantly 76% reported disruption of daily life due to their condition. Despite this, access to appropriate psychological support was reported to be limited. These findings support the systematic integration of mental health assessment and clinical psychology into paediatric IBD services. Planned actions include embedding routine mental health enquiry into consultations, advocating for psychology input within inpatient and outpatient IBD care, strengthening links with schools, and re-auditing after these changes to evaluate their impact.

References

- Raw JA, Waite P, Pearcey S. Examining changes in parent-reported child and adolescent mental health throughout the UK's first COVID-19 national lockdown. JCPP Adv 2021;1(1):e12021.
- Pearcey S, Shum A, Waite P. Report 04: Changes in children and young people's emotional and behavioural difficulties through lockdown. Co-Space Study 2020.
- Department for Education. Mental health and behaviour in schools: departmental advice for school staff. London: Department for Education, 2018.

OC2

Mind the Phosphate Gap: Are We Missing a Key Safety Check in Paediatric IV Iron Therapy?

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Iron deficiency anaemia (IDA) is a frequent sequelae amongst children with chronic gastrointestinal (GI) disorders including inflammatory bowel disease (IBD) (1). Oral iron is often ineffective or poorly tolerated due to malabsorption and gastrointestinal side effects, making intravenous (IV) iron therapy the more suitable option (2). Ferric carboxymaltose and iron sucrose are commonly used IV preparations. Hypophosphataemia is a recognised adverse effect of Ferric carboxymaltose classified by the Electronic Medicines Compendium (EMC) as common (1–10%)(3). The Medicines and Healthcare products Regulatory Agency (MHRA) advises checking and monitoring serum phosphate in patients at risk of hypophosphataemia or receiving repeated doses of IV ferric carboxymaltose, particularly in those with pre-existing risk factors such as malabsorption or chronic inflammatory GI conditions (4). Hypophosphataemia can cause myalgia, bone pain, confusion, seizures, arrhythmias and can be life threatening if severe (5).

In our tertiary paediatric gastroenterology unit, the current practice is to use ferric carboxymaltose if IV iron is required. This audit aimed to evaluate the use of IV Iron for patients attending in our paediatric gastroenterology unit and compare current phosphate monitoring practices against national guidance.

A retrospective review was performed of paediatric patients who received ferric carboxymaltose over a six-month period. Inclusion criteria: < 16 years, IDA diagnosis, GI diagnosis. Data collected included haemoglobin, mean corpuscular volume, haematocrit, serum iron, ferritin, and phosphate measured within seven days pre-infusion and fourteen days post-infusion. Dosing followed standard weight-based protocols, and infusion-related adverse events were documented.

Twenty-five children received IV iron during the audit period. IBD accounted for 60% of cases, with the remainder having other identifiable GI conditions such as short bowel syndrome or intestinal failure. 100% (25/25) patients received Ferric carboxymaltose. No acute infusion-related reactions occurred. Twelve patients (48%) had phosphate measured pre-infusion, eight (32%) post-infusion, and seven (28%) at both time points. All of these blood tests had been checked for reasons other than phosphate monitoring related to ferric carboxymaltose administration. Mean haemoglobin increased by 15 g/L, while mean phosphate decreased by 0.05 mmol/L. One child developed mild hypophosphataemia (0.84 mmol/L) requiring IV phosphate replacement. A further child developed moderate hypophosphataemia (0.6 mmol/L) requiring oral phosphate replacement; a pre-infusion phosphate was unavailable resulting in an inability to assess causality.

Ferric carboxymaltose was effective and appeared well tolerated for the treatment of IDA in children with GI disorders. However, phosphate monitoring was inconsistent and often not aligned with MHRA or published paediatric guidance. Action points arising from this audit include: improving staff education and awareness of the potential side effects of IV iron administration, creation of a standardised electrolyte monitoring protocol for ferric carboxymaltose to improve safety and consistency of patient care. International collaboration work is ongoing with another tertiary paediatric GI centre as this other centre primarily uses Iron Sucrose as first line treatment for paediatric patients with GI disorders. This collaborative project will explore differences in phosphate changes, treatment efficacy, and clinical outcomes for patients, ultimately informing optimal intravenous iron selection for this patient group.

References

1. Guagnozzi D, Severi C, Iezzi ML, et al. Iron deficiency anaemia in inflammatory bowel disease: pathogenesis, diagnosis, and treatment. Nutrients. 2021;13(1):238. Available from: https://pmc.ncbi.nlm.nih.gov/articles/PMC8760031/
2. Short MW, Domagalski JE. Iron deficiency anaemia: evaluation and management. *Am Fam Physician*. 2013;87(2):98–104. Available from: https://pmc.ncbi.nlm.nih.gov/articles/PMC6689119/
3. Vifor Pharma UK Limited. *Ferinject 50 mg iron/mL dispersion for injection/infusion – Summary of Product Characteristics (SmPC)*. Electronic Medicines Compendium (emc). Last updated 19 Jan 2024 [cited 2025 Nov 03]. Available from: https://www.medicines.org.uk/emc/product/5910/smpc
4. Medicines and Healthcare products Regulatory Agency. Ferric carboxymaltose (Ferinject®): risk of symptomatic hypophosphataemia leading to osteomalacia and fractures. *Drug Saf Update*. 2020;13(8):2. Available from: https://www.gov.uk/drug-safety-update/ferric-carboxymaltose-ferinject-risk-of-symptomatic-hypophosphataemia-leading-to-osteomalacia-and-fractures
5. Kaur J, Castro D. Hypophosphatemia. [Updated 2024 Feb 12]. In: Treasure Island (FL): StatPearls Publishing; 2025 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK493172/

OC3

Integrating the biopsychosocial model in paediatric gastroenterology: A pilot clinic experience from a tertiary centre

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Paediatric gastroenterology often involves complex cases in which psychosocial factors significantly influence symptom expression, disease trajectory, and family functioning. Traditional models of care may inadvertently prioritise biological interventions, overlooking the psychosocial components that drive health-seeking behaviour, adherence, and wellbeing. The biopsychosocial (BPS) approach provides a framework for understanding and addressing the predisposing, precipitating, perpetuating, and protective factors contributing to illness (1,2). This pilot clinic was established in a tertiary paediatric gastroenterology service to operationalise this model within routine practice and evaluate its impact on patient management, family dynamics, and team understanding (3).

Over a six-month pilot period, ten dedicated BPS clinics were conducted within a tertiary paediatric gastroenterology unit. Each clinic consisted of one morning session, typically comprising four new 60-minute assessments or, for follow-up clinics, 30-minute review appointments. Inclusion criteria focused on complexity—specifically, children whose presentations involved significant psychosocial difficulties, family distress, diagnostic uncertainty, or difficulties engaging with medical recommendations. The clinical model was explicitly person-centred, grounded in the classical BPS framework. Assessments systematically explored the four Ps (predisposing, precipitating, perpetuating, and protective factors). The consultation structure integrated elements of mental-health formulation, behavioural management, and trauma-informed care. All cases were referred by consultant gastroenterologists because of their recognised complexity.

Overall, twelve children and their families were seen. Qualitative outcomes indicated improvements in clinical management, family engagement, and diagnostic clarity. Representative findings included: enhanced diagnostic accuracy—a young person initially thought to have refractory rumination syndrome was identified as having an underlying psychiatric disorder, leading to appropriate mental-health referral; improved family understanding and trust—a family convinced of undiagnosed Crohn's disease accepted the absence of organic pathology following supportive psychoeducation; reduction in parental distress—targeted de-escalation and containment strategies alleviated anxiety in a parent with high health anxiety; improved emotional wellbeing—a child with inflammatory bowel disease (IBD) and low mood showed marked emotional improvement after coordinated psychological input through the BPS clinic; better symptom outcomes—a patient with dysmotility experienced improved physical outcomes once psychosocial stressors were identified and addressed; and enhanced treatment adherence—a child refusing nasogastric feeding accepted tube placement after a brief behavioural intervention using mindful-breathing techniques. Referring clinicians reported that the clinic clarified diagnostic uncertainty, improved adherence, and reduced repeated contacts and crisis presentations.

This pilot demonstrates that embedding a structured biopsychosocial framework within paediatric gastroenterology practice is feasible and effective. The BPS clinic provided a psychologically informed space for exploring meaning, emotion, and context—elements often overshadowed by biological management. The observed outcomes suggest that incorporating psychosocial assessment and intervention alongside medical care can meaningfully improve engagement, treatment adherence, and family wellbeing. This experience highlights the importance of training paediatric teams in biopsychosocial formulation and the value of dedicated clinical time to address these dimensions of care.

References

1. Borrell-Carrio F, Suchman AL, Epstein RM. The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *Ann Fam Med* 2004; 2(6): 576–82.
2. Van Oudenhove L, Levy RL, Crowell MD, Drossman DA, Halpert AD, Keefer L, et al. Biopsychosocial aspects of functional gastrointestinal disorders: how central and environmental processes contribute to the development and expression of FGIDs. *Gastroenterology* 2016; 150(6): 1355–67.
3. Keefer L, Palsson OS, Pandolfino JE. Best practice update: incorporating psychogastroenterology into management of digestive disorders. *Gastroenterology* 2018; 154(5): 1249–57.

OC4

A systematic review of the effects of probiotics on the treatment of childhood diarrhoea in low-income and lower-middle-income countries.

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Diarrhoea remains an important cause of morbidity and mortality among children, and the bulk of diarrhoeal deaths occur in low- and middle-income countries.[1,2] Dysbiosis has been linked with the occurrence and increased duration of diarrhoea, and evidence suggests that probiotics can help reduce the duration and severity of diarrhoeal illnesses.[3,4] A systematic review was conducted, following the PRISMA guidelines, to evaluate the effects of probiotics on the treatment of childhood diarrhoea in low-income and lower-middle-income countries.

Databases (PubMed, Scopus, Web of Science, EMBASE, CENTRAL and Google Scholar) were searched in November 2024, using search terms including “probiotic”, “diarrhoea”, and “children”. Randomised controlled trials (RCTs) conducted in low-income and lower-middle-income countries which compared specific probiotics with 'no probiotic or a placebo' for the treatment of diarrhoea in children aged five years and below were included. Studies focusing on antibiotic-associated diarrhoea, synbiotics or the prophylactic use of probiotics for the prevention of diarrhoea were excluded. The methodological quality of the included studies was evaluated using the Joanna Briggs Institute (JBI) critical appraisal tool for RCTs.[5] A narrative synthesis approach was employed to summarise the findings of the studies.

A total of 4,528 titles and abstracts were screened, and 33 studies that met the inclusion criteria were included in the review. The PRISMA flow diagram of the study selection process is shown in Figure 1. Thirty-two of the studies focused on acute watery diarrhoea (three were specific for rotavirus aetiology), while one study involved children with persistent diarrhoea. The duration of probiotic therapy was 2 to 10 days, with 5 days being the most frequent. Twenty-five of the studies reported a significant reduction in the duration of diarrhoea with probiotic treatment, while seven found no significant beneficial effect. Probiotics reduced diarrhoea duration by a mean period of 1 day. Of the 21 studies that assessed the effect of probiotics on stool frequency, 16 reported a significant reduction in daily stool frequency with probiotic treatment. In most studies, the beneficial effects were particularly prominent on days 3 - 4 of probiotic therapy. *Saccharomyces boulardii* was the most frequently used probiotic, followed by *Lactobacillus rhamnosus*. Fifteen studies were rated as having a low risk for bias, 12 had a moderate risk, and 6 had a high risk for bias.

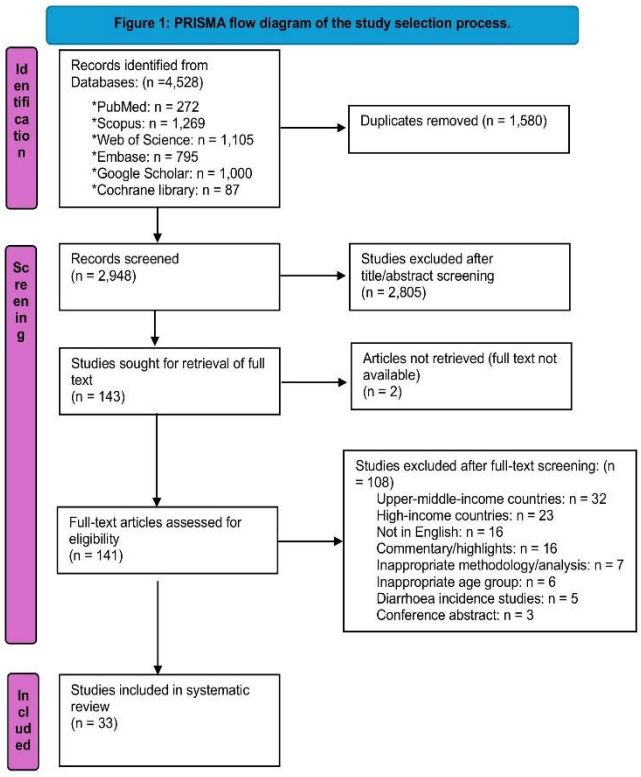

Figure 1: PRISMA flow diagram of the study selection process for the systematic review.

The study showed that probiotics are effective in reducing the duration of diarrhoea and may also decrease stool frequency in children living in low-income and lower-middle-income countries, thereby potentially reducing diarrhoeal deaths. Variability in exclusion criteria across the included studies poses a limitation, as this could have affected the baseline severity of diarrhoea and consequently, the observed response to probiotics. Hence, sensitivity analysis and subgroup effects may be considered in future studies to assess the robustness of these findings.

References

1. Reiner RC, Wiens KE, Deshpande A, *et al*. Mapping geographical inequalities in childhood diarrhoeal morbidity and mortality in low-income and middle-income countries, 2000-17: Analysis for the Global Burden of Disease Study 2017. Lancet 2020; 395: 1779–801.
2. Troeger C, Forouzanfar M, Rao PC, *et al*. Estimates of global, regional, and national morbidity, mortality, and aetiologies of diarrhoeal diseases: a systematic analysis for the Global Burden of Disease Study 2015. Lancet Infect Dis 2017; 17: 909–948.
3. Applegate JA, Fischer-Walker CL, Ambikapathi R, *et al*. Systematic review of probiotics for the treatment of community-acquired acute diarrhea in children. BMC Public Health 2013; 13 (Suppl 3): S16.
4. De Vrese M, Marteau PR. Probiotics and prebiotics: Effects on diarrhea. J Nutr 2007; 137: 803–11.
5. Barker TH, Stone JC, Sears K, *et al*. The revised JBI critical appraisal tool for the assessment of risk of bias for randomized controlled trials. JBI Evidence Synthesis 2023; 21: 494-506.

OC5

Mind the Gap: The ever-widening chasm between UK IBD standards of care and UK Paediatric IBD service provision.

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The IBDUK Standards, published in 2019[1], define the key parameters for delivering high-quality healthcare for IBD patients. Lengthy delays in recognising, diagnosing and instigating treatment for children and young people with suspected IBD not only results in a deterioration in physical health at initial presentation but also increased psychological distress due to prolonged uncertainty. With an ever-rising paediatric IBD incidence and significant post-pandemic operational delivery challenges, getting it right first time for children and young people with suspected IBD has never been more crucial.

In 2023 IBDUK designed and distributed surveys[2] to patients and their families as well as all UK Paediatric IBD services, with the aim to benchmark current UK Paediatric IBD care to the 2019 standards. Tabulations assessed the proportion survey responses to each standard question and categorical outcomes were compared using frequencies (%) and Chi -square test.

In 2023 the UK had 6786 Paediatric IBD patients, of which 651 patients (9.6%) responded. Twenty-six tertiary IBD services, with a mean of 260 IBD patients per centre and 76 new IBD patients annually, provided feedback. The mean diagnostic age was 12.4 years with IBD classification of 60% Crohn's Disease, 32% Ulcerative Colitis and 8% IBDU. Service governance was adequate in most units. 92.3% of services had a named IBD lead consultant but only 65.4% had a formally established IBD leadership team. Locally agreed policies and protocols were established for steroids (70.9%), immunomodulators and biologics (95.9%) and shared care immunomodulator monitoring (75%). The mean whole time equivalent (WTE) workforce in the core Paediatric IBD MDT is demonstrated in ***Figure 1***.

Only 50% of patients with suspected IBD had an initial clinic appointment within the 4-week target. Diagnostic endoscopic evaluation was performed within the 4 weeks in just 54.2% patients and merely 8.3% of histopathology reports were available to IBD clinicians within 5 working days. Completing phenotypic classification with small bowel imaging within 4 weeks, thus allowing risk stratification to optimise upfront treatment, was achieved in only 16% of patients. The majority of new IBD patients, 70.2%, wait up to 3 months for completion small bowel imaging. However, 100% of patients started treatment within 1 week of confirmed IBD diagnosis. Of those with an established IBD diagnosis, 46% reported to have had an IBD flare in the last 12 months. Most patients (74%) received a response with a flare action plan within the 48-hour target, yet 25% are waiting more than one week to start treating a flare.

The Paediatric IBDUK data reflects that most services are failing to meet key diagnostic and treatment targets, with many clinicians locally evidencing that in the intervening time since the survey the chasm has further grown. It remains a call to all UK Paediatric IBD centres to advocate at a national level for increased investment to improve resources and thus rapid access to diagnosis and treatment if we are to shape a better future for our vulnerable patients.

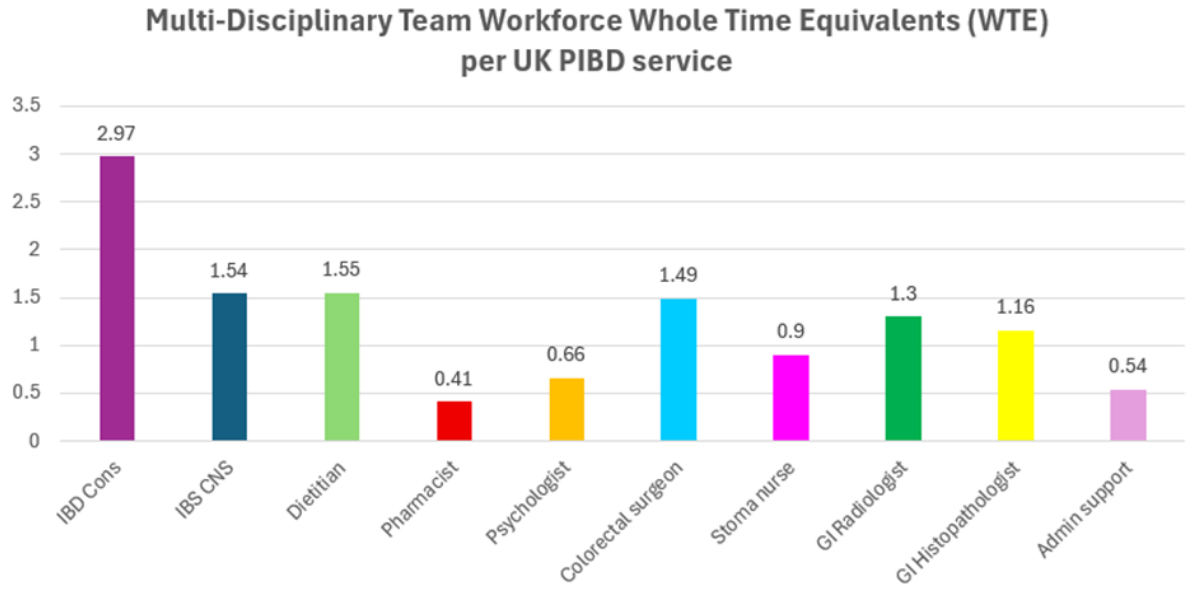

Figure 1: *Multi-Disciplinary Team Workforce Whole Time Equivalents (WTE) per UK PIBD service.*

References

1. IBD UK Standards 2019. Published online at https://s3.eu-west-2.amazonaws.com/sr-crohns-craft/documents/IBD-Standards-Core-Statements.pdf
2. IBD UK report 2024. Published online at https://s3.eu-west-2.amazonaws.com/sr-crohns-craft/documents/IBD-UK-National-Report_7OCT_v9_WITH-HYPERLINKS_compressed.pdf

OC6

Evolving Therapies in Eosinophilic Esophagitis: A Systematic Review and Meta-Analysis of Budesonide and Dupilumab

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Eosinophilic esophagitis (EoE) is a chronic, immune-mediated esophageal condition affecting approximately 34.2 per 100,000 individuals [1]. With increasing clinical recognition, therapeutic approaches have evolved from proton pump inhibitors (PPIs) to topical corticosteroids, and more recently, to biologic agents. Budesonide remains a widely adopted corticosteroid treatment, while dupilumab, a monoclonal antibody targeting interleukin-4 (IL-4) and interleukin-13 (IL-13) pathways [2], has emerged as a promising alternative. However, minimal comparative evidence exists between these two therapies, reinforcing the need for a quantitative synthesis to inform clinical practice and guide future treatment decisions.

A systematic review and meta-analysis was conducted to evaluate and indirectly compare the efficacy of budesonide and dupilumab versus placebo in achieving histological remission in EoE. A comprehensive search of PubMed, Scopus, and the Cochrane Library identified 3,949 records, screened in accordance with PRISMA guidelines. Screening was assisted using Rayyan.AI. Randomised controlled trials (RCTs) published in the last ten years in human subjects were included. The primary outcome was histological remission, as defined by each study. Pooled risk ratios (RRs) and 95% confidence intervals (CIs) were calculated using a random-effects model in R (version 4.5.0) via RStudio. Forest plots were generated to visualise treatment effects, and funnel plots assessed publication bias and small-study effects.

Nine RCTs evaluating budesonide (n = 945) produced a pooled RR of 31.41 [95% CI: 16.13–61.15], demonstrating a substantial benefit over placebo with no observed heterogeneity ($I^2 = 0\%$). Forest plots showed consistent effects across studies. Egger's test for funnel plot asymmetry showed no evidence of small-study effects or publication bias ($p = 0.22$), and visual inspection showed no asymmetry. These findings suggest a low risk of publication bias in the budesonide literature.

Three RCTs assessed dupilumab (n = 199), yielding a pooled RR of 16.31 [95% CI: 5.77–46.09], also indicating strong efficacy with minimal heterogeneity ($I^2 = 0\%$). A funnel plot was generated for dupilumab, though its interpretation was limited due to the smaller number of studies, highlighting the need for further investigation and broader trial data.

Both budesonide and dupilumab significantly outperform placebo in achieving histological remission in EoE. Budesonide remains a consistent and effective therapy, supported by robust and reproducible evidence across multiple trials. Dupilumab presents a promising alternative, particularly for patients with corticosteroid-refractory or intolerant disease. This review provides a timely and methodologically rigorous synthesis of current evidence and contributes to the evolving landscape of EoE management. As new therapies emerge, evidence-based comparisons such as this play a vital role in refining treatment algorithms and improving patient outcomes. Further studies will be essential to clarify the long-term positioning of dupilumab in routine clinical care.

References

1. **Baldovich K.** Increasing incidence rates of eosinophilic esophagitis in active component service members, U.S. Armed Forces, 2009–2021 [Internet]. Military Health System. 2023 [cited 2025 Apr 23]. Available from: https://www.health.mil/News/Articles/2023/05/01/Eosinophilic-Esophagitis
2. **D'Ippolito D, Pisano M.** Dupilumab (Dupixent): an interleukin-4 receptor antagonist for atopic dermatitis. *Pharm Ther*. 2018 Sep;43(9):532. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6110636/

OC7

It's what's on the Inside that counts – Body Composition in Children with Intestinal Failure

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Before the 1960's children with intestinal failure (IF) did not survive. The landmark creation of parenteral nutrition (PN) and further advancements in clinical practice has now made survival a common phenomenon. Regrettably, other complications have emerged including metabolic bone disease, increase fat mass and lower muscle mass compared to healthy children.

The aim of this study was to compare body composition (BC) between children on PN and those weaned off PN in a single tertiary IF centre.

Children attending the IF clinic aged 5-16 years had their BC analysed using the Tanita MC-780MA-N Pro body composition scales. The scale measured the percentages of body fat (BF), muscle mass, skeletal muscle mass, body water and bone mass using sarcopenic index (SI).

21 children had their BC analysed, 10 were on PN (7 males) and 11 off PN (9 males). The median age of those on PN was 11.8 years [IQR 9.4 and 14.8] and 14.4 years [IQR 12.6-15.4] for those off PN. All 11 patients that had come off PN had short bowel syndrome (SBS) and of those still on PN, 6/10 had SBS, 2/10 dysmotility and 2/10, enteropathy.

Those on PN received a median of 64% [IQR 39.7-81.8] of their estimated average requirement (EAR) from PN, had a median BMI of 15.6kg/m2 [IQR 15-16.3], z score for weight of -0.89 [IQR -1.65 to -0.14] and z score for height -0.61 [IQR -1.87-0.26]. Those off PN had a median BMI of 16kg/m2 [IQR 14.2-17.3], z score for weight -1.58 [IQR-2.47 - 0.05] and z score for height -0.72 [IQR -1.60 - -0.05]

1. Body composition of those on and off PN and those on < 80% PN vs. < 80% PN or off PN

Median	**On PN**	**Off PN**	**p value**
% BF	18.8 [IQR 15.4-24.5]	14.1 [IQR 12.1-17.4]	**0.057**
% muscle mass	76.8 [IQR 71.3 – 80.1]	81 [IQR 78.4-83.2]	**0.062**
% skeletal muscle mass	46 [IQR 42.7-47.9]	48.6 [IQR 46.7-49.7]	**0.057**
Bone mass (SI)	4.76 [IQR 4.13-5.55]	5.41 [IQR 4.5-5.54]	**0.457**
Mean	**> 80% PN (n-2)**	**< 80% PN or Off PN (n=19)**	
Bone mass (SI)	3.83 (SD 0.38)	5.13 (SD 0.71)	**0.034**
% body water	56% (SD 1.48)	62.4 % (SD 3.77)	**0.037**

Children that came off PN had less body fat, increased muscle mass, and increased bone density compared to children still on PN. Those that were off PN or < 80% PN had statistically significant better bone density and hydration compared to those on >80% PN.

Children who achieve enteral autonomy have healthier body composition compared those still on PN. Benefits can be seen in bone mass and hydration in those that require less than 80% of PN indicating that even if total enteral autonomy can't be achieved, less PN equals greater benefit for hydration and bone mass.

OC8

22 Years of Scottish Home Parenteral Nutrition – Improved Transplant Free Survival, Rising Prevalence, and now a wave of transition

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The prevalence of paediatric home parenteral nutrition (HPN) has been rising over the last two decades in the UK. The relative contribution of increased survival or incidence is unclear. UK Longitudinal survey of HPN outcomes have incomplete ascertainment. We present over 20 years of Scottish HPN data. Including incidence, point prevalence, demographic trends and outcomes of HPN patients within Scotland from 2003-2025, examining data from all 3 Scottish regions (representing 7.1% of UK population <16yr). (1,2)

Point prevalence (31st October annually) and incidence rates of HPN for 2003-2025 were evaluated. Demographics included age, diagnosis (short bowel syndrome [SBS], Neuromuscular [NM]; mucosal). Outcomes were defined as: still on PN; weaned off PN; transplanted, death; transitioned to adult service; lost to follow up. Two-year transplant-free survival (excluding deaths not attributable to IF/HPN) was also calculated (3). Patients were divided by epoch of first HPN episode; 2002-2008, 2009-2014, 2015-2019 and 2020-2025. Statistical analysis was performed using t test, Mann=Whitney test and Poisson regression where appropriate.

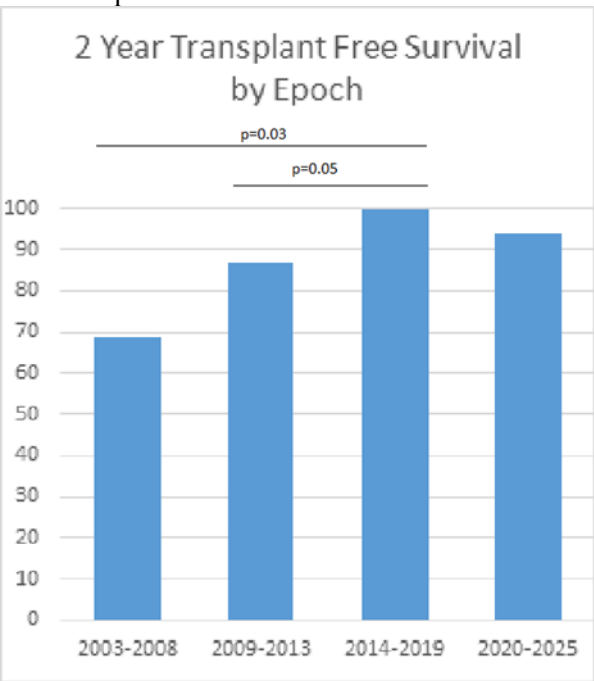
91 cases (57% female) received 106 HPN episodes with 119,976 total HPN days. Median age at first HPN episode was 1.47 years (range 0.25-16.08 years). Distribution of aetiologies were 58% SBS, 25% NM and 17% Mucosal. In the fourth epoch there was a large increase the proportion of NM (47%) having previously been 17%-18%.

Median time on HPN was 608 days (range 8-6790 days). Most recent point prevalence was 16.7/1,000,000 Scottish population under 16 years. Median point prevalence had been rising from epoch to epoch but has stabilised in the fourth epoch at 20.7/1,000,000. Yearly incidence rates ranged from 0.01-0.11/1,000,000/year. Median incidence rates across epochs is at a study low in the most recent epoch at 0.03/1,000,000 (0.03-0.06/1,000,000)

At study end, 24 (26%) were on PN at last review, 43 (47%) weaned, 19 (20%) died, 4 (4%) transitioned to adult services on PN, and 1 (1%) patient transferred outside Scotland. In first 22 years of study 4 patients transitioned on PN, we identify 8 patients approaching transition in next 2 years (0.2 per year vs 4 per year, $p<0.001$)). Extrapolating this data across the United Kingdom would equate to ≠ 110 young people on HPN approaching transition to adult services.

2-year transplant free survival of HPN significantly improved from the two earliest epochs to the third (69% and 87% to 100% ($p=0.02$ and 0.05 respectively). There was a non-significant reduction in transplant free survival from third to fourth epochs (100% to 94%, $p=0.34$).

We report the first longitudinal national survey of outcomes for >20yrs data for HPN in the UK with complete ascertainment and outcomes for cases. Our data shows that incidence is stable and prevalence had been rising. Rising prevalence is a reflection of improved survival rates for patients and our most recent data compare favourably with international centres of excellence (3). Development of improved transitional services is now a priority for Scottish HPN services and HPN services across the UK over the next epoch.



References

1. https://www.nrscotland.gov.uk/publications/population-estimates-time-series-data/ (accessed 3/11/2025)
2. https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2024#age-structure-of-the-population (accessed 3/11/2025)
3. Abi Nader E, Lambe C, Talbotec C, et al. Outcome of home parenteral nutrition in 251 children over a 14-y period: report of a single center. *Am J Clin Nutr*. 2016;103(5):1327-1336. doi:10.3945/ajcn.115.121756

OC9

Carnitine status in children on long term parenteral nutrition - A retrospective study at a Tertiary Centre

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Carnitine is an amino acid derivative synthesized endogenously from methionine and lysine. It is also obtained from dietary sources like meat and dairy products and absorbed in the small intestine.[1] Its principal function is to transport long-chain fatty acids across the mitochondrial membrane, facilitating their β-oxidation to produce energy. This energy is critical for organs with high metabolic demands such as the heart and skeletal muscles, especially during exercise or fasting.
Patients with metabolic disorders, renal or liver insufficiency, intestinal failure patients dependent on long-term parenteral nutrition (PN), neonates, and children on antiepileptic medications are at risk of deficiency.[2] Clinical manifestations are hypoglycaemia, fatigue, muscle weakness, and cardiomyopathy.[3] Importantly, standard PN formulations typically lack carnitine unless it is specifically supplemented.
This study aimed to evaluate the prevalence of carnitine deficiency in paediatric patients receiving long-term PN and to assess the association between carnitine status and enteral feeding tolerance.
We conducted a retrospective review of 36 children receiving PN for six months between 2021 and 2025. Patient data included demographics, PN duration, enteral feeding status, underlying diagnoses, carnitine serum levels, and supplementation. Carnitine deficiency was categorized as mild (15–24 μmol/L), moderate (5–14 μmol/L), or severe (<5 μmol/L).[4]

The cohort had a median age of 10.2 years (range 1.11–17.11 years) and a median PN duration of 7 years (range 6 months to 18 years). Underlying conditions included intestinal motility disorders (47%), short bowel syndrome (SBS, 39%), tufting enteropathy (6%), lipid metabolism disorder, tyrosinemia, and dystonic cerebral palsy (3% each).
Carnitine deficiency was identified in 27 patients (75%). Among these, 48% had intestinal motility disorders, 37% had SBS. Additionally, 2 patients (6%) were diagnosed with tufting enteropathy, 1 (3%) with a lipid metabolism disorder, 1 (3%) with tyrosinemia, and 1 (3%) with dystonic cerebral palsy. Nine patients (25%) had normal carnitine levels despite long-term PN exposure (mean duration ~6 years). Of these, five had SBS, and four had motility disorders. The mean duration of PN was similar in carnitine-deficient patients (6.0 ± 4.2 years) and those with normal levels (6.0 ± 5.6 years), with no significant difference ($p = 0.99$). Only three patients had received carnitine supplementation.
Regarding feeding modality, 22 patients were on combined PN and enteral nutrition, while 14 patients received exclusive PN. Carnitine deficiency was significantly more prevalent in the exclusive PN group, with all 14 patients (100%) deficient compared to 13 out of 22 (59%) in the combined feeding group ($p = 0.002$).

Carnitine deficiency is common among children on long-term PN, particularly in those unable to tolerate enteral feeds. The absence of dietary intake likely exacerbates carnitine depletion, as endogenous synthesis alone may be insufficient to meet metabolic demands. Routine monitoring of serum carnitine levels every three months, along with the incorporation of carnitine supplementation in parenteral nutrition formulations for patients receiving long-term PN with limited or no enteral intake, is recommended. Further prospective studies are needed to establish guidelines for supplementation and to evaluate its impact on clinical outcomes.

References

1. Crill CM, Helms RA. The use of carnitine in paediatric nutrition. Nutrition in Clinical Practice. 2007 Apr;22(2):204-13.
2. Winther B, Jackson D, Mulroy C, MacKay M. Evaluation of serum carnitine levels for paediatric patients receiving carnitine-free and carnitine-supplemented parenteral nutrition. Hospital pharmacy. 2014 Jun;49(6):549-53.
3. Dhanusha K, Elavarasi E, Vasanth Kumar M, Srinivasan R. Understanding causes, symptoms, and treatment options of carnitine deficiency. Journal of Pharma Insights and Research. 2024 Apr 9;2(2):104-9.
4. Longo N, Amat di San Filippo C, Pasquali M. Primary carnitine deficiency. In: Adam MP, Feldman J, Mirzaa GM, et al., editors. *GeneReviews® [Internet]*. Seattle (WA): University of Washington, Seattle; 1993–2022. Available from: https://www.ncbi.nlm.nih.gov/books/NBK84551/

OC10

Yield of Expanded Diagnostic Evaluation in Children with Clinically-Diagnosed Rumination Syndrome

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Rumination syndrome is a functional disorder characterised by effortless regurgitation of recently ingested food from the stomach to oral cavity. Diagnosis is clinical, based on Rome IV criteria, with high-resolution oesophageal impedance manometry (HRM) often performed in cases of diagnostic uncertainty. Although imaging is not routinely indicated in the absence of diagnostic uncertainty, expanded diagnostic evaluations remain common to exclude organic pathology. This study aimed to assess the diagnostic yield of expanded diagnostic evaluations among paediatric patients with clinically diagnosed rumination syndrome at a regional UK paediatric gastroenterology centre.

We conducted a retrospective chart review of 40 children with clinically diagnosed rumination syndrome and had further diagnostic investigations between March 2019 and October 2024. All included children met Rome IV criteria for rumination syndrome and underwent HRM ± additional investigations. Data extracted from electronic medical records included demographic information, medical history, and findings of any of the following investigations: HRM, pH impedance test, oesophagogastroduodenoscopy (OGD), contrast study, gastric emptying scan, and abdominal ultrasound. Descriptive statistics summarised the distribution and diagnostic yield of these studies. This project was deemed exempt from ethics review and categorised as an audit of clinical practice.

Across the 40-patient cohort, the mean age was 11.05 years (SD 3.67) and 55% were female. Each child underwent an average of 3 investigations. Following HRM, the most frequently performed study was OGD ± biopsy (78%), then contrast study (55%), pH impedance study (40%), abdominal ultrasound (18%), and gastric emptying scan (5%). HRM identified rumination syndrome in only 40% of patients. Of the remaining 60% with non-diagnostic HRM, further investigations were normal or nonspecific in 91% of cases and 9% had findings consistent with gastro oesophageal reflux disease (GORD). pH impedance testing identified GORD in each of these cases. There was 1 case in which both rumination and GORD were diagnosed through the expanded evaluation. No alternative diagnoses were identified by OGD, biopsies, contrast studies, abdominal ultrasound, or gastric emptying scans.

Our clinical data demonstrates that among children meeting clinical criteria for rumination syndrome, the diagnostic yield of additional investigation is limited. There may be few cases in which an expanded evaluation identifies GORD as an alternative or concurrent diagnosis, based on interpreting HRM and pH impedance findings together. However, the large predominance of normal or nonspecific findings may inadvertently increase diagnostic uncertainty, patient burden, and healthcare utilisation while delaying treatment. Clinicians should therefore carefully consider their suspicion for organic pathology before expanding their diagnostic evaluation. In the case of initial diagnostic uncertainty, HRM and pH impedance testing are likely to have the greatest diagnostic yield in these patients, and should therefore be prioritised. Further prospective and large sample studies are warranted to refine diagnostic pathways for rumination syndrome in children.

OC11

Seronegative Coeliac Disease: A 5-year single centre retrospective review

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Seronegative coeliac disease (SNCD) is a rare condition and there are no agreed published paediatric criteria for diagnosis.

Our study aimed to evaluate whether the diagnostic and management pathway for SNCD in our centre aligned with current best practice standards.

Retrospective case notes review of children diagnosed with coeliac disease over a 5 year period (July 2019–July 2024) was undertaken and those diagnosed with SNCD identified. Data were extracted from electronic records including demographic information, laboratory results, endoscopy and histology reports and entered into Excel database. A comprehensive literature search, supported by the Illingworth Library, was undertaken to identify diagnostic criteria for SNCD. Parameters for data collection were defined based on the findings of the literature review and descriptive statistical analysis was performed.

According to adult literature, diagnostic criteria for SNCD typically include, Exclusion of IgA deficiency and other causes of enteropathy

1. Negative IgA tTG and IgA EMA
2. Duodenal histology consistent with coeliac enteropathy
3. Presence of HLA-DQ2 or HLA-DQ8 haplotypes
4. Clinical and histological improvement following a GFD, with resolution of enteropathy on repeat endoscopy at one year

337 children were diagnosed with coeliac disease during the study period. Of these, 10 were identified as SNCD (2.96%), consistent with the published frequency of 1.7–5%. None were IgA deficient. One had a positive family history of SNCD, and one had dermatitis herpetiformis. No sex predilection was observed.

The median age at diagnosis was 7.5 years (range 15 months–14 years).

Endoscopic macroscopic findings were documented in all, and 6 had scalloping noted in the duodenum. Histological examination revealed villous atrophy in all patients. Three children underwent repeat endoscopy following a GFD and all demonstrated mucosal healing. Although repeat endoscopy was routinely offered, most families declined, as clinical improvement was observed on GFD.
Clinical symptoms in our cohort mirrored those typically seen in coeliac disease.

When comparing against the adult criteria:
· All children fulfilled criteria such as - IgA deficiency ruled out, IgA tTG neg, IgA EMA neg, Positive histology.
· 70% did not undergo repeat endoscopy.
· HLA typing was not performed in 6 out of 10 cases.

Number	Marsh grading D1	Marsh Grading D3	Symptomatology before diagnosis
1	3a	3a	Family h/o SNCD, Symptomatic on Gluten diet
2	3c	3b	Significant reflux and previous h/o of h/pylori
3	3b	3b	Reflux and improvement on GF diet
4	3c	3c	Reflux and dysphagia
5	3c	Normal	Food refusal and abdominal pain
6	Normal	3a	reflux, vomiting, abdominal pain, poor weight gain
7	3b	1	Abdominal pain and vomiting
8	3b	3b	nausea and vomiting, weight loss
9	3a	Normal	Bloating, intermittent abdominal pain
10	3a	3a	reflux, poor weight gain, lethargy

The frequency of SNCD in our cohort aligns with published literature. This study highlights the absence of agreed paediatric diagnostic criteria for SNCD, leading to variability in clinical practice. This is an important gap that needs addressing and paediatric best practice consensus criteria for diagnosing SNCD are required to guide optimal management.

References

1. Zanini B, Magni A, Caselani F, et al. Diagnosis of seronegative and ultrashort celiac disease. *Gastroenterology*. 2024;167(1):104–115.
2. Aziz I, Evans KE, Hadjivassiliou M. Evaluation and management of seronegative enteropathies. *Gastroenterology*. 2021;160(2):437–444.
3. Cárdenas-Rodríguez N, Donat E, Ribes-Koninckx C. Seronegative coeliac disease: clearing the diagnostic dilemma. *Curr Opin Gastroenterol*. 2018;34(3):154–158.
4. Biagi F, Marchese A, Trotta L, et al. Clinical classification and long-term outcomes of seronegative coeliac disease: a 20-year multicenter follow-up study. *Aliment Pharmacol Ther*. 2021;54(10):1278–1289. doi:10.1111/apt.16599.
5. Singh P, Arora S, Lal SB, et al. Clinical features of children with serology negative, biopsy positive celiac disease. *J Pediatr Gastroenterol Nutr*. 2023;77(2):240–243.
6. Sadeghi A, Ebrahimi Daryani N, Asadzadeh Aghdaei H, et al. Clinical profile of patients with seronegative celiac disease. *Gastroenterol Hepatol Bed Bench*. 2023;16(2):203–209.
7. Oliveira R, De Castro L, Brandão A, et al. Seronegative celiac disease in Brazilian patients: a series of cases. *Arq Gastroenterol*. 2021;58(2):214–216.
8. Schiepatti A, Sanders DS, Baiardi P,. Nomenclature and diagnosis of seronegative coeliac disease and chronic non-coeliac enteropathies in adults: the Paris consensus. Gut. 2022 Nov;71(11):2218-2225. doi: 10.1136/gutjnl-2021-326645. Epub 2022 Jun 8. PMID: 35676085; PMCID: PMC9554081.

OC12

The MIRACLS Study: longitudinal profiling of the gut microbiome in children with short bowel syndrome undergoing intestinal rehabilitation

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Children with intestinal failure (IF) due to short bowel syndrome (SBS) depend on parenteral nutrition (PN) until intestinal rehabilitation (IR) is achieved. The gut microbiome is increasingly recognised as having important roles in health and disease (1). Our previous systematic review demonstrated reduced gut microbial richness and diversity in children with IF due to SBS compared to healthy controls, independent of whether they had achieved IR. However, small sample sizes and mostly cross-sectional designs impacted the robustness of these results (2). The Gut Microbiota and Intestinal Rehabilitation: A prospective Childhood cohort Longitudinal study of Short bowel syndrome (MIRACLS) Study aimed to characterise temporal changes in the gut microbiome of children with SBS and identify clinical factors influencing its composition. A key objective was to determine whether microbial features differ between children who achieved IR and those who did not, and to explore the potential of the microbiome as a biomarker or modulator of IR. The MIRACLS study represents the largest single cohort study to date examining gut microbial changes leading up to and beyond IR in children with SBS. Full-length 16S rRNA gene sequencing was used to profile the gut microbiome, integrated with detailed serial clinical data. The final analysis included 108 stool samples from 18 children with SBS recruited from a major IF specialist centre, with a median (IQR) age of 2.9 years (0.46-6.6) at study entry. Among these, 32 samples were from seven children who achieved IR, and 76 samples were from 11 children who did not achieve IR during the study period. The median (IQR) number of samples per participant was 5.5 (2.8–8.0) over 434 days (214–680). The most abundant and prevalent genera in faecal samples from children with SBS were *Escherichia, Bifidobacterium, Veillonella, Enterococcus*, and *Lactobacillus.* Clinical covariates significantly associated with the gut microbiome include remnant small bowel length, antibiotic exposure, PN dependency (hours per week), type of enteral intake, prior receipt of breastmilk, intestinal failure-associated liver disease, and exposure to ursodeoxycholic acid. Longitudinal analysis revealed that microbial diversity increased across IR and with the introduction of solid food, but not with the timing of PN cessation. Notably, an analysis of faecal samples collected within six weeks before IR, compared to age-matched samples from children that did not achieve IR, showed that the IR group accounted for a significant proportion of total variance in microbiome composition. This suggests that distinct microbiome features may emerge at the pre-IR stage and could serve as indicators of IR. These findings advance understanding of clinical-microbiome interactions in SBS and set priorities for future larger cohorts. Such efforts should be facilitated through multi-centre collaboration, with mechanistic studies to establish causality, identify microbiome biomarkers, and ultimately identify therapeutic targets for IR.

References

1. Valdes, A. M., Walter, J., Segal, E., & Spector, T. D. (2018). Role of the gut microbiota in nutrition and health. *BMJ (Clinical research ed.)*, *361*, k2179.
2. Cleminson, J.S., Young, G.R., Campbell, D.I. *et al.* Gut microbiome in paediatric short bowel syndrome: a systematic review and sequencing re-analysis. *Pediatr Res* (2025)

OC13

Micronutrient levels in children with intestinal failure (IF) on treatment with longterm/Home Parenteral Nutrition (HPN)

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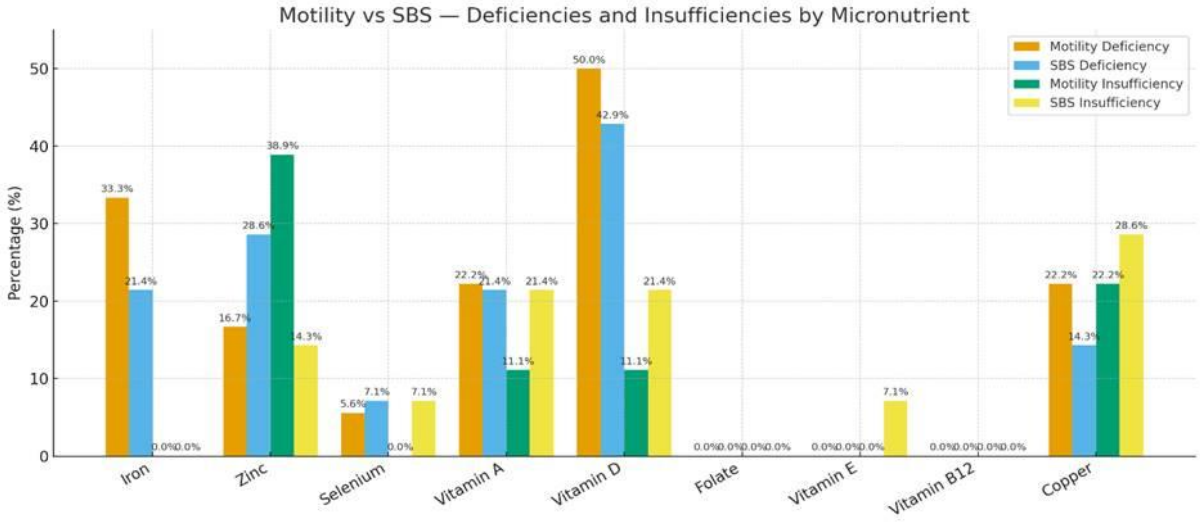
The aim of our study was to evaluate the prevalence of iron, folate trace element, and vitamin deficiencies in children with intestinal failure, (IF) on long-term Parenteral Nutrition at home (HPN) and see if there were any differences in deficient levels according to the underlying IF diagnosis. Patients were divided into those with short bowel syndrome (SBS), intestinal motility disorders, and enteropathies.

We collected data from our hospital's electronic records. We identified all children who were well established on HPN for at least 6 months prior to the study and remained on PN for the study period from September 2024 to September 2025. PN was prescribed and monitored according to 2018 ESPGHAN guidelines[1] We retrospectively reviewed the 34 children identified. Diagnoses were motility disorders (n = 18), SBS (n = 14), enteropathies (n = 2). All laboratory results for iron, zinc, selenium, copper, vitamins A, D, E, B12, and folate (taken when C-reactive protein, CRP normal) were obtained over the 12 month period and the mean values were calculated. Levels within 10% of the laboratory reference range were considered insufficient and >10% below deficient.

We found that 33/34 patients had results checked at least 4-6 monthly and one patient less often. 77/306, 25% mean levels were low over the 12-month period with 30 insufficient levels and 47 deficient levels. The most frequent low levels were vitamin D (11, 61% motility and 9, 61% SBS), zinc (10, 55% motility; 6, 43% SBS) copper (8, 44% motility; 6, 43% SBS), vitamin A (6, 33% motility; 6, 43% SBS) and iron (6, 33% mot; 3, 21% SBS). Folate, Vitamin B12 and vitamin E(apart from one child) were consistently within or above the normal range. There were no statistically significant differences between SBS and motility patient micronutrient levels. Please see figure below.

We conclude that current ESPGHAN recommendations for micronutrient level monitoring are appropriate for detecting deficient levels. Our results indicate that the current guidelines for adding vitamin E, selenium, vitamin B12 and folate to PN are adequate. The high frequency of low levels of zinc, copper, vitamin D and iron indicate that higher amounts may be needed in certain children, probably those with high intestinal losses.



Micronutrient	Motility Deficiency (%)	SBS Deficiency (%)	Motility Insufficiency (%)	SBS Insufficiency (%)
Iron	33.33% (6/18)	21.43% (3/14)	0.00% (0/18)	0.00% (0/14)
Zinc	16.67% (3/18)	28.57% (4/14)	38.89% (7/18)	14.29% (2/14)
Selenium	5.56% (1/18)	7.14% (1/14)	0.00% (0/18)	7.14% (1/14)
Vitamin A	22.22% (4/18)	21.43% (3/14)	11.11% (2/18)	21.43% (3/14)
Vitamin D	50.00% (9/18)	42.86% (6/14)	11.11% (2/18)	21.43% (3/14)
Folate	0.00% (0/18)	0.00% (0/14)	0.00% (0/18)	0.00% (0/14)
Vitamin E	0.00% (0/18)	0.00% (0/14)	0.00% (0/18)	7.14% (1/14)
Vitamin B12	0.00% (0/18)	0.00% (0/14)	0.00% (0/18)	0.00% (0/14)
Copper	22.22% (4/18)	14.29% (2/14)	22.22% (4/18)	28.57% (4/14)

References

1Domellöf M, Shamir R, Braegger C,et al. ESPGHAN/ESPEN/ESPR/CSPEN guidelines on pediatric parenteral nutrition: Iron and trace minerals Clin Nutr 2018;37:2354-9

OC14

Development of a tandem mass spectrometry method for measurement of plasma citrulline for use in the investigation and monitoring of short bowel syndrome

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Citrulline is an amino acid produced by enterocyte metabolism; thus, plasma concentrations may contribute to assessment of intestinal failure (IF) by reflecting enterocyte mass [1]. Citrulline measurement is routinely performed in a full amino acid profile which includes over 40 other analytes. It is expensive, labour-intensive and sample analysis takes over 2 hours. Other abnormalities may be identified, requiring follow-up investigations.

A stand-alone assay for plasma citrulline analysis would overcome these problems, enabling cost-effective investigation of children with IF and short bowel syndrome (SBS). This study reports a novel tandem mass spectrometry (MS/MS) method used to determine whether intestinal rehabilitation (IR) was associated with increased citrulline.

Infants and children with SBS associated with prematurity were recruited to MIRACLS (gut **m**icrobiota and **i**ntestinal **r**ehabilitation: **a** prospective **c**hildhood cohort **l**ongitudinal study of **s**hort bowel syndrome). The primary outcome measure was full IR, i.e. no parenteral nutrition and full enteral feeds for over 28 days. Blood samples taken for routine assays included plasma citrulline at baseline and on achievement of IR or after one year if still PN dependent.

Blood was taken into lithium-heparin tubes, centrifuged within one hour and plasma stored at -80°C until analysis. Plasma was mixed with ^{13}C-citrulline internal standard and centrifuged, the supernatant removed and dried down under nitrogen. Citrulline was butylated and reconstituted in mobile phase for analysis by flow injection mass spectrometry on a Shimadzu 8050 MS/MS system. Analytes were detected by multiple reaction monitoring using transitions *m/z* 232>119 (citrulline) and *m/z* 233>119 (internal standard) and quantitated with a calibration curve up to 100 µmol/L. Injection-to-injection time was 1.5 minutes. Plasma citrulline measured in samples taken at baseline and at study end were compared using a paired t-test in two groups: those who achieved IR and those who did not.

Eleven participants had citrulline measured at two timepoints so were included in this analysis. Age at recruitment was 3.3 years (0.1 – 11.5 years) [mean(range)], gestation at birth was 29 weeks (23 – 38 weeks) and four were female.

Seven patients did not achieve IR during the study, aged 4.9 (0.6 – 11.5) years. Baseline citrulline was 14.6 ± 6.9 µmol/L (mean ± standard deviation), not statistically different from results at study end, 14.7 ± 6.0 µmol/L, p=0.49. Four patients achieved IR aged 0.6 (0.1 – 1.4) years. Citrulline was 15.3 ± 1.4 µmol/L at baseline but increased to 31.1 ± 13.6 µmol/L at study end, p=0.03.

A MS/MS method for citrulline analysis was developed that was straightforward, fast, low-cost and avoided identification of non-specific abnormalities. A study in infants with SBS and IF found that achieving IR was associated with increased plasma citrulline. This is a small study from one centre, so further work is required to determine the role of citrulline as a biomarker in paediatric patients SBS and IF. However, this study confirms the suitability of analysis by MS/MS at low cost. It overcomes many of the challenges associated with wide-scale measurement of citrulline encountered in previous studies.

References

[1] Crenn P, Messing B, Cynober L. Citrulline as a biomarker of intestinal failure due to enterocyte mass reduction. Clin Nutr. 2008;27(3):328-39

OC15

Long-Term Evaluation of glucagon-like peptide-2, GLP-2 treatment in children with Short Bowel Syndrome–Associated Intestinal Failure (SBS-IF): Up to 10 Years Follow-Up

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Short bowel syndrome (SBS) is a malabsorptive condition that can be associated with intestinal failure (SBS-IF), and require long-term parenteral nutrition (PN). Prolonged PN is associated with serious complications, including liver dysfunction and catheter-related sepsis, and SBS is associated with growth impairment. Teduglutide, a glucagon-like peptide-2 (GLP-2) analogue, promotes intestinal adaptation and can reduce PN dependency. However, evidence from long-term real-world follow-up for >2 years in children is lacking.

We conducted a retrospective longitudinal review of Children with SBS-IF who had started treatment with GLP-2 analogue, *teduglutide* 7-10 years ago. Eight patients were identified. Three children were excluded, one with a duodeno-rectal anastomosis failed to respond and stopped treatment and two others had transitioned to adult care. Collected data from electronic patient records included SBS aetiology, residual small bowel length, presence/absence of ileo-caecal valve(ICV), anthropometry (weight, height, BMI z-scores), PN characteristics (weekly volume and nights per week), plasma citrulline concentrations.
Five patients (3 male, 2 female) remained under our long-term care and were reviewed after a mean treatment duration of 9 (range 8 -10) years. See Table below for clinical details:

Table: clinical details

patient	1	2	3	4	5
Age at onset of SBS	neonate	Premature twin neonate 29 weeks	neonate	neonate	neonate
aetiology	Intestinal aganglionosis	Necrotising enterocolitis	Congenital atresia	gastroschisis	Necrotising enterocolitis
Remaining length small intestine	53 cm	29 cm	18 cm	15 cm	8 cm
I-C valve	no	no	yes	no	no
Colon length	None; ileostomy	Rectum only	Full colon	Distal 2/3 colon	50% colon
other	Intestinal mucosa inflammation Alactasia food allergies	Anastomotic ulcer	-	-	Feeding difficulties
On/off PN	on	OFF	on	OFF	on

The mean weekly PN volume per kilogram decreased by 47%, with all patients achieving ≥20% reduction and two attaining full PN weaning. The mean number of PN nights per week decreased by 52% (−1 to −5 nights/week). Plasma citrulline levels remained stable over time (mean Δ +9 µmol/L in responders), within or above the paediatric reference range, indicating preserved mucosal function.

Weight-for-age z-scores (WAZ) showed a modest overall decline, more pronounced in patients with greater baseline PN dependence. Height-for-age z-scores (HAZ) remained between −1 and −4 SDS, indicating persistent, stable growth on lower centiles. Bone age was mildly to moderately delayed, in line with stature deficit, with partial catch-up in some patients.

The two patients who stopped PN have maintained enteral autonomy for 4 and 5 years. There were no unexpected adverse events.

In conclusion, GLP-2 treatment was associated with sustained long-term reduction in PN requirements and no new safety concerns for up to 10 years follow up.

OC16

Is metabolic testing indicated in the first-line investigation of paediatric fatty liver? A literature review, workload analysis and cost estimation following the publication of the BSPGHAN fatty liver guideline

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The Metabolic Biochemistry Network (MetBioNet) comprises 18 inherited metabolic disease (IMD) laboratories in the UK and Ireland, most based in tertiary paediatric centres. In 2021, MetBioNet stakeholders noted a marked increase in metabolic test requests for children with fatty liver disease, particularly free fatty acids (FFA), despite unclear diagnostic value. This increase appeared temporally associated with the publication of the 2020 British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) fatty liver guideline [1], which recommends a broad panel of metabolic tests, including FFA, as first-line investigations in all patients.

A literature review was conducted to evaluate the evidence supporting metabolic testing, including FFA measurement, in the investigation of paediatric fatty liver. Four regional metabolic centres reviewed 12 months of metabolic requests for fatty liver investigations, assessing workload, financial cost, and diagnostic yield. Paediatric hepatologists were consulted regarding local adherence to the BSPGHAN guideline and its perceived appropriateness.

Published literature highlights the importance of identifying treatable causes of fatty liver, including IMDs, hence the recommendations for metabolic testing [2] and advises a stepwise diagnostic approach: metabolic testing is appropriate as first-line in children under 3 years of age, but should be reserved as second-line in older patients when clinically indicated and, in children over 10 years, only following a trial of other interventions. No evidence supporting a role for FFA in the investigation of fatty liver was identified. Across the four centres, the most frequently requested tests in patients over 10 years of age were plasma amino acids, urine organic acids, bloodspot or plasma acylcarnitines and FFA; very long-chain fatty acids were also commonly requested, likely due to confusion with FFA. When extrapolated nationally, the estimated annual cost of IMD investigations in older children with fatty liver was £152,000, equivalent to approximately £700,000 since MetBioNet first raised concerns in 2021. No IMDs were diagnosed during the review period. The review also highlighted that a number of patients were re-bled for further investigations due to mildly abnormal results, which were attributed to dietary influences. Discussions with local hepatologists revealed variable practice: while some centres excluded FFA or deferred metabolic investigations, others adhered closely to the guideline despite recognising its limited utility.

The BSPGHAN fatty liver guideline is widely implemented across the UK, however, current evidence does not support routine first-line metabolic testing in all patients. Inclusion of FFA appears erroneous. Adopting an age-stratified, stepwise approach would reduce unnecessary testing, financial burden, and laboratory workload associated with the guideline. Specialist input from metabolic experts (Clinicians and Laboratory Scientists) should be incorporated into future guideline revisions, with mechanisms for timely updates when evidence or expert consensus identifies areas for improvement.

References

[1] British Society of Paediatric Gastroenterology Hepatology and Nutrition UK Fatty Liver Guideline (2020) https://bspghan.org.uk/wp-content/uploads/2020/08/LSG_UK-Fatty-Liver-Guideline-August-2020.pdf
[2] Vajro P, Lenta S, Socha P *et al*. Diagnosis of nonalcoholic fatty liver disease in children and adolescents: position paper of the ESPGHAN hepatology committee. JPGN 2012; 54: 700–713

OC17

Paediatric Hepatitis C Virus Treatment with Direct-Acting Antivirals: A Single-Centre Experience

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Direct-acting antivirals (DAAs) have transformed the management of Hepatitis C Virus (HCV) infection, offering highly effective, short-duration, and well-tolerated treatment options (1). This study evaluates the safety, efficacy, and treatment outcomes of DAAs in a paediatric population.

We conducted a retrospective analysis of 49 paediatric patients with chronic HCV infection treated at our centre between August 2017 and December 2024. Patient demographics, biochemical parameters, genotype (G) distribution, treatment regimens, and sustained virologic response at 12 weeks (SVR12) were analyzed.

Baseline investigations included liver function tests, full blood count, renal function, alpha-fetoprotein, abdominal ultrasound, Fibroscan, Liver biopsy when available, virology screening for Hepatitis B, Hepatitis A and Human Immunodeficiency Virus. HCV RNA (Ribonucleic acid) quantitative Polymerase chain reaction (PCR) monitoring occurred at weeks 4, 8, and/or 12 after starting DAA. The choice of DAA was guided by the Operational Delivery Network (ODN) set up in the United Kingdom for paediatric HCV infection. The results are summarised in Figure 1.

The treatment was genotype specific. G3 (n=22) and G2a(n=1) received 12 weeks of with Sofosbuvir/Velpatasvir (SOF/VEL) or 8 weeks of Glecaprevir/Pibrentasvir (GLE/PIB). G1a (n=17), G1b (n=3), combined G1a/1b (n=3), and G4 (n=3) received sofosbuvir/ledipasvir (SOF/LDV) for 8 or 12 weeks according to protocol. HCV was acquired as vertical transmission in 46 children (93.8%). None had HBV or HIV co-infection; four had past hepatitis A infection. Three patients were treatment-experienced before DAA, two with pegylated interferon/ribavirin (RBV) and one with telaprevir/RBV and were non-responders or discontinued due to adverse effects.

Two treatment-naïve patients (4.1%) developed primary resistance to SOF/LDV (one G1a, one G1b). Both achieved sustained virologic response after retreatment with alternative regimes—one with GLE/PIB and the other with extended SOF + GLE/PIB + RBV.

Overall, 47/49 patients (95.9%) achieved SVR12 after the primary course, and all after extended therapy or retreatment of the nonresponders with alternative regime. Children who reached 1-year post DAA (n=46), 43 maintained undetectable HCV RNA and results were not available in 3. No hepatic, renal, or haematological toxicity occurred.

DAA therapy was highly effective and well-tolerated in paediatric HCV patients. Resistance testing and access to multiple DAA regimens remain essential for optimizing outcomes in this population.

Table 1: Patient Demographics, Treatment Characteristics, and Outcomes for Paediatric HCV infection

Parameter			Median (range) / n ((%)		
Demographics					
Age at diagnosis (years)			6 (0.16-15.75)		
Age at treatment with Direct Acting Antivirals, years(range)			8.65 (4.51-17.04)		
Male			23 (46.9%)		
Fibroscan	liver stiffness(kPa) (n=44)	<7(n=36)	4.4 (2.5- 6.8)		
		>7(n=8)	8.55 (7.5 55.2)		
Monitoring bloods	Baseline, n=49	At 4 weeks, n=42	At 8 weeks, n=44	At 12 weeks, n=25	
ALT (IU/L) (median and range)	46 (15-143)	18.5(7-100)	16(8-43)	15(9-27)	
AST (IU/L)	41(23-129)	24(14-26)	24.5(14-46)	25(13-41)	
SBR in (µmol/L)	6(2-64)	5(3-28)	6(3-26)	5(3-18)	
HCV RNA (IU/ml)	363,181 (1,193-9,352,070)	Undetectable in 34(80%) Detectable in 7, (16.6%), RNA median 41(20-361)	Undetectable in 41(93.1%) Detectable in 3©, (6.8%), RNA median 122177 (84-244270)	Undetectable in 23(92%) Detectable in 1 (%), RNA (42) ®	

kPa: Kilo pascals, IU/L: International Units/Litre, µmol/L: Micromoles/Litre, IU/ml: International Units/millilitre
©: Child with HCV RNA of 84 extended the treatment by 4 weeks and was negative at 12 weeks. The other two demonstrated resistance to original DAA regime and were treated with alternative regimes successfully.
®: Treatment extended by 4 weeks and undetectable RNA at 16 weeks.

References

HCV Guidance: Recommendations for Testing , Managing and Treating Hepatitis C 2014-2023 AASLD and IDSA v2023. 1

OC18

Real-world performance of paediatric video capsule endoscopy: completion rates, small bowel transit times and the influence of bowel preparation quality

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Video capsule endoscopy (VCE) is widely used for the evaluation of small bowel pathology in children[1]. Important indicators of procedure quality include whether the capsule reaches the caecum, confirming complete small bowel assessment and the quality of bowel preparation, which determines how clearly the mucosa can be evaluated on captured images[2]. Small bowel transit time (SBTT), defined as the time from duodenal entry to caecal exit, provides further information on the flow of the procedure and can influence both interpretation and study duration[3]. Our standard bowel preparation protocol consists of fasting from solids for approximately 16 hours prior to capsule ingestion with ample clear fluids given. No laxatives or prokinetics are used. Despite increasing use of VCE in children, real-world data describing capsule performance and the effect of bowel preparation quality remain limited.

A retrospective review of 43 consecutive video capsule endoscopy procedures performed in a tertiary paediatric centre over a 10-month period (December 2024-September 2025) was undertaken. Each study was examined to determine whether the caecum was visualised. SBTT was recorded in minutes and hours. Bowel preparation quality was categorised during reporting as good or poor/limited, based on mucosal visibility. Studies were classified as failed if the caecum was not seen or if capsule passage beyond the small bowel was uncertain. Capsule retention was defined as persistence of the capsule beyond two weeks or the need for endoscopic or surgical retrieval.

The capsule reached the caecum in 81.4% (35/43) of studies, while 18.6% (8/43) were incomplete due to non-visualisation or uncertainty regarding passage. Among completed studies, the mean SBTT was 4.68 hours (281 minutes) with a range of 1.73 to 9.75 hours, falling within normal paediatric SBTT of 227 to 332 minutes(1). Bowel preparation was judged to be good in 72.1% (31/43) of procedures, while 27.9% (12/43) had poor or limited preparation. Poor bowel preparation appeared more frequently in procedures that did not achieve completion. Older age was significantly associated with incomplete studies (median age 16 vs 14 years, $p = 0.038$). There were no cases of capsule retention, mostly secondary to careful patient selection with pre-procedure MRI and use of patency capsules.

These findings show that VCE in this paediatric cohort achieved an acceptable completion rate above 80%. However, the failure rate of 18.6% was higher than the 0.4% to 4% reported in other paediatric studies[1,2]. Older age was significantly associated with incomplete studies, suggesting possible poor adherence to booster fluids. Strategies to optimise bowel preparation and enhance procedural reliability may improve completion rates and diagnostic yield. Following this study, our centre has revised its protocol to include longer fasting periods and increased booster fluid volumes, with repeat audit planned in one year.

Variable	Result
Completion rate	81.4% (35/43)
Failure rate	18.6% (8/43)
Mean small bowel transit time	4.68 hours (281 minutes)
Bowel prep judged good	72.1% (31/43)
Capsule retention	0%

References

1. Wu J, Huang Z, Wang Y, et al. Clinical features of capsule endoscopy in 825 children: a single-center retrospective cohort study. *Medicine (Baltimore)*. 2020;99:e22864.
2. Oikawa-Kawamoto M, Sogo T, Yamaguchi T, et al. Safety and utility of capsule endoscopy for infants and young children. *World J Gastroenterol*. 2013;19:8342-8348.
3. Rao SS, Camilleri M, Hasler WL, et al. Evaluation of gastrointestinal transit in clinical practice: Position paper of the American and European Neurogastroenterology and Motility Societies. *Neurogastroenterol Motil*. 2011;23:8-23.

OC19

Disorders of Gut–Brain Interaction (DGBI) in the Southwest region of the United Kingdom: Are we doing enough?

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Functional Gastrointestinal Disorders (FGIDs), now defined as Disorders of Gut–Brain Interaction (DGBI), are increasingly recognised in children and adolescents(1). These disorders, though long present in society, have only recently been systematically studied, categorised, and managed through structured evidence-based approaches(2). The Rome IV symptom-based criteria have improved diagnostic consistency and clinical research design(3). International data suggest that over 40% of adults and up to 27% of children experience FGIDs, highlighting a significant global health burden(4). With emerging evidence supporting behavioural interventions such as hypnotherapy and cognitive behavioural therapy (CBT), understanding current clinical practice and access to these treatments in paediatric settings is crucial(4). Pharmacological therapy, though supported by limited evidence, remains integral to management, alone or as an adjunct(5,6).

We aimed to evaluate the prevalence, diagnostic approach, and management of children with DGBI referred to our tertiary centre, alongside assessing clinicians' access to appropriate support services within the Southwest region. A retrospective review of all DGBI referrals between September 2023 and September 2024 was undertaken. Data collected included demographics, DGBI subtypes, comorbidities, investigations, treatments, and supportive measures. Additionally, an anonymous survey was distributed to regional clinicians to assess awareness, clinical burden, and access to specialist services.

Among 579 total referrals, 161 (28%) were diagnosed with DGBI according to Rome IV criteria, comparable to IBD referrals (33%). Most patients were aged between 10–15 years (63%), with a slight female predominance (55%). The most common diagnoses were functional abdominal pain–unspecified (46, 28%), functional constipation (36), irritable bowel syndrome (25), and rumination syndrome (18). Other less frequent presentations included abdominal migraine, functional dyspepsia, functional vomiting, functional nausea, aerophagia, functional dysphagia, and cyclical vomiting syndrome. Twenty-two percent had additional gastrointestinal or non-gastrointestinal diagnoses, and 11% had associated mental health conditions such as anxiety, depression, or chronic fatigue. Seventeen patients were neurodivergent, and one had a learning difficulty. Forty percent underwent specialist investigations, including endoscopy, MRI, or motility studies. Sixty percent received pharmacological therapy, including antispasmodics, PPIs, probiotics, and neuromodulators. Dietary interventions were offered in 14 cases, and supportive measures were offered, including breathing techniques, educational leaflets, hypnosis, or referral to chronic pain and psychology services. However, only nine patients accessed psychological support, and just one received input via school-based services. Ninety-five percent had follow-up appointments.

Clinician survey responses (n=25) revealed that nearly half had over ten years of independent practice, and 40% saw more than three DGBI patients monthly. Most expressed the need for tertiary input, citing limited regional access to psychology—70% reported none, and 30% occasional access.

Our findings suggest a significant clinical burden of DGBI, comparable to IBD, with substantial variability in diagnostic and management approaches. Access to evidence-based psychological and behavioural therapies remains limited both in secondary and tertiary care. Following this audit, we are implementing strategies to enhance care, including improved psychology access, digital self-help resources, and workshops to support children and families. A larger, nationwide study is warranted to better quantify the burden and improve service provision for paediatric DGBI.

References

1. Drossman DA, Hasler WL. *Rome IV—Functional GI Disorders: Disorders of Gut–Brain Interaction.* Gastroenterology. 2016;150:1257–1261.
2. Drossman DA. *Functional Gastrointestinal Disorders: History, Pathophysiology, Clinical Features, and Rome IV.* Gastroenterology. 2016;150:1262–1279.
3. Sperber AD, Bangdiwala SI, Drossman DA, et al. *Worldwide prevalence and burden of functional gastrointestinal disorders: Results of the Rome Foundation Global Study.* Gastroenterology. 2021;160(1):99–114.
4. Robin SG, Keller C, Zwiener R, et al. *Prevalence of pediatric functional gastrointestinal disorders utilizing the Rome IV criteria.* J Pediatr. 2018;195:134–139.
5. Sinopoulou V, Groen J, Gordon M, et al. *Efficacy of interventions for the treatment of irritable bowel syndrome, functional abdominal pain—not otherwise specified, and abdominal migraine in children: a systematic review and network meta-analysis.* J Pediatr Gastroenterol Nutr. 2025;9(5):315–324.
6. Groen J, Gordon M, Borrelli O, et al. *ESPGHAN/NASPGHAN guidelines for treatment of irritable bowel syndrome and functional abdominal pain—not otherwise specified in children aged 4–18 years.* J Pediatr Gastroenterol Nutr. 2023;76(4):650–668.

OC20

Single centre cohort analysis of catheter related blood stream infection in children with type 3 intestinal failure

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Children with intestinal failure (IF) requiring parenteral nutrition (PN) are at risk of catheter-related bloodstream infection (CRBSI), a life-threatening complication (1). With increasing use of home PN (HPN) among paediatric patients (2), ongoing surveillance of CRBSI rates is essential. Annual audits on CRBSI outcome measurements guide best practice in IF and HPN centres (3), with a target CRBSI rate of less than 1 per 1000 catheter days (4). At this tertiary centre, possible CRBSI is defined by a temperature ≥ 38.5°C, or two measurements ≥ 38°C within one hour. Suspected cases would be evaluated for bacteraemia by obtaining blood culture and started on antimicrobial therapy infused through the central venous catheter (CVC) for fourteen days to achieve line salvage. CVC removal is reserved for fungal infections or persistently positive bacteraemia on days five and ten of infection (5). This retrospective cohort analysis evaluates the incidence and outcomes of CRBSI in children receiving long-term HPN for IF in a single large tertiary centre.

A retrospective cohort analysis was conducted at a single large tertiary centre to evaluate rates of CRBSI for children with type 3 intestinal failure requiring long-term HPN. Data on patient demographics, underlying diagnosis, episodes of positive bacteraemia, and use of taurolidine-based antimicrobial locks were extracted from electronic health records (Cerner Millennium) for the years 2023-2024. Episodes involving viral infections or negative blood culture were excluded, even if antimicrobial therapy was initiated for suspected CRBSI. Statistical analysis was performed to compare annual CRBSI rates per 1000 catheter days and identify contributing factors.

A total of 36 and 37 children received HPN in 2023 and 2024, respectively, with ages ranging from 6 months to 18 years. Indications for HPN were short bowel syndrome (65%), congenital enteropathy (19%), and gastrointestinal motility disorders (16%). In 2023, four children experienced eight episodes of CRBSI, corresponding to a CRBSI rate of 0.64 per 1000 catheter days – a 55% reduction from the previous audit. Half of these infections were caused by Gram-positive bacteria, 40% Gram-negative and 10% fungi. In 2024, two children had four CRBSI episodes, with an overall CRBSI rate of 0.31 per 1000 catheter days, reflecting a further 50% reduction in CRBSI rates. CVC salvage was achieved in 75% of CRBSI episodes. All patients made a full recovery from each CRBSI episode. Taurolidine-based antimicrobial lock use for CRBSI prophylaxis increased from 91% in 2023 to 100% in 2024.

The national recommendation of CRBSI rate of less than 1 is achievable in children reliant on HPN. This data highlights the positive impact of a dedicated nutrition team, taurolidine-based antimicrobial lock, and adherence to clear guidelines to minimise this serious complication.

References

1. Pierret ACS, Wilkinson JT, Mann JP. Clinical outcomes in pediatric intestinal failure: A meta-analysis and meta-regression. American Journal of Clinical Nutrition. 2019 Aug 1;110(2):430–6.
2. Wiskin AE, Thomas J, Batra A. Prevalence of home parenteral nutrition in children. Clin Nutr ESPEN. 2021 Apr;42:138–41.
3. Bond A, Chadwick P, Lal S. Diagnosis and management of catheter-related bloodstream infections in patients on home parenteral nutrition. Frontline Gastroenterol. 2020 Jan 1;11(1):48–54.
4. Lal S, Chadwick P. British Intestinal Failure Alliance (IFA) Recommendation Management of Catheter Related Blood Stream Infections (CRBSIs). 2024 Jun.
5. Patel M, Kadir A, Naik S. Standard Operating Procedure for line sepsis in Paediatric patients on long term parenteral Nutrition V1.1. London; 2024 Oct.

OC21

Superior Mesenteric Artery (SMA) Syndrome: A Rare Cause of Common Symptoms. Experience of Two Cases.

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Superior mesenteric artery (SMA) syndrome is a rare cause of duodenal obstruction (prevalence 0.1-0.3%) seen in adolescents and resulting from the position of the SMA compressing the duodenum. The clinical onset is often non-specific, mimicking with functional symptoms which can delay the diagnosis. We report two cases of SMA syndrome seen at our tertiary paediatric gastroenterology centre**.**

Case 1

A 15-year-old girl presented with a 2–3-week history of bilious vomiting, abdominal cramps, reduced oral intake and an estimated weight loss of 13%. Examination revealed a thin but otherwise well adolescent. Blood tests showed mild microcytic anaemia, hypokalaemia, and hypophosphatemia. Imaging, including a water-soluble contrast swallow and intestinal ultrasound (IUS), revealed delayed passage across D3 and a reduced aorto-mesenteric angle, consistent with SMA syndrome. (Figure 1)

She was started on gradual nutritional rehabilitation considering the possibility of refeeding syndrome. Initially, oral liquid supplements were trialled, but in view of persistent vomiting she required escalation to naso-gastric (NG) and eventually naso-jejunal (NJ) feeding. Pain management was challenging, with no benefit from an initial escalation to opioids and patient-controlled analgesia (PCA) initiated by the acute paediatric team. These were rapidly weaned and stopped due to concerns about narcotic syndrome.

Her hospital stay lasted three months, complicated by significant psychosocial and communication difficulties, with both parents requiring interpreters from different languages. Multidisciplinary support, including paediatric gastroenterology, dietetics, and mental health, was crucial. A strong desire to have the NJ tube removed and to trial oral fluids and food again emerged from the psychological assessments. A temporary home leave with safety netting resulted in a spontaneous, rapid recovery, with tolerance of oral fluids/ solid intake until normalisation in 2-3 weeks, emphasizing a major role played by psychosocial factors.

Case 2

A 14-year-old girl presented with a 3-month history of progressive non-bilious vomiting and an estimated 8% weight loss following scoliosis surgery four months earlier. Examination and blood tests were unremarkable. Imaging with a barium swallow and IUS showed mild proximal duodenal dilation and narrowing of the aorto-superior mesenteric angle, consistent with SMA syndrome. Management focused on dietetic support with liquid nutritional supplements to prevent vomiting and ensure adequate calorie intake. After five weeks, she recovered substantially and was asymptomatic on regular diet. She remained under close follow up with dietetic team to address her low weight and ensure optimal nutritional status.

Discussion

SMA syndrome should be considered in adolescents with persistent, otherwise unexplained, severe vomiting leading to significant weight loss. Non-invasive imaging techniques, like barium swallow and IUS, are effective diagnostic tools and avoid the high radiation exposure associated with CT scans. First-line treatment is conservative, with dietetic support and escalation to enteral feeding when necessary. Opiates should be avoided. Recovery duration varies depending on the patient's response, psychological factors, and family support. Multidisciplinary care, including psychosocial support and effective communication with caregivers, is essential to manage prolonged hospitalizations.

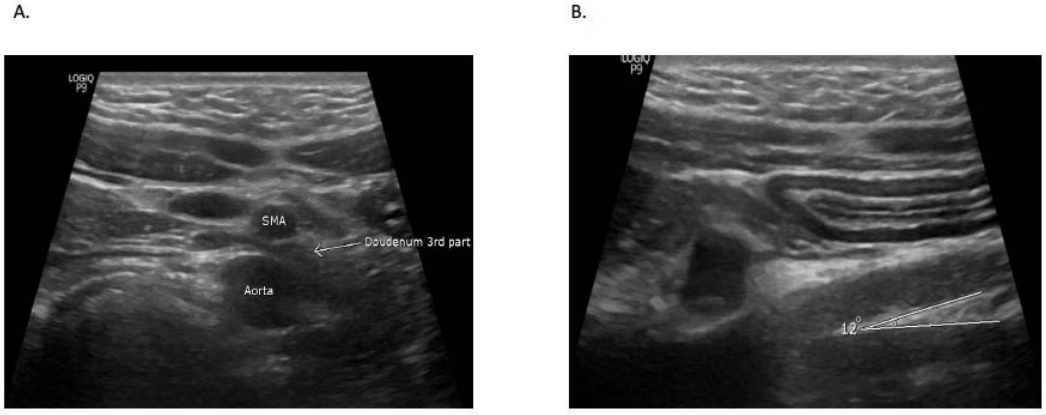

Figure 1 : (A) Reduced aorto-mesenteric distance (B)reduced aortomesenteric angle on intestinal US (IUS) with compression of D3, indicative of superior mesenteric artery syndrome (SMA)

References

1. Welsch T, Büchler MW, Kienle P. Recalling superior mesenteric artery syndrome. *Dig Surg*. 2007;24(3):149-56.
2. Biank V, Werlin S. Superior mesenteric artery syndrome in children: a 20-year experience. *J Pediatr Gastroenterol Nutr*. 2006;42(5):522-5.

OC22

Coil migration causing duodenal stricture after arterial embolisation for upper GI bleeding in B-cell lymphoma

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A 17-year-old male was treated for B-cell lymphoma in December 2023 following a presentation with hypovolaemic shock secondary to massive GI haemorrhage, caused by ulcers found in the second segment of the duodenum. He underwent selective coil embolisation of the dorsal branch of the gastroduodenal artery and the superior pancreaticoduodenal artery. He received four cycles of chemotherapy and was in remission based on MRI/PET imaging from his local hospital.

In April 2024, he developed extrahepatic cholestasis and pancreatitis. MRI showed mild dilatation of the common hepatic and bile ducts. ERCP and OGD were attempted, but the scope could not pass beyond the duodenal bulb. OGD showed a stenotic, oedematous duodenum with loss of normal folds.

In May, he was transferred to a tertiary Gastroenterology/Hepatology centre. OGD reached D1, where multiple embolisation coils were visible at the D1–D2 junction with a large superficial ulcer; the scope could not be advanced further. CT confirmed extensive embolisation coils in D3, biliary dilatation with distal duct narrowing, two hypodense liver lesions and superior mesenteric vein occlusion with collateralisation. A barium meal demonstrated incomplete duodenal obstruction with intraluminal coil material.

A percutaneous transhepatic cholangiogram was performed, with successful placement of an internal–external biliary drain, with the distal end positioned past the duodenal stricture. During this admission, he was severely malnourished and unable to meet his caloric requirements, so he received parenteral nutrition. He was gradually weaned to Modulen nutritional therapy prior to discharge.

In November, he was readmitted for repeat OGD and balloon dilatation of the duodenum. The endoscope was successfully advanced to D3 after the duodenal stricture was dilated to 8 mm and then 10 mm; however, further dilatation was not pursued due to bleeding. He was managed with intravenous proton pump inhibitors and steroids, and continued on half Modulen feeds alongside a soft diet.

Three weeks later, an ERCP performed by the adult gastroenterology team showed that the previously placed embolisation coils remained visible within the duodenal bulb. The major papilla could not be visualised and no target for cannulation was identified.

In early December, another OGD revealed multiple non-bleeding ulcers in both the oesophagus and duodenum, along with moderate gastritis. He was discharged on high-dose proton pump inhibitor therapy twice daily, Creon due to low faecal elastase and ursodeoxycholic acid. He continued follow-up at his local hospital and remained clinically well.

Coil migration is an uncommon but recognised complication, with associated bleeding most frequently seen from duodenal ulcers[1-2]. Rebleeding, however, is rare[3]. This case demonstrates that intraluminal coil migration can lead to ongoing upper gastrointestinal obstruction and cholestasis. It also suggests that a conservative management approach may be effective without requiring coil removal, though careful coordination among multidisciplinary teams is essential.

References

1. Skipworth J R, Morkane C, Raptis D A, et al. Coil migration—a rare complication of endovascular exclusion of visceral artery pseudoaneurysms and aneurysms. *Ann R Coll Surg Engl* 2011; 93: e19–23.
2. Chang C J, Hou M C, Tseng H S, et al. Bleeding gastric ulcer after prophylactic coiling of transarterial chemoembolization. *J Clin Gastroenterol* 2010; 44: 588–91.
3. Shim J J, Chu H H, Shin J H, et al. Clinical outcome of the visible coil during endoscopy after transcatheter arterial embolization for gastrointestinal bleeding. *Cardiovasc Intervent Radiol* 2019; 42: 1537–44.

OC23

Acquired glucose-galactose malabsorption without enteropathy post haematopoietic stem cell transplant

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We present a case of acquired, transient glucose-galactose malabsorption (GGM) following an allogenic haematopoietic stem cell transplant (HSCT).

Congenital glucose-galactose malabsorption is a rare disorder caused by mutations in the SLC51 gene, leading to loss of function in the sodium dependent glucose-galactose transporter protein (SGLT1). SGLT1 is expressed on the apical surface of small bowel enterocytes, with resultant severe osmotic diarrhoea with glucose intolerance as the hallmark feature. Congenital GGM usually presents as congenital diarrhoea and can be fatal if not promptly recognised and managed. Diagnosis shows profuse watery diarrhoea following dioralyte, which switches off with fasting. A fructose-based feed, with exclusion of lactose, sucrose and glucose is conversely well tolerated (1). Acquired cases of isolated glucose-galactose malabsorption are not documented in the literature.

A 7-year-old boy underwent an allogenic, haematopoietic stem cell transplant (HSCT) for congenital dyserythropoeitic anaemia type two (CDAII). Standard conditioning was used. Stem cells were harvested from an HLA matched unrelated donor. Parenteral nutrition (PN) was administered following engraftment, and then weaned as enteral feeds with Nutrini Peptisorb and oral feeds were tolerated. As enteral feeding was built up, the patient developed severe watery diarrhoea.

Initial gastroscopy and flexible sigmoidoscopy with biopsies showed patchy crypt and epithelial destruction involving the upper and lower gastrointestinal tract, with apoptosis, supporting a diagnosis of acute graft-versus-host disease (GvHD). Remission was induced with standard GvHD treatment including steroid, extracorporeal photopheresis (ECP) and infliximab. Large stool losses persisted with both trials of dioralyte-only via NGT and Neocate Junior formula and the patient was put on gut rest and recommenced on PN.

A repeat endoscopy and biopsy approximately six weeks later showed regeneration of the epithelium with resolution of GvHD and no signs of enteropathy, nor colitis. The patient was trialled on a pure starch diet (peeled, boiled potato) after which he had a large loose type 7 stool output. Dioralyte was neither tolerated. A fructose-based feed (Galactomin 19) was commenced which was readily tolerated by the patient with a resolution in symptoms and normal stool output, concentration and volume of this feed was gradually increased. Parental nutrition was stopped when full volume Galactomin 19 feeds were tolerated. On discharge, the patient continued on Galactomin 19 feeds. Over a further 8 weeks, gradual increase in oral glucose/galactose free feeds took place. Gradual and step-wise introduction of glucose containing foods was carried out in the community and was tolerated well. One year post-HSCT the patient is tolerating a normal diet with no exclusions.

In conclusion, GvHD can produce a significant epithelial lesion that appeared to cause an isolated glucose/galactose malabsorption. We propose this observation was likely to be a form of post enteritis syndrome.

References

1. National Center for Biotechnology Information (US). *Genes and Disease* [Internet]. Bethesda (MD): National Center for Biotechnology Information (US); 1998-. Glucose galactose malabsorption. Available from: https://www.ncbi.nlm.nih.gov/books/NBK22210/

OC24

Familial IPEX syndrome due to a rare FOXP3 variant presenting with severe enteropathy

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Immune dysregulation, polyendocrinpathy, enteropathy, X-linked (IPEX) syndrome is a rare and life-threatening condition caused by mutations in the FOXP3 gene, resulting in regulatory T-call dysfunction and multi-organ autoimmunity. The classical clinical triad presents as intractable diarrhoea in infancy, type 1 diabetes and atopic dermatitis. Early diagnosis and prompt immunosuppressive or curative therapy with haematopoietic stem cell transplant (HSCT) markedly improve survival.

We describe two male siblings with OPEX syndrome caused by a FOXP3 variant *(2.991T>Gp.(Phe331Val))*, a mutation previously reported only once in the literature, described in a Vietnamese infant with fatal IPEX syndrome (1).

The index case presented at five weeks of age with severe secretory diarrhoea and 20% weight loss. He had been born at term to non-consanguineous parents following an uneventful pregnancy. He was initially treated for severe dehydration and possible sepsis with intravenous fluids and antibiotics. The patient was trialled on dioralyte and then total parenteral nutrition (TPN) but stool output remained high on both. Stool cultures and virology were negative. Duodenal biopsies revealed total villous atrophy, epithelial apoptosis and mucous inflammation with blood tests showing reduced NK cells and positive anti-GAD and anti-smooth muscle antibodies. Cellular immunology testing showed FOXP3 expressing CD4+ and CD25_ cells by flow cytometry however genomic sequencing confirmed the FOXP3 pathogenic variant. IV Methylprednisolone and Sirolimus led to clinical and histological improvement, allowing weaning from TPN. He also developed eczema which was responsive to topical treatment. He underwent allogenic HSCT from a matched unrelated donor at six moths of age, achieving 100% donor chimerism and full clinical remission at five months post-transplant.

Following diagnosis in the index patient, maternal carrier testing confirmed heterozygosity for the same FOXP3 mutation. In the subsequent pregnancy, non-invasive prenatal testing confirmed a male fetes and chorionic villous sampling confirmed the same FOXP3 variant, enabling an antenatal diagnosis of IPEX syndrome and commencement of early SIrolimus therapy following birth. He underwent HSCT at two months of age and at five months post-transplant he too demonstrated 100% donor chimerism and remained clinically well.

In conclusion, we report two brothers with IPEX syndrome due to a rare FOXP3 variant (*2.991T>Gp.(Phe331Val)*). FOXP3 expressing TReg cells were non-functioning, suggesting that FOXP3 expression does not necessarily infer function. the early recognition of the disorder in the index case enabled successful antenatal diagnosis and timely curative HSCT in the subsequent sibling, emphasising the value of genetic testing, family screening and early transplant in optimising prognosis in IPEX syndrome.

References

1. Johnson et al. Genotype and clinical phenotype do not predict prognosis in IPEX syndrome. [Internet] [cited 03/11/25]; Available from: https://files.core.ac.uk/download/pdf/145645355.pdf

OC25

Partial transition from parenteral to enteral nutrition using a whole-food based formula in a child with intestinal failure secondary to microvillus inclusion disease

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Partial transition from parenteral to enteral nutrition using a whole-food based formula in a child with intestinal failure secondary to microvillus inclusion disease

Microvillus inclusion disease (MVID) is a rare congenital enteropathy characterised by severe secretory diarrhoea and intestinal failure from birth. This case describes a 28-month-old boy with genetically confirmed MVID (homozygous STX-3 mutation), managed within a tertiary paediatric intestinal rehabilitation unit. He has been dependent on parenteral nutrition (PN) since birth and was discharged on home PN at five months of age.

The child's clinical course has been complicated by multiple comorbidities, including suspected proximal tubule dysfunction, microcytic anaemia, and recurrent catheter-related bloodstream infections (CRBSIs). These factors, alongside food aversive behaviours, have necessitated a highly individualised nutritional approach.

Dietetic involvement has been central to care, with a gradual transition from PN to enteral nutrition supported by multidisciplinary input. Initial enteral feeds consisted of amino acid-based formula via nasogastric tube, progressing to bolus feeds via PEG tube. In April 2025, a whole-food-derived-based formula was introduced to reduce volume burden and improve gastrointestinal tolerance.

Over a 10-month period, enteral feed volumes increased from 220 mL to 400 mL per day and to date 600mL per day. PN dependency reduced from seven to four nights per week. The child now receives bolus feeds via PEG on non-PN nights and moderate oral intake of age-appropriate foods. Vomiting resolved by March 2025, laxatives were discontinued by May 2025, and stool consistency improved from loose to formed, indicating enhanced enteral absorption and gut adaptation.

Growth has been modest but steady: weight increased from 9.6 kg to 10.15 kg (just below the 9th centile), while length remained static at 80 cm (0.4th centile), likely reflecting multifactorial influences including genetic and renal factors.

This case highlights the feasibility of a structured, phased reduction in PN dependency using a whole-food-derived-based enteral formula in a child with complex intestinal failure. Improvements in stool quality, feed tolerance, and oral intake suggest that blended feeds may support intestinal adaptation and enhance quality of life. The experience also underscores the importance of evaluating progress through functional outcomes—such as stooling, vomiting, and oral skill development—alongside anthropometric measures.

Key learning points:

- Earlier transition from amino acid formula to whole-protein blends may improve tolerance.
- Whole-food-based formulas can be successfully incorporated into post-pyloric feeding regimens.
- Multidisciplinary collaboration is essential, including early behavioural feeding support.

Table 1. Clinical progress during parenteral to enteral transition

Parameter	Sept 2024	July 2025
Enteral volume (mL/day)	220	400
PN nights per week	7	4
Weight (kg)	9.6	10.15
Length (cm)	80	80
Stool consistency	Loose	Formed
Vomiting episodes	Frequent	None

OC26

Lung nodules in Crohn's: separate pathology or the same disease?

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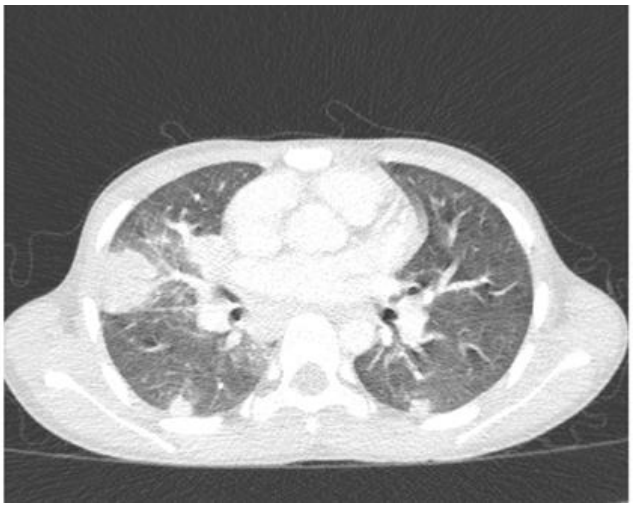
Crohn's disease is primarily an autoimmune condition affecting the gastrointestinal tract, 36% of patients experience extra intestinal manifestations. [1] Pulmonary involvement is reported in 0.4% of patients [1] but bronchioalveolar lavage and lung function tests can be used to demonstrate subclinical involvement in a large proportion of patients [2]. Inflammation is most commonly seen in the bronchioles and large airways and interstitial granulomatous involvement is rare especially in paediatric patients. Here we discuss a paediatric patient with diffuse granulomatous changes throughout both lungs at presentation.

A 13-year-old girl presented to the accident and emergency department in June 2025 with a three-week history of loose stools containing fresh red blood, increased stool frequency, peri-anal pain and lethargy. She was also having fevers and an unintentional weight loss of over 2kg (weight below 0.4th centile). Initial blood results showed Hb67, WCC11.7, CRP107, albumin28, as well as low folate and vitamin D (<15nmol/L) levels. She had no significant family history or travel history. Faecal calprotectin was 1555mcg/gm. Stool MC&S, virology and C. diff testing were negative. MRI of the small bowel and pelvis showed acute inflammation in the left colon and rectum as well as multiple lesions in the lung bases one of which was cavitating. MDT approach involving gastroenterology, ID and respiratory team was undertaken. CT chest showed widespread lung nodules, the largest 28mm was enhancing with central necrosis. All lobes of the lungs were affected and there was ground glass changes and interlobular septal thickening. Differentials of inflammatory bowel disease (IBD), infection including tuberculosis (TB), sarcoidosis, primary immunodeficiencies such as x-linked agammaglobulinaemia (XLA), pulmonary metastases and vasculitis were considered. Screening for infective (including TB), autoimmune and immunodeficient causes was negative. Oesophago-gastro-duodenoscopy, colonoscopy and bronchoscopy were performed. Patchy aphthous ulceration was seen in the rectum and sigmoid colon with snail-track ulceration from the transverse colon to the hepatic flexure, consistent with Crohn's disease. Histology showed crypt abscesses, cryptits and active chronic inflammation in the left colon. Washings from bronchioalveolar lavage had negative cultures (including TB) and showed mostly macrophages with 20% neutrophils. MDT discussion agreed biopsy of the lung nodules was not indicated as they were most likely a pulmonary manifestation of Crohn's disease Pending investigations, the patient was treated with IV metronidazole and ciprofloxacin and subsequently started on exclusive enteral nutrition (EEN). Although initial response to EEN was observed she presented with signs of active disease after 3 weeks and following further MDT discussion was started on IV steroids. Since then she has commenced Infliximab and currently has minimal symptoms and is gaining weight. Gradual resolution of the pulmonary nodules has been demonstrated on sequential chest x-rays and respiratory function tests have also improved (FEV1 64.5% to 77.8% predicted).

This case demonstrates a rare presentation of Crohn's disease for which a standardised guideline for investigation and treatment does not exist, making the input of the MDT crucial in ruling out alternative differentials so that definitive immunosuppressive treatment could be commenced.

Figure 1: CT chest showing widespread lung nodules at presentation.



References

1 Chew MT, Chak E, Matsukuma K. A Rare Cause of Pulmonary Nodules. Case Rep Gastroenterol. 2016 Oct 28;10(3):633-639. doi: 10.1159/000452198. PMID: 27920654; PMCID: PMC5121564.

2. Bonniere P, Wallaert B, Cortot A, Latent pulmonary involvement in Crohn's disease: biological, functional, bronchoalveolar lavage and scintigraphic studies. Gut. 1986 Aug;27(8):919-25. doi: 10.1136/gut.27.8.919. PMID: 3015749; PMCID: PMC1433358.

3. Al-Binali AM, Scott B, Al-Garni A, Granulomatous pulmonary disease in a child: an unusual presentation of Crohn's disease. Pediatr Pulmonol. 2003 Jul;36(1):76-80. doi: 10.1002/ppul.10301. PMID: 12772229.

4. Regalia K, Shelton A, Berry G, Pulmonary Crohn's Disease. Dig Dis Sci. 2017 Jan;62(1):64-67. doi: 10.1007/s10620-015-3993-1. Epub 2015 Dec 21. PMID: 26685911.

5. Lu DG, Ji XQ, Liu X, Pulmonary manifestations of Crohn's disease. World J Gastroenterol. 2014 Jan 7;20(1):133-41. doi: 10.3748/wjg.v20.i1.133. PMID: 24415866; PMCID: PMC3886002.

6. Gándara Gutiérrez C, Rodríguez Arboleya S, Galiana Martín D. Pulmonary nodules in a patient with Crohn's disease. Rev Esp Enferm Dig. 2022 Jun;114(6):358-359. doi: 10.17235/reed.2022.8499/2021. PMID: 35187943.

OC27

The mystery within the mesentery

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A 15-year-old male presented to A&E with a six-week history of nausea and vomiting, which had increased to be a daily occurrence. Apart from some recent unintended weight loss, he was otherwise fit and well, and reported no abdominal pain save for some epigastric tenderness on palpation. Initial bloods were unremarkable, including normal inflammatory markers and negative coeliac screen, save a mild B12 and folate deficiency for which he commenced oral replacement therapy. In view of persistent symptoms despite trial of proton pump inhibitor, he was then referred for an upper GI endoscopy which was reported as normal including normal biopsies.

He then represented six months later with abdominal pain localising to the left iliac fossa. His blood tests and faecal calprotectin were normal. A subsequent MRI revealed a 4.6cm x 3.4cm x 2.5cm hypoechoic rim-enhanced cyst with restricted diffusion, located in the left iliac fossa, close to the internal iliac vessels and seemingly in contact with the distal bowel loops in the mesogastrium. Discussion at our regional oncology MDT suggested a likely non-malignant nature.

In view of this finding, he was referred for surgical excision and at time of surgery, surgeons resected a 5cm smooth and solid mass which they found completely encapsulated within the mesentery, with no attachment to either bowel or mesenteric vessels *(Figure 1)*. Histology of the specimen revealed an extensively necrotised collagenous myofibroblastic neoplasm, which was suggested to be either a Gardner fibroma or desmoid-type fibromatosis, although the degree of necrosis rendered exact identification impossible.

The majority (60%) of Gardner fibromas are typically located within the back and paraspinal regions in children, teenagers and young adults, although they can arise anywhere and are usually painless.[1] They are thought to arise from germline mutations in the APC tumour suppressor gene at 5q21 and strongly associated with either familial adenomatous polyposis or familial desmoid fibromatosis in up to 70% of cases.[1] Further genetic workup in this patient is ongoing.

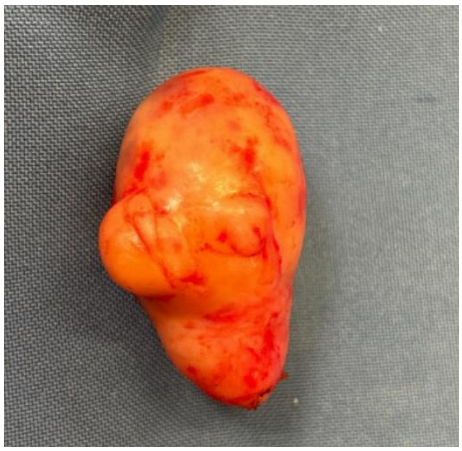

Figure 1: Excised mass, dimensions approximately 5cm x 3cm x 2cm

References

1. Coffin CM, Hornick JL, Zhou H, et al. Gardner fibroma: a clinicopathologic and immunohistochemical analysis of 45 patients with 57 fibromas. Am J Surg Pathol. 2007 Mar; 31(3):410-6.

OC28

Some habits are hard to grow out of: a case report of bloating and weight loss in an adolescent linked to a childhood habit

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The list of differential diagnoses for a child presenting with abdominal pain is extensive. However, clues may lie in a detailed history, even stretching back to before their symptoms appeared. We present a case of a teenager with significant gastrointestinal symptoms resulting from a seemingly innocuous childhood habit.

A 13-year-old girl presented to clinic with an 8-month history of abdominal pain, bloating and weight loss. The pain was localised to the epigastrium and triggered by eating. There was no history of diarrhoea, mucous or blood in the stools. She had a past medical history of campylobacter gastroenteritis 6 months prior, hypermobility and thinning hair. There was a family history of ulcerative colitis and constipation. Investigations showed calprotectin 2229, normal thyroid function and negative coeliac screen. An ultrasound the previous year did not show any abnormalities. On examination there were no extra-intestinal features of inflammatory bowel disease or nutritional deficiency, but there was a smooth hard mass in the palpable epigastrium. A repeat ultrasound correlated this finding with a distended gas-filled stomach. The gas extended through the bowel to the point where it limited abdominal views and central structures could not be visualised. Throughout these investigations, the patient continued to lose weight and her symptoms did not improve with a trial of omeprazole and a lactose-free diet. Reassessment in clinic confirmed the persistence of the mass so an MRI was arranged. This revealed a large intraluminal mass within the stomach measuring up to 17cm in transverse diameter. After a surgical consultation, the patient underwent surgery and a 3.5kg trichobezoar was extracted. It was subsequently revealed that she had developed a habit of sucking her hair from the age of 5.

Trichobezoar is rare and mostly diagnosed in young females. It is associated with trichotillomania (the urge to pull out one's hair) which has an incidence of 0.6-1.6%. However, even amongst these individuals, just 30% will engage in trichophagia and only 1% to the extent of requiring surgical removal [1]. Initial symptoms may be nonspecific, such as nausea or early satiety, but over years the build-up of indigestible material can lead to pain, gastrointestinal bleeding or perforation [2]. It is unlikely when the patient first started sucking her hair she had any significant symptoms, and the only indication of trichophagia was when she visited her GP for thinning hair.

This case highlights the importance of enquiring early on about dietary exposures and to consider bezoars in young females presenting with abdominal pain and weight loss, especially with an abdominal mass [1]. It cautions against over-reliance of radiological reports (repeat ultrasound reported gas rather than a solid mass) when this is inconsistent with the examination findings. Interpretation of imaging is limited by its modality, and the rarer the condition the less likely it will appear as a differential in a radiological report [3]. By asking appropriate questions and performing suitable imaging, prompt diagnosis can be made to avoid the adverse outcomes associated with large bezoars.

References

1. Frey A, McKee M, King R et al. Hair Apparent: Rapunzel syndrome. American Journal of Psychiatry. 2005; 162 (2). *Article*
2. Eng K, Kay M. Gastrointestinal bezoars: History and Current Treatment Paradigms. Gastroenterol Hepatol (NY). 2012 Nov; 8(11):776-8. Article
3. Zhang L, Wen X, Li JW et al. Diagnostic error and bias in the department of radiology: a pictorial essay. Insights Imaging. 2023 Oct 2;14(1):163. *Article*

OC29

Scurvy presenting as limp: the importance of nutritional assessment in children with restricted diet

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Nutritional deficiencies are an important but often under-recognised cause of musculoskeletal symptoms in children. In the context of selective eating behaviours, particularly among those with neurodevelopmental conditions, inadequate intake of essential micronutrients can lead to significant morbidity. Deficiencies in vitamins such as C and D may present with bone pain, weakness, and radiological findings that mimic inflammatory or infective conditions. This case report illustrates how vitamin C deficiency (scurvy) can masquerade as infective or inflammatory bone conditions, such as osteomyelitis or chronic non-bacterial osteitis (CNO). It highlights the vital importance of early nutritional assessment in children with severely restricted dietary intake.

The patient's electronic medical records were reviewed retrospectively, including laboratory investigations, imaging, and histology. A detailed dietary history was obtained in collaboration with the paediatric dietitian. Written consent for presentation was obtained from the patient's mother.

A seven-year-old boy presented with a three-month history of right leg pain and limp, progressing to non-weight-bearing. He was non-verbal with developmental delay and was under assessment for autism spectrum disorder. His oral intake was severely restricted, limited to commercially available milkshakes, and he refused solid food or prescribed oral nutritional supplements.

On admission, he was undernourished with a weight below the 0.4th centile and had developed a non-blanching rash behind both knees. He developed a low-grade fever, and was initially treated as bacterial osteomyelitis. Magnetic Resonance Imaging (MRI) of his legs showed symmetrical metaphyseal enhancement of long bones and thigh muscle oedema. Laboratory results demonstrated microcytic anaemia, borderline vitamin D deficiency, and normal inflammatory markers. Bone biopsy excluded infection and malignancy and culture and biopsy.

Given the patient's highly restrictive diet a nutritional aetiology was suspected. Dietetic assessment confirmed inadequate vitamin C intake. Plasma vitamin C levels were subsequently undetectable, confirming scurvy. High-dose vitamin C supplementation and nasogastric feeding with a nutritionally complete formula were initiated, alongside multidisciplinary rehabilitation. Within two months, he regained full mobility and was walking independently.

This case highlights the critical role of nutritional assessment in children presenting with limb pain in the context of a restricted diet. Nutritional deficiencies, particularly scurvy, remain relevant and preventable causes of morbidity in children with selective eating. Early recognition through comprehensive dietary history and dietetic involvement is essential for accurate diagnosis and effective management.

OC30

Case presentation: Coeliac disease associated chronic pancreatitis with markers of autoimmunity.

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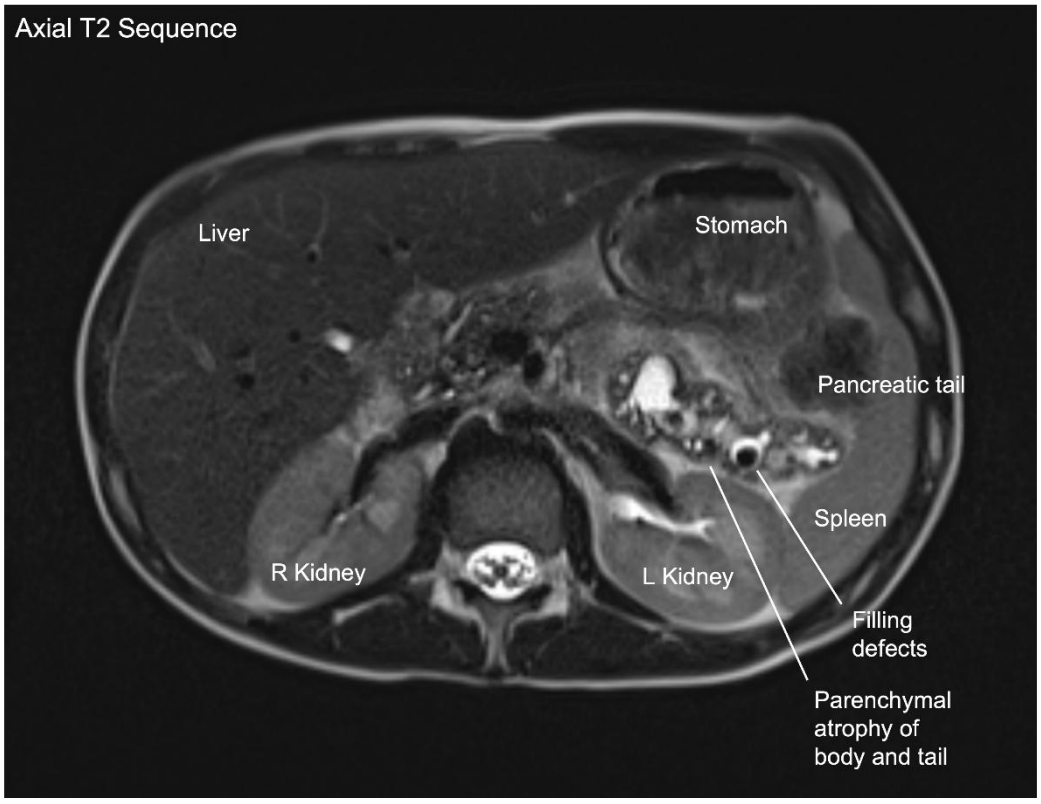
Coeliac disease (CD) associated pancreatitis is rare in children. Pathogenesis is thought to be related to malabsorption and chronic duodenal inflammation [1]. We highlight a case of coeliac disease with chronic pancreatitis (CP) and the importance of early baseline imaging in children diagnosed with CD.

A 12 year old female with a duodenal biopsy diagnosis of CD, presented with 2 months of abdominal pain and vomiting. No diarrhoea was reported although parameters indicated faltering growth. She maintained a gluten free diet for 3 years and antitissue transglutaminase (TTG) were normal on annual review. Amylase, lipase, and inflammatory markers were normal at presentation. An abdominal ultrasound showed a heterogenous pancreas with an irregular dilated pancreatic duct and distended side branching ducts.

Magnetic resonance cholangiopancreatography was carried out, showing pancreatic duct dilatation with stones and atrophy of the pancreatic body and tail consistent with CP**.** There was no peripancreatic fluid or biliary abnormalities.

Image 1: MRCP Axial T2 Sequence



Further investigations were carried out to determine the cause of CP. Genetic panels for hereditary pancreatitis (including PRSS1, CFTR, SPINK1) as well as for syndromes associated with pancreatic disease (Shwachman-Diamond Syndrome, Pearson Syndrome) were negative. IgG and IgG4 were normal. Liver specific antibodies were negative. There were positive autoantibodies: ANA (1/1280), SMA (1/40), ENA Centromere Protein B (13). Triglycerides and apolipoprotein were normal. Imaging did not demonstrate any anatomical or obstructive causes such as pancreas divisum or sphincter of Oddi dysfunction.

In summary, genetic, metabolic, and anatomical causes were ruled out. Therefore, a diagnosis of coeliac disease and pancreatitis with a very strong autoimmune profile was made.

Faecal elastase showed moderate pancreatic insufficiency (124µg); to avoid malabsorption she was commenced on pancreatic exocrine replacement therapy and referred for dietetic support. Fat soluble vitamins, bone profile and HbA1c were within normal range.

In view of pancreatic duct changes we proceeded with endoscopic retrograde cholangiopancreatography. This demonstrated a dilated main pancreatic duct with prominent side branches. There was no stricture at the head of the pancreas. A biodegradable stent was inserted. As the patient was now asymptomatic, we opted to monitor with MRI/MRCP and manage conservatively. The long-term malignancy risk in children with CP is not yet known, so this patient will likely need lifelong monitoring.

To conclude, the differentials for this patient included autoimmune pancreatitis and CD associated chronic pancreatitis. There is an increased risk of pancreatitis in CD [2], although this is likely underdiagnosed and its nature is not clearly defined with limited paediatric studies. Pancreaticolithiasis is a rare feature in this condition in children. We highlight the importance of early imaging, autoimmune markers, and screening for pancreatitis in children with CD who present with persistent abdominal pain, elevated TTG, or poor growth.

References

[1] Freeman HJ. Pancreatic endocrine and exocrine changes in celiac disease. World J Gastroenterol. 2007;13(47):6344.
[2] Ludvigsson JF, Montgomery SM, Ekbom A. Risk of Pancreatitis in 14,000 Individuals With Celiac Disease. Clin Gastroenterol Hepatol. 2007 Nov;5(11):1347-1353.e2.

OC31

Triaging Infantile Cholestasis: Validation of Non-Invasive Diagnostic Modalities and a Composite Scoring System for Early Detection of Biliary Atresia

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Biliary atresia (BA) is a time-critical cause of neonatal cholestasis, where early Kasai portoenterostomy markedly improves outcomes. Given that 2–15% of newborns in the United Kingdom remain jaundiced beyond 14 days of life[1], an efficient triage strategy is essential to identify high-risk infants who warrant urgent evaluation at tertiary hepatobiliary centres.

A retrospective analysis was conducted of all infants referred with prolonged neonatal jaundice a major tertiary paediatric liver unit between January 2023 and September 2025. Diagnostic performance of clinical, biochemical, and ultrasonographic parameters was assessed against the gold-standard intraoperative cholangiogram for BA confirmation. Continuous and categorical variables were compared using the Student's *t*-test and χ^2 test, respectively, and diagnostic accuracy was quantified using the area under the receiver operating characteristic curve (AUROC). A composite predictive index, the **Simple Biliary Atresia Score (SBAS)**[2], integrating laboratory and imaging features was validated.

Forty-eight infants (median referral age: 42 days) were included, of whom 19 (39.6%) had biliary atresia. The mean total bilirubin level at referral was 140.5 µmol/L. Among non-invasive modalities, the presence of **acholic stools** demonstrated the highest diagnostic accuracy for BA (AUROC = 0.819). Other parameters—including the direct-to-total bilirubin ratio, triangular cord sign, absent gallbladder, and pre-portal vein echogenicity—showed moderate predictive performance (AUROC = 0.614–0.760). Integration of these metrics into the **Simple Biliary Atresia Score** substantially improved overall diagnostic discrimination.

The Simple Biliary Atresia Score (SBAS) is a clinically practical and accurate composite tool for triaging infants with cholestasis. Incorporating non-invasive laboratory and ultrasonographic findings enhances early identification of biliary atresia and optimizes referral timing for surgical evaluation.

Table 1. Patient Variables

Patient Variables	Non-BA Cases (n = 29)	BA Cases (n = 19)	*p* - value
Demographics			
Age at Referral (days)	46.7 (37.7 – 55.7)	46.1 (37.4 – 54.8)	0.923
Gender			
Male (%)	25 (86.2%)	8 (42.1%)	0.003
Female (%)	4 (13.4%)	11 (57.9%)	
Presented with acholic stools	9 (31.0%)	18 (94.7%)	<0.001
Laboratory Variables			
Total Bilirubin (µmol / L)	140.2 (109.4 – 171.0)	160.5 (147.6 – 173.3)	0.299
Direct Bilirubin (µmol / L)	94.9 (73.9 – 115.9)	118.6 (108.1 – 129.2)	0.082
Direct to Total Bilirubin Ratio	0.68 (0.64 – 0.73)	0.74 (0.71 – 0.77)	0.074
ALT (U / L)	155.7 (97.6 – 213.8)	185.4 (111.2 – 259.5)	0.515
AST (U / L)	258.9 (147.9 – 370.0)	256.2 (177.4 – 355.0)	0.970
GGT	204.9 (108.9 – 300.9)	268.7 (193.3 – 344.1)	0.331
Ultrasound Findings			
Gallbladder Length (mm)	17.4 (12.7 – 21.9)	15.8 (10.7 – 20.9)	0.643
Common Bile Duct Diameter (mm)	3.21 (0.43 – 6.00)	6.45 (1.55 – 11.4)	0.212
Triangular Cord Sign	1 (3.4%)	8 (42.1%)	0.003
Gallbladder not seen?	1 (3.4%)	5 (26.3%)	0.058
Pre-portal vein echogenicity	3 (10.3%)	12 (63.2%)	<0.001

Categorical variables expressed as (%) with χ^2 – test for significance
Continuous variables expressed as (mean with 95% confidence intervals), with Student-t test for significance.

References

1. Hannam S, McDonnell M, Rennie J M. Investigation of prolonged neonatal jaundice, Acta Paediatrica. 2000;89(6):694-7. doi: 10.1080/080352500750044025.
2. Toh Q, Chen Y, Lee YY. Simple biliary atresia score - a validated diagnostic aid for infantile cholestasis, Pediatric Surgery International. 2024;40:212.

OC32

Greater improvements in bilirubin were observed in pruritus responders after maralixibat treatment in patients with PFIC: data from the MARCH/MARCH-ON trials

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Background: Progressive familial intrahepatic cholestasis (PFIC) comprises a heterogeneous group of disorders linked to genetic defects in hepatocanalicular transporters. Prior data has demonstrated total bilirubin (TB) is associated with improved transplant-free survival in this disorder. Maralixibat, an IBAT inhibitor, is approved in the US for the treatment of cholestatic pruritus in individuals ≥12 months old with PFIC, has been shown to reduce TB. Here, we evaluate the relationship between pruritus response and changes in TB in MARCH and MARCH-ON.

Methods: MARCH/MARCH-ON have been previously described. Changes in TB were evaluated during the first 26 weeks of MRX treatment (average of weeks 18, 22, and 26). Pruritus was assessed with average morning ItchRO(Obs)severity score in week 15-26 and response was defined as ≥1-point reduction from baseline or having the average score ≤ 1 point. Differences between pruritus responders and non-responders were analyzed using Wilcoxon signed-rank test and Fisher's exact test.

Results: Fifty-nine children were treated with MRX [PFIC1: n=12 (20%); nt-PFIC2: n=28 (47%); PFIC3: n=9 (15%); PFIC4: n=7 (12%); PFIC6: n=3 (5%)]. Pruritus response was observed in 37 (63%). Pruritus responders had lower Baseline TB compared to non-responders (52 vs. 107 µmol/L, p=0.006) and had greater reductions in TB following treatment (-23.9 vs. -9.7 µmol/L, p=0.048). Normalization of TB occurred more frequently in pruritus responders (p<0.01).

Conclusions: Changes in bilirubin and pruritus are linked in patients on MRX with greater reductions in bilirubin, an important marker of liver health, being observed in pruritus responders. People treated earlier in the course of disease (i.e., lower bilirubin) may have greater likelihood of improvement in pruritus.

OC33

Parenteral nutrition in children with biliary atresia and end-stage liver disease: a descriptive retrospective review from a single paediatric liver centre.

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Biliary atresia remains the most common cause of paediatric end-stage liver disease and the leading indication of liver transplantation in children. Despite early Kasai portoenterostomy, some children progressed to cholestatic liver failure, nutritional compromise and ascites. Severe malnutrition in this group worsens transplant outcomes and long waiting time for the graft. Enteral feeding is frequently limited by intolerance, gastrointestinal bleeding or marked ascites. Parenteral nutrition, therefore, becomes an essential bridge to stabilise nutritional status before transplantation. However, data on its practical use, duration and complications in biliary Atresia patients with end-stage liver disease remain sparse. This review describes our experience with parenteral nutrition in this unique population.

To describe the indications, duration and outcomes of parenteral nutrition in children with Biliary atresia and end-stage liver disease in a single paediatric liver centre

We performed a retrospective review of all children with biliary atresia and end-stage liver disease who received PN at our centre within 5 years. Demographics, indication and duration of parenteral nutrition, transplant status, biochemical profile and parenteral nutrition-related complications were extracted from the electronic record. Continuous data are expressed as medians (with interquartile ranges, IQRs), and categorical data are presented as numbers and percentages (%).

Sixteen children with biliary atresia received parenteral nutrition. Fifteen (93.8%) were infants, median age at parenteral nutrition initiation of 7 months (IQR 6-8): one child, aged 6 years had hepatopulmonary syndrome secondary to biliary atresia-related complications. All 16 patients received parenteral nutrition due to nutritional compromise. At baseline, the median (interquartile range) weight was 6.4 kg (5.8-6.9): the corresponding biochemical parameters were bilirubin 319 umol/L (192-386) albumin 25 g/L (22-28); INR 1.5 (1.2-1.65) and median parenteral nutrition duration before transplant was 35 days (IQR 23-75); while the pretransplant median (interquartile range) parameters were; weight 6.24 kg (6.04-8.14), bilirubin 241 umol/L (122-302), albumin 26 g/L (24-28), INR 1.55 (1.3-1.8). Most children required short-term parenteral nutrition (<6weeks), although one child with complex bowel obstruction remained parenteral nutrition-dependent for approximately two years.
Fourteen children (87.5%) proceeded to liver transplantation and survived; two (12.5%) died while on the transplant waiting list. Of those transplanted, all survived to discharge. Post-transplant recovery was generally favourable; most resumed full enteral feeds within 2-3 weeks. There was no significant deterioration in the cholestatic parameters, and a single case of line-related sepsis (6%) was treated with meropenem.

Our study showed that short term parenteral nutrition aided nutritional recovery and decreased morbidity related malnutrition without major complication. As wait time for graft is significantly increasing, nutritional stabilisation is important while awaiting a definite treatment of liver transplant. Further multicentre studies are needed to define the optimal timing, duration, and criteria for the use of parenteral nutrition, as well as its impact on transplant readiness and long-term outcomes.

References

1. Sullivan JS, Sundaram SS, Pan Z. Parenteral nutrition supplementation in biliary atresia patients listed for liver transplantation. Liver Transplantation. 2012 Jan;18(1):120-8.
2. Choe U. Nutritional Management for Peadiatric Biliary Atresia Patients Preparing for Liver Transplantation. Children. 2025 Mar 20;12(3):391.

OC34

Infantile Acute Liver Failure due to Hepatitis B virus

OC35

Spatial transcriptomics identifies mechanisms of hepatocellular carcinoma development in BSEP deficiency

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Background

Hepatocellular carcinoma (HCC) is a rare tumour in children, but has limited treatment options and typically requires liver transplantation. In adults, immunotherapy is a promising treatment for HCC but there is limited understanding of paediatric HCC microenvironment to know which pathways to target. In addition, certain genetic conditions have a predisposition towards HCC in children, including BSEP deficiency, which is caused by biallelic mutations in *ABCB11*. We hypothesised that the fibro-inflammation associated with BSEP deficiency contributes to development of HCC through a tumour-promoting microenvironment.

Methods

We performed VisiumHD on two samples of liver explants from patients with BSEP deficiency and HCC, plus control liver tissue (histologically normal, unaffected tissue adjacent to hepatoblastoma resections). VisiumHD is a cutting-edge spatial transcriptomics technology that profiles ~15,000 genes in up to 8µm regions. We utilised standard Seurat pipelines for data analysis. Candidate targets were validated with mulitplex immunohistochemistry.

Results

Unbiased clustering demonstrated separation of HCC from background liver parenchyma (Fig 1A and D). Both tumours were GPC3 positive (Fig 1B). Comparing HCC and hepatocytes clusters using differential gene expression, we found 112 down-regulated and 153 up-regulated genes that were consistent across both patients. Down-regulated genes included many fundamental metabolic enzymes, including *ALDOB*, *HPD*, *ARG1*, and *OTC*. The top upregulated gene pathway was "Regulation of DNA-templated Transcription (GO:0006355)" due to increased expression of genes promoting transcription (e.g. *HDAC10*). Genes related to B-cell activity (e.g. immunoglobulin heavy chains - *IGHG3*, Fig 1C) were strongly expressed in clusters in the peri-tumour tissue but excluded from the tumour tissue. Whereas tumour associated macrophages (*CD163*+ *CD5L*+) were increased in HCC.

Conclusions

HCC arising on the background of BSEP deficiency is associated with profound metabolic perturbation. The peri-tumour fibroinflammation is rich in B-cells, whilst the tumour is infiltrated with macrophages typically associated with cancer progression. Further mechanistic work is required to understand how these interact to lead to tumour development.

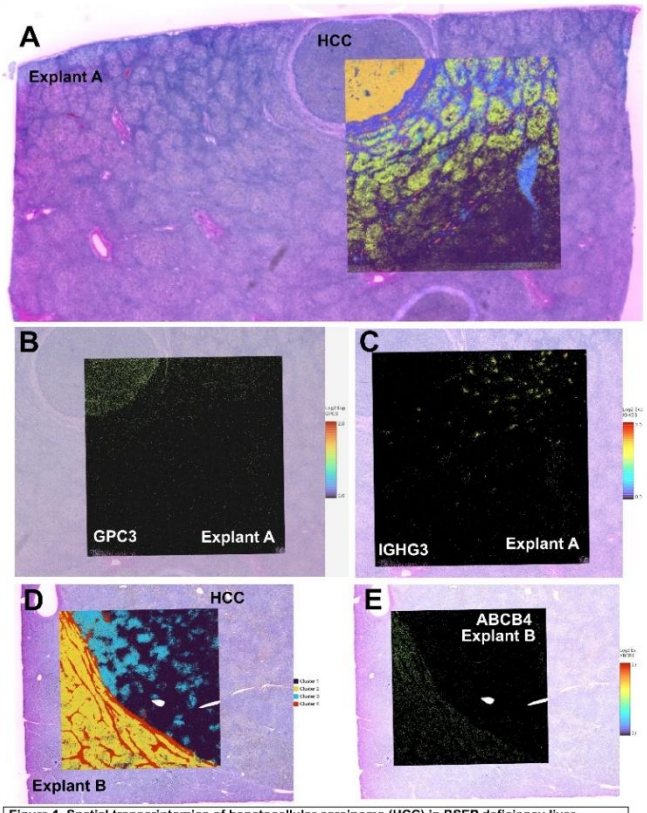

Figure 1. Spatial transcriptomics of hepatocellular carcinoma (HCC) in BSEP deficiency liver explants. A: overview of explant A, showing the region captured by VisiumHD, with colours representing different clusters. Spatial distribution of expression of GPC3 (**B**) and IGHG3 (**C**) in explant A. **D:** overview of explant B, showing different clusters across tumour (blue and dark blue), background cirrhotic nodules (yellow) and fibrotic regions (red). **E:** expression of ABCB4 in explant B.

OC36

Meta-analysis identifies that therapeutic response in multi-drug resistance 2-deficient (Mdr2-/-) mice mirrors severe biallelic mutations in ABCB4.

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Background: Biallelic mutations in humans *ABCB4* causes MDR3 deficiency which manifests as progressive familial intrahepatic cholestasis (PFIC) type 3. In mice, deletion of *Abcb4* causes Mdr2 deficiency ($Mdr2^{-/-}$); these mice develop chronic liver injury, progressing to biliary fibrosis. They are used to study primary biliary cholangitis (PBC), primary sclerosing cholangitis (PSC) and intrahepatic cholestasis. However, there has been no systematic assessment of how these mice respond therapeutically. A better understanding of this could provide insights into how effectively this model recapitulates human pathology.

Aim: We performed a systematic review and meta-analysis of published studies which used $Mdr2^{-/-}$ mice to investigate the effect of different therapies in cholestatic liver disease.

Methods: We searched PubMed, GoogleScholar, and MEDLINE (from inception to February 2024) for studies that used $Mdr2^{-/-}$ mice to assess the effect of therapeutic interventions. Four categories with the most studies were selected for further analysis: bile acid analogues (BAAs e.g. ursodeoxycholic acid), farnesoid X receptor (FXR) agonists (e.g. obeticholic acid), fibroblast growth factor 19 (FGF19) analogues, and apical sodium-dependent bile acid transporter (ASBT) inhibitors (e.g. Maralixibat). Outcomes were serum ALT and total bilirubin, bile duct proliferation (measured by immunohistochemical CK19 levels) and fibrosis (measured by immunohistochemical COL1A1 levels or Ishak fibrosis score). Random effects meta-analysis was performed throughout.

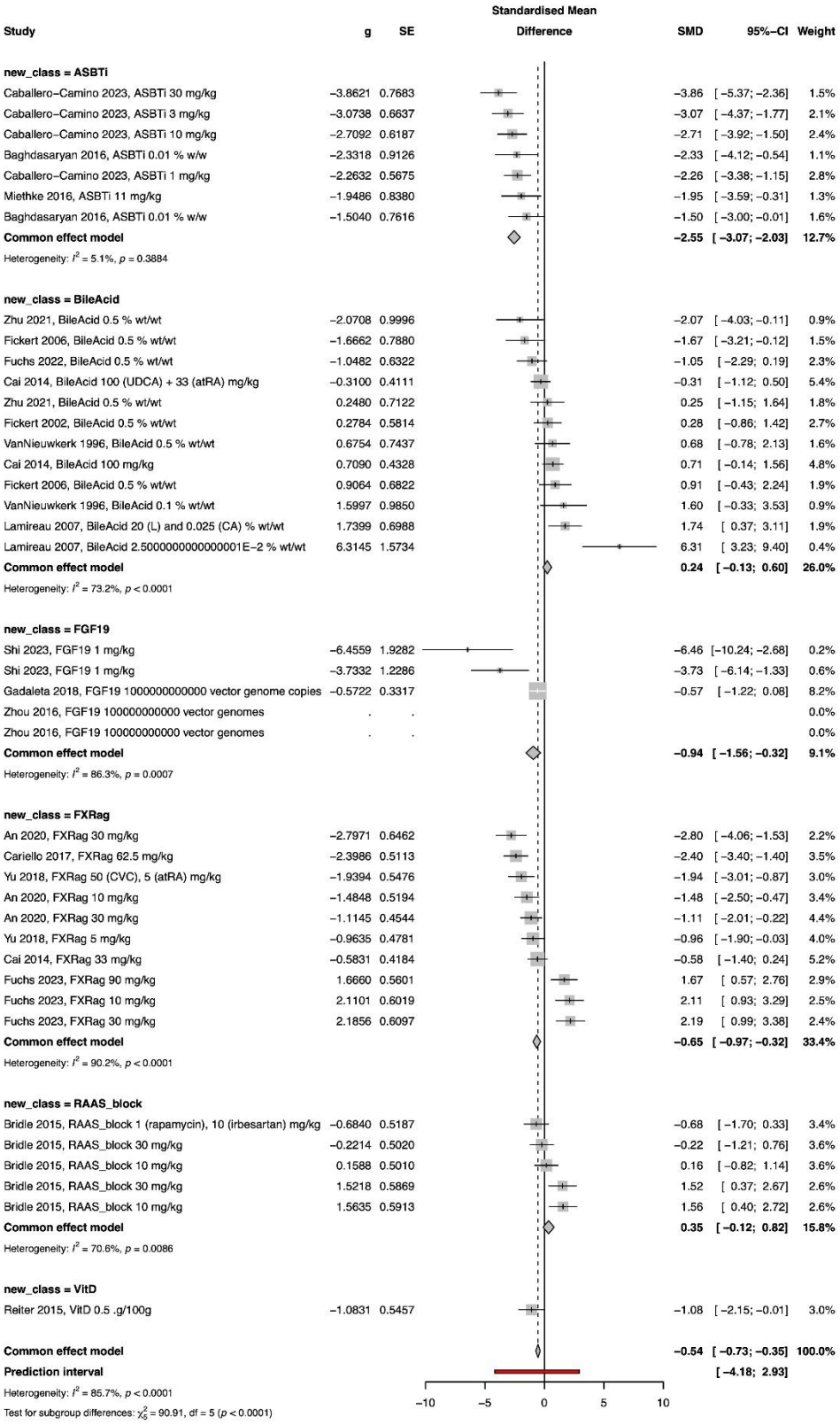
Results: 666 studies were screened. 109 studies underwent full-text review. Data was extracted from 88 studies, including 20 studies on BAAs (n=8), FXR agonists (n=5), FGF19 analogues (n=4) and ASBT inhibitors (n=3).

BAAs were not associated with significant improvements of any of the assessed outcomes, similar to patients with severe protein truncating mutations in *ABCB4* and patients with PSC. **FXR agonists** were associated with significant reductions in: bilirubin ($p=.01$), COL1A1 levels, and Ishak fibrosis score ($p<.0001$), though with substantial inter-study heterogeneity ($I^2=82\%$). These drugs are known to improve biochemistry in patients with PBC and have positive data in in phase 2B studies in PSC. **FGF19 analogues** were only associated with a reduction in Ishak fibrosis score ($p=.03$). **ASBT inhibitors** were associated with a strongly statistically significant reduction in ALT ($p=1.2\times10^{-21}$) with minimal heterogeneity ($I^2=5.1\%$), though there was insufficient studies for other outcomes. ASBT inhibitors improve liver biochemistry and transplant-free survival in patients with PFIC.

All outcomes were strongly affected by publication bias (Egger's test $p<1\times10^{-4}$) except bilirubin.

Conclusions: Mdr2-/- mice show a limited response to BAAs (including ursodeoxycholic acid), consistent with humans who have severe loss-of-function ABCB4 mutations and PSC but not PBC. Mdr2-/- mice appear to respond to modulation of other bile acid pathways (i.e. FGF19 and FXR); this is consistent with PBC and PSC and has not yet been extensively studied in PFIC. The data is heavily skewed by publication bias, except for bilirubin. With this in mind, Mdr2-/- mice effectively model severe *ABCB4* deficiency in humans, but have variable overlap with phenotype of PBC and PSC.

OC36 – Continued



OC37

Hereditary haemochromatosis in pediatrics

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Hereditary haemochromatosis (HH) is a genetic disorder causing systemic iron overload due to impaired hepcidin regulation. While extensively studied in adults, paediatric HH remains under-recognised and under-reported. Most children are identified incidentally or through family screening. Traditionally, HH has been categorised into four main types (type 1- 4) based on the genetic mutation and protein involved (Table 1). Type 1 also called classical or Human Factors Engineering (HFE)-HH results from homozygous mutation at a single locus in the Hepcidin Antimicrobial Peptide (HAMP) gene that leads to downregulation of hepcidin synthesis. Type 2- 4 HH (Table 1) is caused by pathogenic mutations in one of four genes, HFE2 (encoding hemojuvelin, type 2A), HAMP (encoding hepcidin, type 2B), encoding transferrin receptor 2 (TFR2, type 3), and solute carrier family 40 member 1 (SLC40A1, type 4). The rarity of paediatric cases mean that management strategies are largely extrapolated from adult guidelines, which may not account for differences in growth, iron requirements, and disease penetrance in children.

The aim of the study was to describe the genetic spectrum, clinical presentation, management, and outcomes of children with HH in a tertiary paediatric hepatology centre. A retrospective review was conducted of all children (≤16 years) diagnosed with genetically confirmed HH between 2007 and 2025. Demographic, clinical, biochemical, imaging data and outcomes were collected from electronic medical records. Patients were classified as HFE-related (Type 1) or non-HFE (Types 2–4) according to BIOIRON Society criteria. Descriptive statistical analysis compared disease characteristics between subgroups.

Twelve children were identified (median age at diagnosis 11 years, range 3–15). HFE-related HH accounted for 75% (n=9), while 25% (n=3) had non-HFE mutations: HJV (n=1), HAMP (n=1), and SLC40A1 (n=1). Median ferritin at diagnosis was significantly higher in the non-HFE group (2311 µg/L) compared with HFE-HH (238 µg/L). Transferrin saturation levels were similar between groups (mean 56–60%). Three patients (25%) required treatment. Two children with non-HFE HH commenced oral chelation (deferasirox) for hepatic iron overload, and one adolescent with HFE-HH received chelation for symptomatic iron excess with arrhythmia. None developed cardiac, endocrine, or cutaneous complications during follow-up. Among untreated HFE-HH patients, ferritin levels remained stable (mean 207 µg/L), and no progression of liver disease occurred. The median age at final review was 14.6 years (range 5–18); all patients remain under surveillance or have transitioned to adult care.

HFE-related HH typically follows a benign paediatric course, rarely requiring intervention before adulthood. In contrast, non-HFE (juvenile) forms present earlier with severe iron overload and warrant prompt initiation of iron-reducing therapy to prevent irreversible organ injury. Current paediatric management relies heavily on adult treatment protocols, which may risk overtreatment in growing children. A genotype-guided, risk-stratified approach incorporating serial biochemical monitoring, MRI iron quantification, and multidisciplinary follow-up is needed. Development of paediatric-specific management guidelines and structured transition pathways to adult hepatology services will be essential to optimise long-term outcomes in this rare but important condition.

References

1. Kowdley KV, Brown KE, Ahn J, Sundaram V. ACG Clinical Guideline: Hereditary hemochromatosis. *Am J Gastroenterol* 2019; 114: 1202–1218.
2. Girelli D, Busti F, Brissot P, Cabantchik ZI, Enculescu M, Kruszewski M, et al. Hemochromatosis classification: update and recommendations by the BIOIRON Society. *Blood* 2022; 139: 3018–3029.

OC38

Bile Acid Synthesis Disorders in Children: A Case Series from a Tertiary Paediatric Hepatology Centre

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Background:
Bile Acid Synthesis Disorders (BASDs) are rare, autosomal recessive causes of progressive cholestatic liver disease in childhood. Early recognition is critical, as timely medical therapy can prevent progression to liver failure and transplantation. We present a case series of children diagnosed and managed at a tertiary paediatric hepatology centre.

Methods:
We retrospectively reviewed clinical, biochemical, and genetic data of children diagnosed with BASD between 2015–2025. Diagnosis was established using urinary bile acid profile analysis and confirmed with targeted genetic testing. Clinical course, management, and outcomes were evaluated.

Results:
Children presented predominantly with cholestasis, hepatomegaly, and varying degrees of coagulopathy and growth impairment. The underlying diagnoses included 3β-hydroxy-Δ^5-C_{27}-steroid oxidoreductase deficiency and Δ^4–3-oxosteroid 5β-reductase deficiency, confirmed by urinary bile acid profiling and genetic analysis. All patients received oral cholic acid therapy as first-line treatment. The majority demonstrated significant biochemical and clinical improvement, with resolution of jaundice and normalisation of liver enzymes. A smaller subset progressed to end-stage liver disease requiring transplantation. No deaths occurred during follow-up.

Conclusion:
This series highlights the phenotypic diversity of BASDs and reinforces the importance of early diagnosis using bile acid profiling and molecular testing. Prompt initiation of bile acid replacement therapy can result in significant clinical improvement and may obviate the need for transplantation in many patients.

References

- Heubi JE, Setchell KDR, Bove KE. *Inherited disorders of bile acid metabolism.* Semin Liver Dis. 2007;27(3):282–294.
- Clayton PT. *Disorders of bile acid synthesis.* J Inherit Metab Dis. 2011;34(3):593–604.
- Subramaniam P, Clayton PT, Portmann B, et al. *Diagnosis and management of 3β-hydroxy-Δ⁵-C₂₇-steroid oxidoreductase deficiency.* Arch Dis Child. 2010;95(6):499–504.
- Vaz FM, Ferdinandusse S. *Bile acid analysis in diagnosis and monitoring of bile acid synthesis disorders.* Clin Chim Acta. 2017;459:45–52.
- Horslen SP, Davit-Spraul A, Gonzales E, et al. *Bile acid synthesis disorders and the role of liver transplantation.* J Pediatr Gastroenterol Nutr. 2021;73(2):161–169.

OC39

SINGLE-CENTRE EXPERIENCE OF USING TRIENTINE IN PAEDIATRIC WILSON'S DISEASE

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Wilson's disease (WD) is an inherited metabolic disorder which affects biliary copper excretion and synthesis as well as functional maturation of protein ceruloplasmin, leading to excessive copper accumulation in various organs, particularly the liver and brain(1). The mainstay of treatment includes chelating agents such as D-penicillamine (DP) and trientine, and zinc which reduces intestinal copper absorption. Although DP is the preferred first-line therapy, approximately 10–30% of patients experience significant adverse effects that may necessitate drug discontinuation(2). Trientine has a similar mechanism of action but has a lower incidence of side effects, making it a suitable alternative for patients who are intolerant to DP(3). In this study, we present a cohort of paediatric WD patients from a single tertiary care centre who required trientine for disease management. Their clinical characteristics, reasons for switching from penicillamine to trientine, and treatment outcomes are discussed.

The medical records of 55 children (<16 years age) diagnosed with WD in the last 20 years at our center were reviewed. Seven patients (12.7%) received trientine at some point during their treatment course. A descriptive analysis of the clinical data of these patients was performed.

Among the seven patients, three (42.9%) were detected from family screening, two (28.6%) of them had an incidental finding of liver enzymes elevation, one had co-existing autoimmune haemolytic anaemia and one presented with tremors who later developed systemic lupus erythematosus (SLE). The median age at WD diagnosis was 10 years (range 4–13 years). Six patients were initially started on DP. Indications for switching to trientine were penicillamine-induced hepatitis (n=2), proteinuria (n=1), Raynaud's phenomenon (n=1), poor treatment response (n=2). The patient who presented with tremors was treated with zinc sulfate and later developed SLE was switched to trientine directly in view of worsening liver function. The median duration between WD diagnosis and trientine initiation was 2.9 years (range 1.1–8.3 years). At the most recent follow-up, four patients had transitioned to adult care while stable on trientine, and three remained under paediatric follow-up with mild transaminitis but good overall clinical stability. No patient discontinued trientine due to adverse effects.

DP can cause early-onset (1-3 weeks) and late-onset adverse effects. Early hypersensitivity reactions are characterized by fever, cutaneous eruptions, cytopenias, and proteinuria. Much rarer late-onset (years or decades) reactions which are potentially fatal include drug-induced lupus, nephrotic syndrome leading to renal failure, severe thrombocytopenia, or aplastic anemia(4). All our patients experienced late-onset adverse effects, with Raynaud's phenomenon being a particularly rare occurrence. In the event of a severe reaction, DP should be discontinued and patient switched to an alternative therapy. Although hypersensitivity reactions and pancytopenia can occur with trientine as well, however these were not seen in our cohort.

To conclude, trientine is effective and well tolerated in children when used as second line for therapy for Wilson's disease.

References

1. Leung M, Wu Lanzafame J, Medici V. Switching Pharmacological Treatment in Wilson Disease: Case Report and Recommendations. Journal of Investigative Medicine High Impact Case Reports. 2020 Jan;8:2324709619896876.
2. Socha P, Jańczyk W, Zanetto A, Burra P, Czlonkowska A, Debray D, et al. EASL-ERN Clinical Practice Guidelines on Wilson's disease. Journal of Hepatology. 2025 Apr 1;82(4):690–728.
3. Nagral A, Sarma MS, Matthai J, Kukkle PL, Devarbhavi H, Sinha S, et al. Wilson's Disease: Clinical Practice Guidelines of the Indian National Association for Study of the Liver, the Indian Society of Pediatric Gastroenterology, Hepatology and Nutrition, and the Movement Disorders Society of India. Journal of Clinical and Experimental Hepatology. 2019 Jan;9(1):74–98.
4. Aggarwal A, Bhatt M. Advances in Treatment of Wilson Disease. Tremor and Other Hyperkinetic Movements. 2018 Feb 28;8(0):525.

OC40

Clinical characteristics, predictors, and outcomes of transaminitis in children presenting to a paediatric emergency department: a retrospective evaluation

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Liver function tests (LFTs) are frequently requested in paediatric emergency departments (PEDs), often yielding incidental findings of derangement.[1] While many abnormalities are benign and transient, some reflect underlying liver pathology.[2] There is limited guidance on interpreting mildly deranged LFTs and determining when follow-up is warranted.[3] The aim of the study was to evaluate the demographic and clinical characteristics of children undergoing LFT testing in PED at a major urban paediatric hospital in Wales, and to determine associations with transaminitis and LFT derangement.

This retrospective service evaluation included 80 children aged 6 months to 16 years who underwent LFT testing between August 2023 and August 2024. Clinical records were reviewed for biometrics, demographics, symptoms, past medical and drug history, nutritional status, and follow-up outcomes. Alanine aminotransferase (ALT) derangement (transaminitis) was used as a primary outcome due to its relative specificity as a marker of hepatocellular injury[4], and was defined based on the local reference ranges (ALT ≥26 IU/L in children aged 1-13 years, ≥23 IU/L in females 13-19 years old and ≥25 IU/L in males 13-19 years old). Using STATA software, univariable logistic regression was performed to assess predictors of transaminitis and LFT derangement, and linear regression was used to examine associations with ALT value.

Of the 80 children, 41 (51.3%) had at least one LFT derangement and 18 (22.5%) had transaminitis. Due to missingness of data, BMI had to be excluded from the analysis. In univariate analysis, none of the variable were statistically significantly associated with transaminitis. Multivariable regression modelling could not be performed for transaminitis as only dehydration met the inclusion threshold. For LFT derangement, age and hepatotoxic medication use were included in the multivariable analysis but were not statistically significant. In multivariable analysis of ALT values, hepatological symptoms and acute febrile illness with liver symptoms were significantly associated with ALT elevation (coefficient = 347.66 and 347.84 respectively, both $p < 0.001$). These associations reflect a single patient with marked transaminitis. No other symptom groupings demonstrated significant associations.

Only 7 children (38.9% of those with transaminitis) received follow-up. Three were diagnosed with the following: metabolic dysfunction-associated steatotic liver disease, gallstones, Epstein-Barr virus-induced hepatitis. The remaining four children had blood tests that normalised or remained mildly elevated, leading to discharge. The median ALT among those followed up was higher (129 IU/L, IQR 44.5 – 196.4) than in those not followed up (31 IU/L, IQR 28-53). This may reflect selective follow-up of patients with more pronounced derangement.

The study was limited by its retrospective design, missing data, a small sample size and a single-centre source of data. However, it addressed a clinically relevant, under-researched area directly applicable to frontline practice, and could therefore be treated as a useful pilot study for further research.

In summary, transaminitis is a common finding in children undergoing LFTs in PED but most cases are not followed up. Developing local protocols for LFT interpretation and follow-up could help ensure that significant cases are identified while avoiding unnecessary investigations.

References

1. Er A, Çakar S, Ermiş N, et al. Etiology, Laboratory and Clinical Course of Elevated Transaminases in Pediatric Emergency Department. Journal of Pediatric Emergency and Intensive Care Medicine. 2021 Apr 1;8(1):42–9.
2. Bugeac N, Pacht A, Mandel H, et al. The Significance of Isolated Elevation of Serum Aminotransferases in Infants and Young Children. Archives of Disease in Childhood [Internet]. 2007 Dec 1 [cited 2025 Apr 24];92(12):1109–12. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2066067/
3. Vajro P, Maddaluno S, Veropalumbo C. Persistent Hypertransaminasemia in Asymptomatic children: a Stepwise Approach. World Journal of Gastroenterology. 2013;19(18):2740.
4. Ventureira VF, Arnal IR, Martínez GR, et al. Evaluation of Liver Function Tests in the Paediatric Patient. Anales De Pediatria. 2021 Jun 1;94(6):359–65.

OC41

Evaluating non-invasive serum fibrosis markers against histological findings in paediatric liver transplant recipients

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Non-invasive assessment of liver fibrosis is increasingly important in paediatric liver transplant recipients, as ongoing graft fibrosis threatens long-term outcomes but biopsies remain invasive and associated with morbidity (1). Serum indices such as APRI (AST to Platelet Ratio Index), Forns index, and FIB-4 (Fibrosis-4) have been widely studied in adults; however, recent studies suggest reduced diagnostic reliability in paediatric and post-transplant settings, with variable sensitivity and specificity. Despite advances in novel biomarkers and imaging modalities, data directly comparing these indices with histological findings in paediatric transplant cohorts remain limited (2,3). This study evaluted non-invasive serum fibrosis markers against histological findings in paediatric liver transplant recipients

This retrospective study included 109 children who underwent protocol liver biopsies at 1 and 5 years post-transplant between 2017 and 2023. Patients were included if blood tests results were available within 24 hours of biopsy. Non-invasive fibrosis assessment included the APRI, Fib-4 index, and Forns index. Histopathology fibrosis was graded as nil, mild, moderate, or severe as reported by a specialist histopathologist.

Ordinal proportional-odds regression models were used to assess associations between each score and fibrosis severity. Diagnostic performance was evaluated using receiver operating characteristic (ROC) curve analysis. Two ROC comparisons were performed: (1) any fibrosis (mild–severe) vs nil (ROC-1) and (2) clinically significant fibrosis (moderate + severe) vs nil + mild (ROC-2). For each score, the area under the ROC curve (AUC), optimal thresholds, and corresponding sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV) were calculated.

In the proportional-odds models, none of the three indices demonstrated statistically significant associations with fibrosis severity (all $p > 0.05$). In ROC-1 analysis, discrimination was poor for all scores: AUC = 0.47 (95% CI 0.33–0.59) for APRI, 0.49 (0.36–0.62) for FIB-4, and 0.48 (0.35–0.60) for Forns. ROC-2 analysis showed modest improvement: AUC = 0.59 (0.46–0.71) for APRI, 0.59 (0.47–0.72) for FIB-4, and 0.63 (0.50–0.75) for Forns. At optimal thresholds (APRI = 0.44, FIB-4 = 0.24, Forns = –2.53), sensitivities/specificities were 0.59/0.63, 0.63/0.61, and 0.84/0.49, respectively. PPVs ranged from 0.35–0.37 and NPVs from 0.83–0.91.

Table 1-Diagnostic performance of non-invasive serum fibrosis markers versus histology in paediatric liver transplant recipients

Score	Odds ratio (per unit)	95% CI	ROC-2 AUC (Mod/severe vs Nil/mild)	95% CI	Optimal threshold	Sensitivity	Specificty	PPV	NPV
APRI	1.30	0.9 - 1.96	0.59	0.46 - 0.71	0.44	0.59	0.63	0.34	0.82
Fib-4	1.93	0.83 - 11.83	0.59	0.47 - 0.72	0.24	0.63	0.61	0.35	0.83
Forn's	1.07	0.92 - 1.22	0.63	0.50 - 0.75	-2.53	0.84	0.49	0.35	0.91

In differentiating moderate or severe fibrosis from nil or mild disease, Forns index showed the greatest diagnostic accuracy, followed by FIB-4 and APRI. Although none achieved strong discriminatory performance, all three demonstrated acceptable NPVs (>0.8) suggesting potential utility as screening tools to exclude advanced fibrosis. The absence of contemporaneous FibroScan (elastography) data limited direct comparison between serum markers and imaging-based assessment. Non-invasive markers alone remain insufficiently sensitive post-transplant, underscoring the need for protocol biopsies and further correlation with elastography and novel biomarkers.

References

1. Ozdogan E, Moore NA, Park WD et al. Liver fibrosis in children: a comprehensive review of pathogenesis, diagnosis and current treatment strategies. Pediatr Gastroenterol Hepatol Nutr. 2022;25(1):1-14.
2. Vo HD, Xenidis D, O'Riordan A et al. Diagnostic performance of non-invasive tests for evaluation of hepatic graft fibrosis in children. Clin Transplant. 2020;34(11):e14017.
3. Vo HD, Harp KA, Mauch TJ. Diagnostic performance of non-invasive tests for evaluation of hepatic graft fibrosis in pediatric liver transplantation: a scoping review. Transpl Rev (Orlando). 2020;34(4):100568. doi:10.1016/j.trre.2020.100568

OC42

Granulomatous interstitial nephritis in paediatric Crohn's disease. A case report.

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Introduction: Inflammatory bowel diseases (IBD) comprise Crohn's disease, ulcerative colitis, and IBD-unclassified (IBDU). Although primarily affecting the gastrointestinal tract, extraintestinal manifestations (EIMs) occur in 6-46% of patients, most frequently involving the joints, eyes, skin, liver, and biliary tract. Renal EIMs are reported in 4-23% of adults with IBD, while their prevalence in children remains uncertain[1]. Renal involvement may arise as a direct manifestation of systemic inflammation or as a complication of treatment[2]. The most frequent renal pathologies include nephrolithiasis, tubulointerstitial nephritis, glomerulonephritis, and amyloidosis[1]. Granulomatous interstitial nephritis (GIN) is a particularly rare EIM of Crohn's disease, accounting for 0.5-0.9% of renal cases, and is most often drug-induced, especially by 5-aminosalicylic acid (5-ASA)[3]. However, non-drug-induced cases have also been described in both adults and children[4].

Case presentation: We report the case of a 15-year-old female diagnosed in November 2023 with IBD-U, presenting with pancolitis and histological evidence of moderate inflammation with granuloma formation in the left colon. Small bowel MRI demonstrated no terminal ileum involvement. The patient's initial IBD treatment included oral prednisolone and mesalamine, achieving clinical remission and mucosal healing by September 2024, at which point mesalamine was discontinued. Concomitantly, at diagnosis, blood tests showed mild renal impairment with raised creatinine (81 µmol/L), while urine output and blood pressure were normal, and there were no clinical symptoms. Baseline investigations for abnormal creatinine were unremarkable. The patient underwent regular gastroenterology follow-up visits, during which renal function was repeatedly monitored, showing fluctuating levels of urea and creatinine over time. In summer 2025, the patient experienced a relapse characterized by abdominal pain, diarrhoea, fatigue, poor appetite, and weight loss.. Simultaneously, the creatinine level increased further, reaching its peak value of 123 µmol/L. A reassessment colonoscopy was planned and, in view of the persistent renal function abnormalities, she was referred to the paediatric nephrology unit for further diagnostic evaluation. Although the patient remained asymptomatic from a renal perspective and all repeated baseline evaluations were normal, a renal biopsy was performed in October 2025. It showed marked interstitial inflammatory infiltrate with tubulitis and tubular injury, with epithelioid histiocytes probably associated with a disrupted tubule. This was likely an extraintestinal manifestation of Crohn's disease or a complication of 5-ASA use. Colonoscopy revealed active inflammation, subsequently confirmed at histology as Crohn's colitis with ill-defined granulomas. Extensive investigations for infectious and systemic granulomatous diseases, including tuberculosis, sarcoidosis, and ophthalmology evaluation for uveitis, were all negative. A diagnosis of acute tubulointerstitial nephritis with early granulomatous formation was made. The case was discussed at a multidisciplinary team meeting involving gastroenterologists and nephrologists, and upon completion of investigations the patient was commenced on oral corticosteroids. She will continue follow-up in the outpatient clinic, with biologic therapy with anti-TNF to be considered if required.

Conclusion: This case illustrates a rare instance of granulomatous interstitial nephritis associated with Crohn's colitis, emphasizing the need for systematic renal monitoring in paediatric IBD and the crucial role of MDT collaboration in managing complex presentations.

References

1. Corica D, Romano C. Renal involvement in inflammatory bowel diseases. J Crohns Colitis. 2016;
2. Pardi DS, Tremaine WJ, Sandborn WJ et al. Renal and urologic complications of inflammatory bowel disease. Am J Gastroenterol. 1998;
3. Itoh N, Kasuno K, Yasutomi M, et al. Crohn's disease with granulomatous interstitial nephritis as an extraintestinal complication from the time of the diagnosis. Intern Med. 2025;
4. Mohamed MMB, Flores-Santiago J, Perincheri S, et al. Granulomatous interstitial nephritis in a treatment-naïve patient with ulcerative colitis. Ren Fail. 2022.

OC43

The Successful Use of Infliximab In A 3-Month-Old Infant With Non-Monogenic Inflammatory Bowel Disease

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Inflammatory bowel diseases (IBD), including ulcerative colitis and Crohn's disease , are chronic immune-mediated inflammatory disorders of the gastrointestinal tract that often emerge in adolescence or early adulthood. Approximately one quarter of IBD cases present before 20 years of age, and 4% occur before age five. Very early-onset IBD (VEO-IBD) is defined as diagnosis before six years, and infantile-onset IBD (IO-IBD) refers to diagnosis before two years. IO-IBD constitutes roughly 1–2% of all paediatric IBD cases. Known causative monogenic mutations account for only about 7.8% of VEO-IBD, representing 30% of IO-IBD. Consequently, non-monogenic IO-IBD remains underreported.

A three-month-old male presented with frequent bloody diarrhoea to local hospital, he was suspected to have infection therefore was started on ceftriaxone, gentamicin and metronidazole. Also, breastfeeding was switched to amino-acid formula. Initial workup at the referring hospital revealed positive cytomegalovirus (CMV) serology and DNA; ganciclovir was commenced. Despite all treatments and feeding change his symptoms persisted, prompting referral to our hospital. On admission, he continued to have bloody, loose stools, requiring multiple blood and albumin transfusions. He was maintained nil by mouth and on parenteral nutrition (PN). Esophagogastroduodenoscopy (OGD) revealed erythematous, exudative mucosa in the stomach and duodenum, while colonoscopy (limited by a descending colon stricture) demonstrated friable, ulcerated mucosa. Histopathology confirmed active inflammation consistent with IO-IBD and CMV was ruled out. Comprehensive immunological and genetic evaluation for monogenic IBD, revealed no abnormalities. Intravenous corticosteroid induction was initiated but discontinued after 11 days due to non-response and worsening gastrointestinal bleeding. Emergency endoscopy identified large ulcerations in the descending colon requiring haemostatic spray. As steroid-refractory disease was evident, infliximab (5 mg/kg) was commenced. After two loading doses, clinical and biochemical remission was achieved: normalised CRP, improved albumin and haemoglobin, and reduction in stool frequency to 3–4 formed motions daily without blood or mucus. Follow-up endoscopy showed marked mucosal healing though residual oedema and skip lesions persisted. Histopathology confirmed quiescent proctocolitis, and the patient was discharged on oral sulfasalazine.

From a nutritional perspective, the infant received tailored PN for 68 days, providing ~100 kcal/kg/day and 3.3 g/kg/day of protein per ASPEN and BSPGHAN recommendations. Adjustments for catabolic stress and protein loss were made, and metabolic stability was maintained through PN cycling and lipid modulation. A gradual oral transition using an amino-acid-based formula achieved full enteral feeds over 18 days, resulting in significant catch-up growth from below the 1st percentile to above the 3rd percentile.

This case represents one of the youngest reported examples of non-monogenic IO-IBD, an under-reported cohort. It highlights the importance of considering broader differential diagnosis in infants presenting with bloody diarrhoea. Also, our experience with this case demonstrated safe use of infliximab in very young infants.
Early multidisciplinary management—including full endoscopic evaluation with OGD, exclusion of immunodeficiency and monogenic causes, early biologic therapy with proactive therapeutic drug monitoring, and comprehensive nutritional support—is essential for optimising outcomes in steroid-refractory IO-IBD.

Comparison of basic blood test and faecal calprotectin pre and post treatment

Parameter	Reference Range	11/04/25	15/06/25	Trend
White Cell Count (10^9/L)	(6.0 - 18.0)	17.6	10.4	↓
Haemoglobin (g/L)	(111 – 141)	80	87	↑
Haematocrit (L/L)	(0.300 - 0.400)	0.246	0.266	↑
MCV (fL)	(68 – 84)	76	81	↑
Platelet Count (10^9/L)	(200 – 550)	313	284	↓
Neutrophils (10^9/L)	(1.00 - 6.00)	10.63	1.35	↓
Lymphocytes (10^9/L)	(4.00 - 12.00)	6.24	7.93	↑
Albumin (g/L)	(25 – 46)	15	32	↑↑
CRP (mg/L)	(<5)	78	42	↓
ALT (U/L)	(5 – 51)	55	60	→
AST (U/L)	(23 – 83)	87	63	↓
GGT (U/L)	(<55)	28	-	
ALP (U/L)	(60 – 425)	114	324	↑
Total Bilirubin (µmol/L)	(<21)	6	4	↓
Sodium (mmol/L)	(133 – 146)	135	134	→
Potassium (mmol/L)	(3.5 - 5.7)	4.2	4.5	→
Phosphate (mmol/L)	(1.30 - 2.40)	1.11	1.87	↑
Magnesium (mmol/L)	(0.70 - 1.00)	0.66	0.74	↑
Adjusted Calcium (mmol/L)	(2.20 - 2.70)	2.27	2.44	↑
Infliximab Level (µg/mL)	—	-	19.4	—
Faecal calprotectin		2770	603	↓

References

Kelsen JR, Sullivan KE, Rabizadeh S, Singh N, Snapper S, Elkadri A, et al. North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition Position Paper on the Evaluation and Management for Patients With Very Early-onset Inflammatory Bowel Disease. J Pediatr Gastroenterol Nutr. 2020;70(3):389-403.

2. Guz-Mark A, Aloi M, Scarallo L, Bramuzzo M, Escher JC, Alvisi P, et al. Infantile and Very Early Onset Inflammatory Bowel Disease: A Multicenter Study. Pediatrics. 2024;154(2).

3. Chapuy L, Leduc B, Godin D, Damphousse A, Patey N, Dal Soglio D, et al. Phenotype and outcomes of very early onset and early onset inflammatory bowel diseases in a Montreal pediatric cohort. Front Pediatr. 2023;11:1157025.

4. Kammermeier J, Dziubak R, Pescarin M, Drury S, Godwin H, Reeve K, et al. Phenotypic and Genotypic Characterisation of Inflammatory Bowel Disease Presenting Before the Age of 2 years. J Crohns Colitis. 2017;11(1):60-9.

5. Mesotten D, Joosten K, van Kempen A, Verbruggen S, nutrition EEECwgopp. ESPGHAN/ESPEN/ESPR/CSPEN guidelines on pediatric parenteral nutrition: Carbohydrates. Clin Nutr. 2018;37(6 Pt B):2337-43.

6. Uhlig HH, Charbit-Henrion F, Kotlarz D, Shouval DS, Schwerd T, Strisciuglio C, et al. Clinical Genomics for the Diagnosis of Monogenic Forms of Inflammatory Bowel Disease: A Position Paper From the Paediatric IBD Porto Group of European Society of Paediatric Gastroenterology, Hepatology and Nutrition. J Pediatr Gastroenterol Nutr. 2021;72(3):456-73.

OC44

Ustekinumab in Paediatric Inflammatory Bowel Disease: A single tertiary centre experience

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Ustekinumab, a monoclonal antibody to interleukins (IL) 12 and 23, is proven to be effective in induction and maintenance of remission in both adult and paediatric inflammatory bowel disease (PIBD), although it remains unlicensed for the paediatric population. Anti-tumour necrosis factor (TNF) (infliximab and adalimumab) are recommended as first line biologics in PIBD, but are associated with primary non-response rates of around 30% with further patients experiencing secondary loss of response over time (1). Multicentre studies have shown remission rates of 50%, 59.6% and 63.8% at 16, 26 and 52 weeks respectively in ulcerative colitis (UC) and inflammatory bowel disease unclassified (IBDU) (1) and 41.2% at week 48 in Crohn's disease (CD) (2). Standard dosing involves an initial weight based IV dose followed by weight based subcutaneous dose at 8 weeks then 12 weekly thereafter. There is limited data on therapeutic level targets and antibody formation and variable access between centres to this monitoring.

We aimed to evaluate the outcomes of patients treated with ustekinumab in our tertiary centre.

11 patients receiving ustekinumab were identified from the departmental database and electronic records were retrospectively reviewed. Data was collected on diagnosis, age at diagnosis, disease location, perianal disease, previous treatment with biologics or immunomodulators, reason for switching to ustekinumab, response to ustekinumab, need for any dose modification or switch to an alternative biologic.

Age ranged from 3 – 14 years. All patients had Crohn's disease. 7/11 (64%) had ileocolonic disease, 3/11 (27%) colonic and 1/11 (9%) upper gastrointestinal and ileocolonic disease. 7/11 (64%) had perianal disease. Ustekinumab was the 2nd biologic for 3/11 (27%), 3rd for 7/11 (64%), 4th for 1/11 (9%). Of those receiving ustekinumab as 3rd line biologic, 6/7 (86%) switched from one anti-TNF to the other before switching to ustekinumab, 1/7 switched from infliximab to vedolizumab then to ustekinumab. The patient receiving ustekinumab as 4th line had received infliximab, adalimumab and vedolizumab prior to switching to ustekinumab.
Reasons for switching to ustekinumab were recorded as primary non-response to 2 anti-TNF agents (1/11), primary non-response to 2 anti-TNF agents and vedolizumab (1/11), secondary loss of response to anti-TNF (4/11), secondary loss of response to anti-TNF then vedolizumab (1/11), antibody formation to anti-TNF (3/11), and 1/11 did not have rationale for switching clearly documented.

7/11 (64%) had documented clinical response or remission after switching to ustekinumab. 2 patients not responding subsequently switched from ustekinumab to vedolizumab. 1 patient underwent surgery due to failing medical management. 1 patient required dose optimisation based on symptoms. Measurement of levels and antibodies were not available during the period of this study. There were no adverse events reported.
In conclusion, ustekinumab is a safe and effective therapy in paediatric Crohn's disease with response rates in line with published literature. Response may be seen after failure of 2 or more alternative biologics. Large scale multicentre studies to establish therapeutic levels and access to level and antibody measurement may assist with dose optimisation and prevent treatment failure.

References

1. Cohen S, Rolandsdotter H, Kolho KL, Turner D, Tzivinikos C, Bramuzzo M, Pujol-Muncunill G, Scarallo L, Urlep D, Rinawi F, Granot M, Kang B, Longueville Y, Rodríguez-Belvís MV, Weintraub Y, Navas-López VM, Yerushalmy-Feler A. Effectiveness and Safety of Ustekinumab in Pediatric Ulcerative Colitis: A Multi-center Retrospective Study from the Pediatric IBD Porto Group of ESPGHAN. Paediatr Drugs. 2024 Sep;26(5):609-617. doi: 10.1007/s40272-024-00631-z. Epub 2024 May 23. PMID: 38780740; PMCID: PMC11335845.
2. Turner D, Rosh JR, Cohen SA, Griffiths AM, Hyams JS, Kierkuś J, Adedokun OJ, Strauss R, Kim L, Volger S; UniStar Study Group. Ustekinumab in paediatric patients with moderately to severely active Crohn's disease: UniStar study long-term extension results. J Pediatr Gastroenterol Nutr. 2024 Aug;79(2):315-324. doi: 10.1002/jpn3.12252. Epub 2024 May 27. PMID: 38801079.

OC45

The use of subcutaneous infliximab in a cohort of post-pubertal patients in a paediatric setting.

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Infliximab is recommended for treatment of patients with severe active inflammatory bowel disease, those who have not responded to or are intolerant to conventional therapy (1) ESPGHAN recommends trough infliximab levels of 5-10 for maintenance treatment, with higher levels for perianal disease (2)

Within this paediatric tertiary centre there was an increasing clinical demand for patients commencing biologics. 31% of patients receiving intravenous infliximab were aged 16-18. Increasing biologic use resulted in 6-8 week waiting times for patients to start biologics due to limited capacity. Lack of day case capacity delayed discharge by up to 7 days in 4 patients at the time of review.

Subcutaneous infliximab has been widely used since 2020 within the adult sector across Europe. Clinical advantages and positive impact on health-related quality of life were observed(3.)

Subcutaneous infliximab has been shown to be non-inferior to IV infliximab from pharmacological and clinical perspectives (4). Safe switching from IV to subcutaneous infliximab whilst ensuring continued clinical remission has been demonstrated (5).

Whilst the majority of evidence is adult based, there has been a single centre cohort of paediatric patients evidencing clinical remission and therapeutic trough levels (6)

We aimed to evaluate a cohort of IBD patients switching from intravenous to subcutaneous infliximab. Inclusion criteria were post pubertal, >40kg, stable disease (inflammatory markers in range, asymptomatic, with therapeutic infliximab levels and no antibodies (with the exception of low levels due to difficult IV access). Suitable patients were identified from the IBD database and the virtual biologics clinic. Registration with the hospital's Quality Improvement department was completed and approval granted from the hospital's Medicines Management Committee.

17 paediatric patients were switched with a mean age of 16.2. 15/17 had therapeutic levels, 2/17 had suboptimal levels but switched due to poor IV access. Patients received written information and verbal counselling in order to consent to the switch.

Bloods including inflammatory markers and infliximab levels are obtained pre: 5th dose of subcutaneous infliximab. 5 patients in the study have not yet reached this period to have these bloods taken.

Patient	Levels pre switch	Levels post switch	ESR pre switch	ESR post switch
A	1.4	17.3	21	10
B	2.1	20.3	6	2
C	6	16.60	6	9
D	8.5	14.8	6	13
E	7.5	22.5	5	2
F	12.2	12.7	2	2
G	9.6	16.1	2	2
H	9.3	15.1	2	2
I	4.4	24.1	17	0
J	4.2	13.9	16	29
K	6.2	21.7	2	2

Clinical advantages were identified following the switch to subcutaneous infliximab, demonstrated by increased serum levels, efficacy outcomes, and reduction in IV access issues. Patient feedback identified the change has impacted positively on quality of life, improved access to treatment, and improved attendance in education.

This change has also impacted the healthcare burden as this has reduced attendance to the daycase unit following induction. Whilst there is little difference in cost of subcutaneous infliximab compared to intravenous, there is a considerable saving through reduction in need for regular hospital attendance for drug administration.

References

1.NICE (2019). *Recommendations | Crohn's disease: Management | Guidance | NICE*. [online] www.nice.org.uk. Available at: https://www.nice.org.uk/guidance/ng129/chapter/Recommendations#maintaining-remission-in-crohns-disease.

2.Turner et al (2018) Management of Paediatric Ulcerative Colitis, Part 2: Acute Severe Colitis—An Evidence-based Consensus Guideline From the European Crohn's and Colitis Organization and the European Society of Paediatric Gastroenterology, Hepatology and Nutrition. *JPGN*. 67 (2), pp.292-310.

3. Alten R, An Y, Kim DH, Yoon S, Peyrin-Biroulet L. Re-Routing Infliximab Therapy: Subcutaneous Infliximab Opens a Path Towards Greater Convenience and Clinical Benefit. Clin Drug Investig. 2022 Jun;42(6):477-489. doi: 10.1007/s40261-022-01162-6. Epub 2022 Jun 3. PMID: 35657560.

4.Stefan Schreiber, Shomron Ben-Horin, Jaroslaw Leszczyszyn, Robert Dudkowiak, Adi Lahat, Beata Gawdis-Wojnarska, Aldis Pukitis, Marek Horynski, Katalin Farkas, Jaroslaw Kierkus, Maciej Kowalski, Sang Joon Lee, Sung Hyun Kim, Jee Hye Suh, Mi Rim Kim, Seul Gi Lee, Byong Duk Ye, Walter Reinisch,Randomized Controlled Trial: Subcutaneous vs Intravenous Infliximab CT-P13 Maintenance in Inflammatory Bowel Disease,Gastroenterology,Volume 160, Issue 7, 2021,Pages 2340-2353, ISSN 0016-5085, https://doi.org/10.1053/j.gastro.2021.02.068.(https://www.sciencedirect.com/science/article/pii/S0016508521004741)

5. Philip J Smith et al. Efficacy and Safety of Elective Switching from Intravenous to Subcutaneous Infliximab [CT-P13]: A Multicentre Cohort Study, *Journal of Crohn's and Colitis*, Volume 16, Issue 9, September 2022, Pages 1436–1446, https://doi.org/10.1093/ecco-jcc/jjac053

6. Gianolio L, Armstrong K et al. Effectiveness of Switching to Subcutaneous Infliximab in Pediatric Inflammatory Bowel Disease Patients on Intravenous Maintenance Therapy. J Pediatric Gastroenterol Nutr. 2023 Aug 1;77(2):235-239. doi: 10.1097/MPG.0000000000003838. Epub 2023 May 23. PMID: 37219971.

OC46

A Single-Centre Retrospective Study on the Response and Effectiveness of Exclusive Enteral Nutrition in Children Newly Diagnosed with Crohn's Disease at a Tertiary Care Centre

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Exclusive enteral nutrition(EEN) is the cornerstone for the induction of remission in the mild to moderate form of active paediatric Crohn's disease(CD)[1,2]. While this steroid-sparing treatment, endorsed by the ECCO-ESPGHAN 2021 guidelines, is effective in inducing short-term remission in CD patients [3], exploration of sustained effects in the multi-ethnic UK paediatric cohort remains limited in the literature.

Objective

This study evaluated the remission rates post-EEN at 6 weeks and 6 months in children newly diagnosed with CD at a tertiary care centre. The study focused on exploring anthropometric, demographic, biochemical and phenotypic predictors of remission in the cohort.

Methods

The single-centre retrospective study included 58 out of 74 eligible children aged <17 years with a new diagnosis of CD, who completed a 6-week course of EEN from January 2023 to January 2025. Data were extracted from an electronic medical record system called Cerner Millennium (CRS) from a tertiary care centre in London, UK. Remission rates were calculated 6 weeks and 6 months post-EEN completion through biochemical markers (ESR, CRP and albumin), from physician assessment through clinic letters and Paediatric Crohn's Disease Activity Index (PCDAI) scores. Statistical analysis using SPSS was performed. Odds ratios and p-values were calculated to assess significance, which was set at $p < 0.05$.

Results

Following the completion of EEN at 6 weeks, 38/58 (66.0%) of patients achieved both biochemical and clinical remission. Sustained remission rate at 6 months was 36/58 (62.1%), of whom 80.6% required escalation therapy with biologics or immunomodulators, or a combination of both. CRP and ESR emerged as the strong predictors of remission ($p < 0.001$ and $p = 0.006$ at 6 weeks, respectively) and ($p < 0.001$ for both) at 6 months. The odds ratios at 6 months were 17.6 and 13.6, respectively. Serum albumin and BMI improved during EEN therapy ($p < 0.001$); however, they did not retain their predictive value at 6 months post-EEN ($p = 1.000$). Terminal ileal disease (L1) showed the highest remission rate with EEN alone, 88.9% at 6 weeks. At 6 months, Ileocolonic disease (L3) showed the highest remission rate, 70.4% with EEN and combination therapy. However, they did not reach statistical significance ($p>0.05$) when compared to other phenotypes. Child's age and gender also did not influence remission rates across both time points.

Conclusion

EEN is effective in inducing remission in active paediatric CD, especially in the short term. However, maintenance often requires escalation to combination therapy with immunomodulators or biologics, reflecting the high-risk cohort in this centre. The CRP and ESR are significant predictors of response to EEN, and their predictive strength is independent of phenotype and escalation, suggesting their normalisation as a biochemical threshold for the durability of the treatment. The nutritional benefits from EEN are undeniable, but they are not predictive of remission, thus reinforcing the need for CRP and ESR-driven monitoring approaches in clinical practice. The study aligns with the growing consensus that disease phenotype should not limit EEN use, supporting its universal application as induction therapy in paediatric Crohn's disease.

References

1. Ashton JJ, Gavin J, Beattie RM. Exclusive enteral nutrition in Crohn's disease: Evidence and practicalities. Clin Nutr. 2019 Feb;38(1):80-89. doi: 10.1016/j.clnu.2018.01.020. Epub 2018 Feb 15. PMID: 29398336.

2. Sandrine C, Emmanuelle D, Jérôme V, Martinez-Vinson C. Exclusive enteral nutrition for induction of remission in pediatric Crohn's disease: Short- and long-term tolerance and acceptance. JPGN Rep. 2024 Dec 30;6(1):11-18. doi: 10.1002/jpr3.12163. PMID: 39944105; PMCID: PMC11810808.

3. van Rheenen PF, Aloi M, Assa A, Bronsky J, Escher JC, Fagerberg UL, et al. The Medical Management of Paediatric Crohn's Disease: An ECCO-ESPGHAN Guideline Update. J Crohns Colitis. 2021;15(2):171–194.

OC47

Audit of catheter-related bloodstream infections in paediatric intestinal failure patients on home parenteral nutrition

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Catheter-related bloodstream infections (CRBSI) are a life-threatening complication in children who require long-term parenteral nutrition (PN).[1] The CRBSI rate for our centre was 1.17/1000 catheter days between 1st October 2022 and 1st October 2023.[2] This was a follow-up study to assess our current infection rate.

Patients enrolled in the centre's tertiary intestinal failure (IF) rehabilitation home PN service from 1st October 2024 to 1st October 2025 were included. Information regarding infections and potential risk factors for CRBSI were prospectively recorded.

42 patients were included. Half of the patients were female, and the median (25th-75th Q.I.) age was 10 (5.75-15) years. PN was initiated primarily for short bowel syndrome (45.2%), followed by gastrointestinal motility disorders (40.5%), intestinal mucosal diseases (9.5%) and immune-haem-oncological disorders (4.8%). Unlike the previous study, no patients in this cohort received PN due to severe neurodevelopmental impairment. 7/42 (16.7%) patient families on home PN were identified as vulnerable with difficulty prioritising their child's health needs, which resulted in a delayed presentation of suspected CRBSI. Patient characteristics are shown in Table 1.

Table 1. Characteristics of children in the home PN programme

	n	%
Total patients	42	
Females	21	50.0
Recorded episodes of infections (hospital-acquired)	5	50.0
Short bowel syndrome	19	45.2
Gastrointestinal motility disorders	17	40.5
Intestinal mucosal diseases	4	9.5
Immune-Haem-Oncological disorders	2	4.8
Severe neurodevelopmental impairment	0	0.0
Vulnerable families*	7	16.7
Central venous catheter care with gloves	15	35.7
Single lumen	37	88.1
Central line	38	90.5
Taurolock	30	71.4

*Psycho-social issues interfering with ability to prioritise PN care

10 episodes of CRBSI occurred among 5/42 (11.9%) patients, with one patient experiencing two episodes and two patients having three episodes each. The median (25th-75th Q.I) age of patients with CRBSI was 6 (2.5-8.5) years. 3/5 (60.0%) patients with CRBSI were female, with 1/5 (20.0%) patients coming from a vulnerable family.

The overall CRBSI rate was 0.72/1000 catheter days, with no significant reduction compared to the previous infection rate of 1.17/1000 catheter days (p=0.18). When separated by diagnosis, the CRBSI rates were 0.92/1000 catheter days for short bowel syndrome, 0.87/1000 for mucosal disorders and 7.14/1000 for immune-haem-oncological disorders. There were no infections among home PN patients with gastrointestinal motility disorders. Factors such as family vulnerability, gender, use of gloves during central venous catheter (CVC) care, and TauroLock administration did not significantly influence infection rates. The CRBSI rate among patients from vulnerable families significantly decreased from 3.86 to 1.39/1000 catheter days (p = 0.049).

In summary, our CRBSI rate of 0.72/1000 catheter days was lower than previously reported. Infection rates also improved amongst patients from vulnerable families, possibly due to additional support provided by the clinical team to those identified as high risk. In contrast to previous studies, family vulnerability, gender, the use of gloves during CVC care, and TauroLock use were not associated with changes in infection rates in this cohort. These results suggest that current practices are effective, supporting their continued implementation to reduce CRBSI rates in paediatric IF patients on home PN.

References

1. Puoti MG, D'Eusebio C, Littlechild H, King E, Koeglmeier J, Hill S. Risk factors for catheter-related bloodstream infections associated with home parental nutrition in children with intestinal failure: A prospective cohort study. Clin Nutr 2023; 42: 2241-2248.
2. Littlechild H, Montgomery-Stuart S, Mari A, et al. OC91 Trends in catheter related blood stream infections rates in children on home parenteral nutrition. Frontline Gastroenterology 2024; 15: A61-A62.

OC48

Intestinal ultrasound (IUS): a “new” old friend and vital tool in diagnosing inflammatory bowel disease (IBD) in children.

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The use of intestinal ultrasound (IUS) has grown rapidly as a vital tool for diagnosing and monitoring inflammatory bowel disease (IBD). [1] While paediatric data on IUS is emerging, evidence is limited and primarily from individual centres. [2]

This study aimed to evaluate the sensitivity, specificity, and overall accuracy of IUS in diagnosing IBD in children. Secondary objectives included assessing the role of IUS in: (1) to help determine the indication for upper and lower gastrointestinal (GI) endoscopy in suspected IBD cases; and (2) ruling out the need for endoscopy in symptomatic patients with suspected gut-brain interaction disorders (DGBI).

A retrospective analysis was conducted at our tertiary paediatric gastroenterology centre, including all patients who underwent IUS between September 2022 to September 2024. Patients were identified via electronic procedure lists from Radiology Department. IUS examinations were performed by three GI radiologists trained in adult and paediatric ultrasound, with two paediatric radiologists. Data were collected and analysed using Microsoft Excel.

A total of 69 children were included of which 51 (73%) were males with a mean age of 12 ± 3.2 years. Diagnoses included Crohn’s disease (CD) in 31 (44%), ulcerative colitis (UC) in 18 (26%), DGBI in 18 (26%), and infective entero-colitis in 2 cases. The most common presenting symptoms were abdominal pain in 56 (81%), loose stools in 47(68%), and increased bowel movements in 36 (52%)

Clinical impression correlated with IUS findings in 84% (58/69) of the cases, and with endoscopic findings in 91% (63/69). In 76% (53/69), IUS and endoscopy findings aligned with clinical impression. IUS demonstrated a sensitivity of 88%, positive predictive value (PPV) of 89%, specificity of 73%, negative predictive value (NPV) of 70%, and overall accuracy of 84%. Notably, all six false negatives, where IUS did not detect the final diagnosis confirmed clinically and endoscopically, involved UC proctitis or distal colitis, with IUS performed 3–6 months after treatment initiation. Additionally, in two CD cases, disease was detected solely by IUS, as the lesions involved small bowel segments inaccessible to endoscopy. In 8 patients, IUS suggested nodular lymphoid hyperplasia (NLH), with endoscopic confirmation in 5. Only 1 patient underwent magnetic resonance enterography (MRE), which showed a longer diseased segment than measured by IUS.

Advances in technology and operator expertise position IUS as a valuable, non-invasive, baseline modality for children with suspected IBD. Its accuracy approaches that of more traditional imaging like MRE, with reduced cost and improved patient comfort. Limitations include operator dependence, patient body habitus, disease location, and timing relative to treatment initiation. Skilled IUS-trained practitioners can reduce reliance on MRE, optimising resource use and patient satisfaction.

Table 1. Parameters defining accuracy of IUS in detecting IBD, benchmarked against clinical and endoscopic criteria.

	FN n=6	**FP** n=5
TP n=44	**Sensitivity** TP/ (TP+FN) 88%	**PPV** TP/(TP+FP) 89.8%
TN n=14	**NPV** TN/(TN+FN) 70%	**Specificity** TN/(TN+FP) 73.7%
Accuracy **84%**		

Table 1: TP: true positive, TN: true negative, FP: false positive, FN: false negative, PPV: positive predictive value, NPV: negative predictive value

References

[1] Kellar A, Dolinger M, Novak K, et al. Intestinal Ultrasound for the Pediatric Gastroenterologist: A Guide for Inflammatory Bowel Disease Monitoring in Children. Expert Consensus on Behalf of the International Bowel Ultrasound Group (IBUS) Pediatric Committee. JPGN 2023; 76(2).
[2] Green Z, Towriss C, Ashton JJ, et al. Noninvasive monitoring with bowel ultrasound (NIMBUS) in paediatric inflammatory bowel disease: Feasibility in a single centre. J Pediatr Gastroenterol Nutr 2025 Jul 21.
doi: 10.1002/jpn3.70159.

OC49

Evaluation of induction dosing regimens for infliximab therapy in paediatric inflammatory bowel disease in a single tertiary centre

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Infliximab, a monoclonal antibody against tumour necrosis factor alpha (TNF-alpha), is highly effective in achieving both clinical and endoscopic remission in paediatric inflammatory bowel disease (PIBD).[1] Current ECCO-ESPGHAN guidelines recommend intravenous induction dosing of 5mg/kg at week 0, 2 and 6 with 8 weekly maintenance dosing thereafter. [1] Pro-active therapeutic drug monitoring is recommended; as adequate trough infliximab levels during induction have been proven to predict clinical remission.[1,2] However, younger paediatric patients are at particular risk of under-dosing due to decreased drug exposure with lower body weight.[3] Up to 50% patients develop secondary loss of response (LOR) at one year; therefore requiring dose escalation or change in biologic therapy.[1, 4] Studies have shown early dose optimization can reduce this secondary LOR and improve remission rates by way of preventing low trough levels and subsequent anti-drug antibodies (ADA).[4]

The aim of this study was to review infliximab induction dosing regimens for PIBD patients. Specifically, to quantify the number of patients starting on 5mg/kg dosing that needed dose and/or frequency escalation. The hypothesis was that the majority of patients starting on lower dose induction would need dose intensification.

A retrospective review of PIBD patients currently receiving infliximab in a single tertiary centre identified 120 patients receiving induction between 2013 and 2025. Data were collected and analysed on epidemiology, diagnosis, severity of disease, initial dosing and need for subsequent dose and/or frequency escalation. Post induction (pre-3rd or 4th infusion) trough infliximab levels were compared to recommended targets (>15 and 5 mg/L respectively) as per ECCO-ESPGHAN guidelines.[1]

78/120 (65%) were male and 42/120 (35%) female; with age of diagnosis between 2 and 15 years. 102/120 (85%) had Crohn's disease, 16/120 (13%) ulcerative colitis and 2/120 (2%) had IBD-unclassified. 88/120 (73%) started on 5mg/kg induction dosing; 78/88 (89%) of these patients required either dose or frequency escalation. 58/88 (66%) needed escalation to 10mg/kg as well as escalation to 4 or 6-weekly. 13/32 (41%) patients starting on 10mg/kg needed frequency escalation. Indications for initial 10mg/kg dosing were early onset (diagnosis younger than 6 years) disease (5), fistulating (35), stricturing (3) or severe disease (8). In the 5mg/kg cohort, 9/10 (90%) early onset patients and 31/35 (89%) patients with fistulating disease needed escalation. Similarly, in the 10mg/kg cohort, 4/5 (80%) early onset patients and 6/18 (33%) patients with fistulating disease needed escalation. In the 5mg/kg cohort; 51/77 (66%) patients with available post-induction infliximab had below target levels. In the 10mg/kg cohort; 10/23 (43%) patients with available levels were below target.

Infliximab is a highly effective therapy in PIBD but adequate induction dosing is essential in attaining therapeutic drug levels and therefore early clinical remission.[2] This study goes someway to support the need for dose optimisation during induction; particularly in those with early onset and/or fistulating/stricturing disease. Of note, many (41%) patients who started on higher dosing still needed further optimisation. This suggests the need for starting infliximab induction with 10mg/kg dosing (rather than 5mg/kg) with pro-active post-induction therapeutic drug monitoring.

References

1. van Rheenen P F, Aloi M, Assa A et al. The Medical Management of Paediatric Crohn's Disease: an ECCO-ESPGHAN Guideline Update, *Journal of Crohn's and Colitis*, Volume 15, Issue 2, February 2021, Pages 171–194, https://doi.org/10.1093/ecco-jcc/jjaa161
2. Kantasiripitak W, Wicha S G, Thomas D et al. A Model-Based Tool for Guiding Infliximab Induction Dosing to Maximize Long-term Deep Remission in Children with Inflammatory Bowel Diseases, *Journal of Crohn's and Colitis*, Volume 17, Issue 6, June 2023, Pages 896–908, https://doi.org/10.1093/ecco-jcc/jjad009
3. Jongsma MME, Winter DA, Huynh HQ et al. Paediatric IBD Porto Group of ESPGHAN. Infliximab in young paediatric IBD patients: it is all about the dosing. Eur J Pediatr. 2020 Dec;179(12):1935-1944. doi: 10.1007/s00431-020-03750-0. Epub 2020 Aug 19. PMID: 32813123; PMCID: PMC7666662.
4. Dubinsky MC, Mendiolaza ML, Phan BL et al. Dashboard-Driven Accelerated Infliximab Induction Dosing Increases Infliximab Durability and Reduces Immunogenicity, *Inflammatory Bowel Diseases*, Volume 28, Issue 9, September 2022, Pages 1375–1385, https://doi.org/10.1093/ibd/izab285

OC50

Renal calculi incidence in paediatric short bowel syndrome: a single centre experience.

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Patients with short bowel syndrome (SBS) are at high risk of developing renal stones. Multiple factors contribute to the risk of nephrolithiasis including repeated dehydration episodes with reduced urine volume, hyperoxaluria and reduced citrate urine excretion.[1] Patients with ostomies are at risk for both uric acid and oxalate stones, while patients with colon in continuity form mainly calcium oxalate renal calculi[1,2]. Renal calculi can lead to nephrocalcinosis, renal parenchymal disease, tubulopathy or interstitial disease with long term sequelae including chronic renal failure and end stage renal disease.[3] SBS patients are at risk of renal calculi and nephropathy years after parenteral nutrition (PN) cessation.[2] The incidence of renal calculi in SBS patients is described at 15-60%.[3,4]

The aim of this study was to determine incidence of renal calculi in paediatric patients with short bowel syndrome (SBS) who have achieved enteral autonomy (EA) and remain under follow-up by the intestinal failure multidisciplinary team in this tertiary centre. In addition, the study aimed to explore potential associations between renal calculi and patient characteristics, including residual bowel anatomy.

A retrospective review of the patient records of paediatric SBS patients in EA identified 79 eligible patients (49 males, age 10 months to 19 years); with PN initiated between 2005-2025 and time on PN from 3 months to 2 years. Data were collected on demographics, bowel anatomy, PN duration, time in enteral autonomy and follow up abdominal ultrasound scans (USS). For those children with renal calculi found on USS; urine biochemistry results and therapeutic intervention were reviewed.

5/79 (6%) patients reviewed had USS proven renal calculi. 4/5 patients were of extreme prematurity (birth before 28 weeks gestation) and had intestinal resection due to necrotising enterocolitis (NEC). 1/5 had resection due to volvulus at the age of 3 years.

All patients had colon in continuity. 2/5 had ileocolonic anastomoses with absent ileo-caecal valves and partial colectomy. 3/5 had jejunoileal anastomosis with intact colons and estimated small bowel lengths of 33, 44 and 49cm at time of resection.

2/5 patients had hyperoxaluria, 2/5 had hypocitraturia and 1/5 had no urine biochemistry available: due to stones resolving. 2/5 patients developed renal calculi whilst still receiving PN with the other 3 patients developing calculi at 6, 7 and 13 years post PN cessation.

1 patient with hyperoxaluria (volvulus, absent ICV, calculi diagnosed 7 years from PN cessation) required urological stenting; the other 4 patients required medical management alone.
The incidence of renal calculi was low in our cohort and nephrolithiasis resolved spontaneously in one patient. Notwithstanding, 1 patient in our cohort required surgical intervention at 7 years post PN. Renal calculi formation is a known and often serious long-term complication of SBS, which may be evident many years following PN cessation; therefore, vigilance is recommended with regular urine oxalate and citrate monitoring and pro-active renal USS to enable early diagnosis and management of renal calculi.[3]

References

1. Thomson CRV. Nephrocalcinosis and nephrolithiasis. In: Nightingale JMD, ed Intestinal failure, San Francisco, CA: Greenwich Medial Media, 2001, pp.227-242
2. Schaefer JT, Schulz-Heise S, Rueckel A et al. Frequency and impact of enteric hyperoxaluria in pediatric short bowel syndrome: a retrospective single centre study. Front Pediatr. 2023 Jul 12;11:1157696. doi: 10.3389/fped.2023.1157696. PMID: 37502194; PMCID: PMC10369460.
3. Adler M, Millar EC, Deans KA et al. Dietary Management of Chronic Kidney Disease and Secondary Hyperoxaluria in Patients with Short Bowel Syndrome and Type 3 Intestinal Failure. Nutrients. 2022 Apr 14;14(8):1646. doi: 10.3390/nu14081646. PMID: 35458207; PMCID: PMC9030588.
4. Grocholski C, Chambrier C, Lauverjat M et al. Circulating Oxalate Levels in Short Bowel Syndrome as a Severity Marker of CKD. Kidney Int Rep. 2023 Dec 28;9(3):686-693. doi: 10.1016/j.ekir.2023.12.023. PMID: 38481504; PMCID: PMC10927470.

OC51

Incidence and persistence of elevated vitamin A levels in paediatric patients on home parenteral nutrition

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Vitamin A is an essential fat-soluble vitamin required for vision, bone growth, immune function, and differentiation of epithelial and nerve tissues (1). Both deficiency and toxicity are associated with significant morbidity in children, such as vision loss and increased intracranial pressure or headaches. Vitamin A has a long half-life; levels can remain elevated for extended periods (2). Regular monitoring is recommended for children receiving long-term parenteral nutrition (PN) (3).

The aim of the study was to review the frequency and duration of high serum vitamin A levels in children receiving home PN, and explore any associations between elevated levels with lipid provision or supplemental feeds.

A retrospective review was conducted of all children currently receiving home PN under the care of the intestinal failure multidisciplinary team. Data were collected on demographic characteristics, underlying pathology leading to IF, time on PN, vitamin A levels, lipid and vitilipid doses, and any clinical symptoms suggestive of hypervitaminosis A. Episodes of high vitamin A were defined as levels above the laboratory reference range for at least three consecutive months over the last two years, while the child had a normal CRP.

Thirty-nine children were on home PN (20 male, mean age 9 years, range 1–18 years). The main underlying conditions included short bowel syndrome (27/39, 69.2%), congenital diarrhoea (7/39, 17.9%), dysmotility (3/39, 7.7%), and other pathologies such as cystinosis (1/39, 2.6%) and eosinophilic colitis (1/39, 2.6%).
Twenty-three of 39 (59%) children had elevated vitamin A lasting three months or more. Of these, 19/39 (48.7%) had one episode lasting at least three months and 4/39 (10.3%) had two prolonged episodes. None had more than two episodes. Four of 39 (10.3%) patients had prolonged elevation for the entire 24-month study despite reduced vitilipid dose (2/4 children (50%) had cholestasis).
The median initial vitamin A concentration across all episodes was 2.05 (95% SD 3.32).
Of all 27 episodes of raised vitamin A, 6/27 (22.2%) normalised after one reduction of vitilipid by 10%–25%. A further 4/27 (14.8%) resolved after multiple reductions in vitilipid content, ranging from a total reduction of 40%–55%. The remaining 13/27 (48.1%) episodes remained unresolved with levels above the reference range in September 2025, despite reductions in vitilipid on one (8/13) or more (5/13) occasions, ranging from 15% to 79% total reduction.
Only one episode was associated with clinical symptoms compatible with hypervitaminosis A, including headache and irritability.
Comparison between patients requiring a 10%–40% reduction of vitilipid (n=13) and those requiring >40% (n=8) did not differ in lipid nights per week (4.9 vs 4.6 nights, p=0.35) or the number on supplemental feeds (8/13 vs 3/8 respectively).

Conclusion:
Episodes of high vitamin A levels are common in children on home PN and may persist for several months. Although vitilipid provision should be amended, other factors—including interindividual variation in metabolism—may affect vitamin A levels. Any reduction in vitilipid should be made cautiously to avoid secondary deficiencies of other fat-soluble vitamins.

References

1. Ross AC. Vitamin A. In: Ross AC, Caballero B, Cousins RJ, et al., editors. *Modern Nutrition in Health and Disease.* 11th ed. Baltimore (MD): Lippincott Williams & Wilkins; 2014. p. 260–277.
2. Haskell MJ, Lembcke JL, Salazar M, et al. Population-based plasma kinetics of an oral dose of [2H4]retinyl acetate among preschool-aged Peruvian children. *Am J Clin Nutr.* 2003 Mar;77(3):681–686.
3. Berger MM, Shenkin A, Schweinlin A, et al. ESPEN micronutrient guideline. *Clin Nutr.* 2022 Jun;41(6):1357–1424.

OC52

Therapeutic challenges in three infants with TTC7A-related intestinal failure and liver disease: a case series

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Tetratricopeptide repeat domain 7A (TTC7A) deficiency is a rare autosomal-recessive disorder characterised by intestinal atresia, congenital enteropathy, inflammatory bowel disease, recurrent stricture formation, and variable immunodeficiency. Reported median survival is 8 – 12 months, though outcomes depend on phenotype and access to interventions such as haematopoietic stem cell transplantation (HSCT) and intestinal or multivisceral transplantation. We describe three male infants dependent on parenteral nutrition, with TTC7A-related intestinal failure–associated liver disease, each illustrating distinct disease trajectories.

Case 1: A neonate with postnatal bowel obstruction required resection of 20 cm of atretic terminal ileum, caecum, and ascending colon with end ileostomy formation on day 2 of life. At 18 months, he required gastroduodenotomy for pyloric stricture and mucous fistula formation for multiple colonic atresias and strictures. Subsequently, he developed portal hypertension with portosystemic shunting, and symptomatic stomal varices requiring embolisation, sclerotherapy, and treatment with carvedilol, and eventually transjugular intrahepatic portosystemic shunt (TIPSS). Whilst awaiting assessment for HSCT for well-controlled primary immunodeficiency, he died aged 2 years 3 months from sepsis and multiorgan failure.

Case 2: This infant presented at six weeks with vomiting, secretory diarrhoea, and hypoalbuminaemia. Imaging revealed long segments of left colonic narrowing, and at 3.5 years, he underwent a colonoscopy complicated by colonic perforation requiring ileostomy and mucous fistula formation. He had recurrent, paroxysmal microbiology-negative pyrexia, vomiting, and increased stooling, and multiple endoscopies demonstrated variable mucosal inflammation. Symptoms improved with leflunomide and low-dose prednisolone, but were non-responsive to infliximab. At 4 years, he awaits bone marrow transplantation assessment before consideration of a size-matched modified multivisceral transplant with splenic preservation.

Case 3: Infant with multiple intestinal atresias requiring three laparotomies within 4 months of life, including pyloroplasty, loop ileostomy, and mucous fistula formation. Due to symptoms of combined immunodeficiency, he had HSCT at 18 months, which was complicated by multiple episodes of sepsis and chronic Epstein-Barr viraemia. He developed evolving hypersplenism with stomal varices, prominent portosystemic collaterals, and chronic symptoms of per rectal bleeding and haematemesis. After initial multidisciplinary transplant discussion, he was listed for multivisceral transplant (liver, stomach, and small bowel), however following subsequent decompensation with episodes of gastrointestinal bleeding requiring TIPSS, pulmonary haemorrhage, and renal failure requiring haemofiltration, the decision was withdrawn.

There is no established standard of care for patients with TTC7A deficiency. Surgery for intestinal atresias does not prevent recurrent stricture formation, and intestinal inflammation often remains refractory to immunosuppressive therapy, as demonstrated in all three infants reported. Although HSCT may be considered to correct immunological defects, patients are likely to continue to experience gastrointestinal symptoms without definitive treatment such as intestinal or multivisceral transplantation. Both interventions should be considered in select cases depending on phenotype, although optimal timing and sequence remain unknown.

Table: Summary of clinical features of infants with TTC7A deficiency

Feature	Case 1	Case 2	Case 3
Initial presentation	Birth - antenatal bowel dilation, postnatal bowel obstruction	Infant - faltering growth, vomiting, secretory diarrhoea, hypoalbuminaemia	Birth - neonatal bowel obstruction
Gastrointestinal findings	Terminal ileal, caecal, and colonic atresias, pyloric stricture	Long left-colonic narrowing, pyloric stricture requiring pyloromyotomy and two dilatations Recurrent, paroxysmal microbiology-negative pyrexia, vomiting, and increased stooling, with variable mucosal inflammation	Multiple small and large bowel atresias and pyloric stricture requiring pyloroplasty, resulting short bowel syndrome
Hepatic manifestations	Portal hypertension with portosystemic shunting, symptomatic stomal varices	Early signs of liver disease	hypersplenism with symptomatic stomal varices, prominent porto-systemic collaterals, chronic rectal bleeding and haematemesis
Liver histology	Mild–moderate fibrosis		
	Cholestatic pattern	Biliary pattern	
Immunological manifestations	Well-controlled primary immunodeficiency		Combined immunodeficiency Recurrent episodes of sepsis pre/post-HSCT
Parenteral nutrition dependence	7 nights/week		
Selected interventions	Carvedilol, embolization, sclerotherapy, TIPS	Leflunomide (stopped due to abnormal liver blood tests), low dose prednisolone, infliximab (no response)	Blood products, high dose immunosuppression, HSCT, TIPS, eculizumab, rituximab
Transplant evaluation	Awaited HSCT prior to assessment for intestinal/multivisceral transplant	Undergoing HSCT evaluation prior to assessment for intestinal/multivisceral transplant	Initially listed for multivisceral transplant; delisted after decompensation
Outcome	Died age 2 years 3 months	Alive	Died age 2 years

OC53

Delivering home parenteral nutrition to children over the years: experience from a tertiary intestinal failure service

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Parenteral nutrition (PN) was developed over 50 years ago and has evolved through advances in formulation, technology and line care. By the late 1990s, the establishment of paediatric home PN (HPN) services at multiple UK tertiary centres enabled the safe delivery of long-term nutritional support for children outside of hospital.

The aim of this study was to review the long-term outcomes of paediatric HPN patients at a single tertiary intestinal failure (IF) centre.

Retrospective data was collected from electronic records and nutrition service databases for all paediatric patients who received HPN between March 1999 and October 2025. Demographic, clinical and outcome data were analysed.

Over a 26-year period, 89 patients (51 males) were identified. Eight patients (9%) had severe neurodisability. Indications for HPN included short bowel syndrome (SBS) in 46/89 (52%) patients, dysmotility 23/89 (26%), congenital diarrhoeal disorders 6/89 (7%) and other conditions in 14/89 (16%) cases.

For SBS, 20/46 (43%) had gastroschisis, 12/46 (26%) volvulus, 10/46 (22%) necrotising enterocolitis (NEC) and 4/46 (9%) intestinal atresia. The median residual small bowel length was 30cm [IQR 20-40]. Successfully weaned patients had a median bowel length of 35cm [IQR 21.25-40] versus 19cm [IQR 11.25-20] amongst PN-dependant patients. Thirty-four/46 (74%) SBS patients achieved enteral autonomy.

For dysmotility, 7/25 (30%) had Hirschsprung's disease, 5/25 (22%) intestinal pseudo-obstruction, 2/25 (9%) megacystic microcolon intestinal hypoperistalsis syndrome (MMIHS) and 4/25 (17%) gastroschisis or atresia. Among the congenital diarrhoeal disorders, 3/6 (50%) had microvillous inclusion disease (MVID), 2/6 (33%) trichohepatoenteric syndrome and 1/6 (17%) idiopathic protracted diarrhoea. For the other group, 5/12 (36%) had gastrointestinal (GI) dystonia, 3/12 (21%) Crohn's disease, 2/12 (14%) IF secondary to radiotherapy and 1/12 (7%) graft-versus-host disease.

The median duration of HPN was 18 months [IQR 6-70]. Fifty/89 (56%) patients were successfully weaned - 34/50 (68%) had SBS, 13/50 (26%) dysmotility, 2/50 (4%) congenital diarrhoea and 8/50 (16%) other diagnoses. Weaned patients had a median duration on HPN of 11 months [IQR 5-24]. Ten patients with SBS had lengthening procedures, only 1 came off PN. Four/8 patients with severe neurodisability were successfully weaned including 2 with GI dystonia.

Twenty-two/89 (25%) patients transitioned to adult services – 15/22 (68%) were no longer dependent on HPN while 7/22 (32%) remained on therapy. Six/89 (8%) patients underwent intestinal transplant: 1 isolated small bowel and 5 multi-organic (4 of which included liver).
Eleven/89 (12%) patients died during the study period: 4 deaths occurred after PN weaning and 7 while on PN. Of those that died whilst on PN, 3/7 were secondary to sepsis, 1/7 PN-associated liver disease, 1/7 transplant rejection, 1/7 underlying neurological conditions and 1/7 unspecified (1/7 had SBS, 2/7 Hirschsprung's disease, 1/7 MMIHS, 1/7 MVID, 1/7 GI dystonia and 1/7 Crohn's disease).

SBS was the main cause of IF requiring HPN. Greater residual bowel length was associated with successful outcomes, highlighting the value of bowel-preserving surgery. Over half of patients achieved enteral autonomy. Mortality was relatively low (12%) over 26 years, though sepsis caused nearly half of deaths, highlighting the importance of preventing central line infections.

OC54

A retrospective cohort comparison study to assess the rate of intestinal failure associated liver disease in paediatric patients using home parental nutrition in a single tertiary centre over time: 1996-2010 Vs 2010-2025.

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Intestinal failure associated liver disease (IFALD) has a multifactorial aetiology, which is becoming better understood[1,2]. We compared our current rates of IFALD with a previously reviewed cohort of patients born between 1996-2010[3].

Patients were included if using home parenteral nutrition (PN) for medical or surgical events before 3 months age. The definition of IFALD was matched to our previous review. We used the 2009 British society of paediatric gastroenterology, hepatology and nutrition: nutritional working group definition: type 1 = increased alkaline phosphatase >1.5 times upper limit for over 6 weeks, type 2 = plus total bilirubin > 50umol/l and a 50% conjugated fraction for 6 weeks, type 3 = plus clinical signs of end stage liver disease[4].

Table 1, results:

Date of birth		**1996-2010**	**2010-2025**
Numbers		21 (67% male)	25 (64% male)
Gestation (weeks)	Range Mean Median	33-40+ 36 36	24-40 35 36
Mortality		3 died, 14%	5 died, 20%
IFALD	Total Stage 1 Stage 2 Stage 3	7 2 (9.5%) 1 (4.8%) 4 (19%)	5 2 (8%) 1 (4%) 2 (8%)
Weaned off PN		13 (54%)	5 (20%)
Time to wean off PN (months)	Range Mean Median	8-118 36 28	5-60 41 48
Total duration of PN use for all patients (months)	Range Mean Median	8-119 46 44	18-187 77 60
Residual small bowel length (cm)	<25 25-65 >65	6 8 7	5 6 13 1 – information unavailable
Liver transplants:		1	0
Small bowel transplants:		1	0
Liver & small bowel transplant combined		1	1
Aetiology			
Necrotising	enterocolitis	3	4
Gastroschisis		6	3
Atresia		5	2
Volvulus/malrotations		1	3
Other	anatomical	0	2
Motility		3*	6**
Medical		3[#]	5[##]

*(*1x Hirschprung's; **5x Hirschprung's; [#]1x microvillous inclusion disease, 1x tufting enteropathy, 1x congenital enteropathy; [##]3x feed intolerance of undiagnosed aetiology, 1x ischaemic event, 1x TTC7A deficiency)*

The rate of IFALD, was lower in the newer cohort with fewer patients developing more severe liver disease with an associated decrease in transplantation. There was an increase in prematurity, motility and medical comorbidities. There was a lower rate of patients being weaned off PN, which could be associated with the increase in motility and medical indications for home PN. From the 5 patients weaned off PN in the newer cohort, 1 weaned off post-transplant, 3 had neonatal surgery, and 1 had anatomical abnormalities. The majority of those unable to achieve enteral autonomy have medical/motility problems likely needing home PN long term. The increased mortality was linked to comorbidities outside of intestinal failure.

IFALD decreased despite the increase in time on PN. The older cohort predominantly used lipofundin lipid whereas the new group used SMOF which is more liver protective. Hepatoprotective measures such as early feeding, lipid free nights and an awareness of the causes of IFALD have had a liver guarding effect, enabling action when the condition may still be reversible.

Further review of patient records to explore liver protective management plans and which interventions had the biggest impact would yield useful clinical information.

References

1. Cuerda C, Pironi L, Arends J, et al. ESPEN practical guideline: Clinical nutrition in chronic intestinal failure. Clin Nutr. 2021 Sep;40(9):5196–220.
2. Lacaille F, Gupte G, Colomb V et al. Intestinal failure-associated liver disease: a position paper of the ESPGHAN Working Group of Intestinal Failure and Intestinal Transplantation. J Pediatr Gastroenterol Nutr. 2015 Feb;60(2):272–83.
3. Garrett H, Jones E, J Minford et al. Successful management of infants with intestinal failure over two decades. Conference poster presentation, ESPGHAN, Athens, 2016.
4. British Society for Paediatric Gastroenterology Hepatology And Nutrition (BSPGHAN) Nutrition Working Group. Review of current management practices in Intestinal Failure Associated Liver Disease; 2009

OC55

Vitamin C levels in Home Parenteral Nutrition patients - the need for monitoring

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Introduction: Patients on Home Parenteral Nutrition (HPN) are routinely monitored for several micronutrient and vitamin deficiencies[1]. However, there are no established guidelines regarding the screening or management of plasma vitamin C levels in paediatric HPN patients.

Aims: Assess the vitamin C status in paediatric patients on HPN, describe the clinical features associated with deficiency and review the treatment provided.

Methods: Retrospective data collection from electronic records for paediatric HPN patients (<17 years) assessing the vitamin C levels on a single tertiary IF unit. Most blood samples were collected in clinic by 2 PN nurses, light protected and hand delivered to the laboratory within 20 minutes.

Results: Thirteen paediatric HPN patients (8 females, median age 7.4 years [IQR 5–13]) were assessed after a median of 2.9 years on PN [IQR 2.5–5.7]. Underlying diagnoses included dysmotility 8/13 (62%), short bowel syndrome (SBS) 3/13 (23%), and enteropathy 2/13 (15%). Vitamin C levels were normal (>26µmol/l) in 6/13 (46%) patients, low (10-26µmol/l) in 4/13 (31%) and very low (<10µmol/l) in 3/13 (23%).

Patients received PN a median of 7 nights/week (range 5–7) for 16 hours/night (range 12–24), with a median EAR% of 83% [IQR 75–105]. Five patients received enteral nutrition (two Neocate, three standard diet), while eight were nil enterally. Although not statistically significant, all patients with very low vitamin C levels had dysmotility, all with SBS had low levels, and all with enteropathy had normal levels. Patients with low levels were asymptomatic, while among those with very low levels, one presented with scurvy and one with lower limb pain. All patients with very low levels received 24-hour PN vs. a median of 16 PN hours [IQR 12-20] (p=0.019). The median PN duration was significantly longer in patients with abnormal vitamin C levels compared with those with normal levels (69 vs. 27 months, p=0.003). No associations were observed between vitamin C levels and CRP, EAR%, or enteral feeding. Vitamin C deficiency was corrected with Pabrinex® infusions and doubling of ascorbic acid in PN to 200 mg for the ones with very low levels or by only doubling the dose in the ones with low levels leading to symptom resolution and normalization of levels.

Conclusions: Paediatric HPN patients are susceptible to vitamin C deficiency, emphasizing the need for monitoring. Sample instability requires full consideration. Prolonged PN and long-term administration further increases deficiency risk, potentially due to temperature-related degradation.

References

1. Bronsky J, Campoy C, Braegger C; ESPGHAN/ESPEN/ESPR/CSPEN working group on pediatric parenteral nutrition. ESPGHAN/ESPEN/ESPR/CSPEN guidelines on pediatric parenteral nutrition: Vitamins. Clin Nutr. 2018 Dec;37(6 Pt B):2366-2378. doi: 10.1016/j.clnu.2018.06.951. Epub 2018 Jun 18. PMID: 30100105.
2. Gorman SR et al (2002). Journal of Pediatric Gastroenterology and Nutrition 35:93–95

OC56

A single centre experience: The lifespan of Central Venous Catheters in a cohort of Home Parenteral Nutrition patients at a Paediatric Intestinal Failure Centre

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Home Parenteral Nutrition (HPN) provides life-sustaining nutritional support for children with intestinal failure[1]; this requires a Central Venous Catheters (CVC)[2]. CVCs are prone to complications necessitating replacement such as Central Line-Associated Bloodstream Infection (CLABSI) and mechanical issues: these include line fractures, displacement, thrombotic events and blockages[3]. This study reviews CVC lifespan and complications amongst HPN patients.

We report a retrospective review of electronic records of all HPN patients managed from September 2021-September 2025. Data was collected on demographics, indication, lifespan, complications, repairs and replacements.

Indication	**Number**	**CLABSI** Number % Episodes/1000 CDs*	**Mechanical Issue** Number % Episodes/1000 CDs	**Repair** Number Episodes/1000 CDs	**Replacement** Number Episodes/1000 CDs	**Lifespan** months Range
Surgical Short Gut	14	3 (10.1%) 0.14	25 (89.9%) 1.2	10 0.48	17 0.82	28.7 0.1-107
Motility	4	3 (27.3%) 0.51	8 (72.7%) 1.34	3 0.51	7 1.28	19.5 7-58
Enteropathy	3	3 (42.9%) 0.67	4 (57.1%) 0.89	1 0.22	5 1.12	11.6 3-32
CIPO	5	16 (55.2%) 2.2	13 (44.8%) 1.74	5 0.67	23 3.09	7.6 0.5-60
Total	26	25 (33%) 0.64	50 (67%) 1.3	29 0.75	52 1.34	16.9 0.1-107

Table 1: CVC complication/repair data
*CDs: Catheter Days

26 patients were reviewed with a mean age of 8.7 years. A total of 78 CVCs were inserted. A total number 35,222 catheter days were studied. The median lifespan was 330 days (IQR 21-630). The complication rate was 1.68 events/1000 CDs.

52 of 78 CVCs were replacements. 14 of the 52 CVC replacements followed failed line repairs; half of the total repairs were unsuccessful. CIPO patient cohort contributes to a higher proportion of line replacements.

67% of complications were due to mechanical issues such as line fracture (34%) and line blockage (33%). There were 6 incidents of line cuff displacement outside the skin. There were no reported thrombotic events. Of the CLABSI events, 11 CVCs were salvaged. One CIPO patient accounted for 10 replacements.

The median CVC lifespan in this cohort compares with literature, where survival ranges between 200–400 days[1,4]. Complication rates are equally comparable[1,3,5]. The rate of successful line repairs does not compare favourably to literature[2]; assessment of repair techniques is desirable.

The incidence of mechanical complications is lower than reported in literature (3.37 events/1000 CDs)[3]. Whilst our numbers of line fracture and occlusion correlate with published studies, our numbers demonstrate higher incidences of cuff displacement[3,5]. This is an area that prompts further investigation into the existing processes/surgical techniques.

The cohort's total CLABSI rate replicates results from published studies (0.57-2.1 events/1000 CDs)[1,3,5]. The significantly higher rate of CLABSIs in CIPO patients implies additional vascular protection work should be implemented with this cohort. CVC lifespan secondary to complications remains a significant challenge in HPN care. Our centre experience suggests that review of the approaches toward surgical repair and surgical techniques are required to reduce complication rates. The CIPO cohort has a notably increased CLABSI rate, which needs addressing. This review offers valuable insights into planning quality improvement initiatives for optimising CVC management for paediatric intestinal failure patients.

References

1. Gandullia P, Lugani F, Costabello L. Long-term home parenteral nutrition in children with chronic intestinal failure: A 15-year experience at a single Italian centre. Dig Liver Dis. 2011 Jan;43(1):28-33
2. Zaidi Z, Littlechild H, Hill S. Causes and Outcome of Central Venous Catheter Repair in Children with Intestinal Failure on Home Parenteral Nutrition. J Pediatr Gastroenterol Nutr. 2023 Dec 1;77(6):796-800
3. Hartman C, Shamir R, Simchowitz V. ESPGHAN/ESPEN/ESPR/CSPEN Working Group on Paediatric Parenteral Nutrition. ESPGHAN/ESPEN/ESPR/CSPEN guidelines on pediatric parenteral nutrition: Complications. Clin Nutr. 2018 Dec;37(6 Pt B):2418-2429.
4. Hojsak I, Strizic H, Misak Z. Central Venous Catheter Related Sepsis in Children on Parenteral Nutrition: A 21 year single centre experience. Clin Nutr 2012 Oct, 31(5): 672-675
5. Unal KN, Park T, Lopez LG. Investigation of urgent reasons for central venous catheter replacements and outcomes in paediatric home parenteral nutrition patients. Frontline Gastroenterol 2025. 16. 34

OC57

Feasibility of collecting stool tests for surveillance of children with eosinophilic oesophagitis (EoE) - the BioEvocs study

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There is limited understanding of the aetiology, disease progression and prognosis of children with EoE. One hypothesis suggests that intestinal epithelial barrier impairment leads to eosinophil activation and migration into the oesophagus. Repeat endoscopies are required to monitor treatment response.

As part of the BioEvocs study, we assessed the feasibility to collect stool samples in children with EoE compared to controls for subsequent analysis of the gut metabolome and microbiome.
The aim was to enrol 60 patients with EoE (EOB for baseline and EOF follow-up), 30 with non-EoE oesophageal controls (OCB), and 30 normal (NCB)controls (for baseline) in 4 UK sites over a 12-month period. Following informed consent, patients were invited to bring in stool samples to clinic, endoscopy appointment, or within a month of baseline visit or follow-up endoscopy. Samples were stored in freezer, freezer-fridge, fridge or for limited room temperature until storage at -80C at study centres. Patients and parents were asked to complete clinical (CRF), oesophageal symptoms (PEESS) and nutritional (NUT) questionnaires, endoscopy and histology data were collected, and samples stored for subsequent metabolome and microbiome analysis.

Due to post-COVID and logistic restrictions, recruitment period was limited to 9.5 months (ending September 2025) and increasing hospital waiting lists, reduced face-to-face clinic appointments, cost-of-living, willingness to undergo repeat endoscopies, and availability of endoscopy lists, patients were included for the study if their disease-related medication/diet was reported unchanged since their previous endoscopy, whereas NCB patients were recruited from routine ophthalmology clinics.

Table 1: Feasibility of collecting stool samples in EoE patients and controls

	EoE baseline n and %	**EoE follow-up** n and %	**Oesophageal controls** n and %	**Normal controls** n and %
Approached	n=71	n=70	n=69	n=78
Consented	n=54	n=51	n=32	n=31
Completed correctly	n=23/44, (52.3%)	n=27/51 (52.9%)	n=9/30 (30%)	n=30/31 (97%)
Failed CRF/PEESS	n=1 (1.9%)	n=3 (5.8%)	n=1 (3%)	0
Failed stool sample	n=3 (5.5%)	n=8 (15.6%)	n=2 (6.7%)	0
Patient withdrew	n=2 (3.7%)	0	0	0
Logistic reasons	n=1 (1.9%)	n=3 (5.8%)	0	n=1 (3%)
Total withdraw	n=7 (12.9%)	n=4 (12.9%)	n=1 (0.3%)	n=1 (0.3%)

Median time interval from endoscopy date to stool sample was mean 53d (SD 75d), for EOB, 19d (SD 25.5d) for EOF, 318.5d (SD 405d) for OEB and 1d (SD 0d) for NCB patients.

These results suggest that collection of stool samples in patients with EoE and non-EoE clinical conditions is feasible, when appointments were scheduled and coordinated by clinical and research staff. Under research conditions requiring informed consent, and delivery of stool samples in person to the tertiary hospital, collection of stool samples with clinical questionnaires was feasible in nearly all normal control patients with a clinic visit upcoming, and in half of EoE and a third of oesophageal control patients who required correlation with baseline and follow-up endoscopy and histology data. In clinical setting, patients with EoE may require additional information at time of diagnosis and follow-up to signpost and motivate them for the potential use of stool samples as biomarker for surveillance in EoE.

BSPGHAN/GutsUK/Dr Falk sponsored BioEvocs.

References

OC58

Clinical and nutritional characteristics of children with eosinophilic oesophagitis (EoE) in the multi-centre BioEvocs study

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There is limited understanding of the aetiology and disease progression of children with eosinophilic oesophagitis (EoE). Repeat endoscopies are required to monitor treatment response. In the BioEvocs study we will investigate volatile organic compounds (VOCs metabolome) and composition of the gut microbiome from stool samples in EoE patients and controls.

As part of the BioEvocs study, we assessed demographics and nutritional characteristics in children with EoE and controls who provided stool samples for subsequent analysis.

Over a period of 9.5 months, we obtained stool samples from 44 eligible EoE patients and 27 EoE follow-up patients, and samples from 30 non-EoE oesophageal control (OCB) patients and 30 normal control patients (NCB) from 4 sites in the UK. Patients between 3-17 years were eligible for the study. Normal controls were recruited from ophthalmology clinics. Mean age was 11.2 years (SD 4.0) for EoE patients with 80.7% male, 11.1 years for non-EoE oesophageal controls (SD 3.9) (n.s. p=0.99 compared to EoE) with 77.4% male, and normal controls 5.2 years (SD 1.9) (p-value<0.0001 compared to EoE and non-EoE controls, using Tukey's HSD test with ANOVA), with 56% male.
Histology was the gold standard and endoscopy data (6 questions (Q)). EoE was defined as in remission when eosinophils (eos) were <15/high power field (HPF), mild activity when eos 15-50/HPF, moderate when 51-100 eos/HPF and severe when eos >100/HPF. Clinical (50 Q) and nutritional (14 Q) questionnaires and PEESS scores (20 Q) were collected, as supplementary information to stool samples (4Q).PEESS scores (0 indicating no symptoms and 80 maximal oesophageal-associated symptoms) were completed by parents in EOB, EOF and OCB patients. Response type was defined by decreasing activity by one or more levels. and non-response as increasing activity compared to baseline.

Table 1: Demographics at baseline and follow-up from patients who provided stool samples

		PEESS points in mean (SD)	**Neurodi-verse (Y)** proportion of patients	**Breast-feeding (Y)** proportion of patients	**Processed food (Y)** proportion of patients
Base-line					
EOE	**EOB** (baseline)	23.96 (16.78)	18/48 (0.375)	20/47 (0.425)	35/47 (0.744)
Controls	**OCB** *Oesophageal*	28.66 (14.13)	9/31 (0.290)	9/31 (0.290)	25/30 (0.833)
	NCB *Normal*	N/A	10/32 (0.312)	9/32 (0.281)	29/32 (0.906)
	Chi-Square	N/A	0.69 (n.s.)	2.3 (n.s.)	3.4 (n.s.)
Follow-Up*EoE*					
	Responders	17.61 (12.19)	9/22 (0.409)	8/22 (0.363)	18/22 (0.818)
	Non-Responders	20.85 (18.58)	8/14 (0.571)	6/14 (0.428)	10/14 (0.714)
	Chi-Square	N/A	0.9 (n.s.)	0.01 (n.s.)	0.5 (n.s.)

Selected questions from 94 variables:
-Processed food: Does your child eat daily one or more portions of packaged food
-Breastfeeding: Exclusively breast fed over 3 months
-Neurodiversity: Diagnosed or assessed with autism, ASD, ADHD, sensory processing disorder, other neurodiversity

In this pilot study, patients with EoE and non-EoE oesophageal controls showed similar age, but older than normal controls. EoE patients were not statistically different in terms of neurodiversity, indicators of processed food, and duration of breastfeeding compared to controls. We will present detailed analysis from 94 variables and findings from the gut metabolome and microbiome which are currently being analysed.

BSPGHAN/GutsUK/Dr Falk sponsored BioEvocs.

References

OC59

Real-World Effectiveness of Budesonide Orodispersible Tablets in Paediatric Eosinophilic Oesophagitis

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Eosinophilic Oesophagitis (EO) is a chronic, antigen/immune-mediated disease of the oesophagus. First-line treatments include proton pump inhibitors (PPIs), elimination diets, and topical swallowed corticosteroids (TSC). Budesonide orodispersible tablets (BOT) have demonstrated efficacy in adult EO patients in recent randomized trials[1,2], although their use remains off-label in individuals under 18 years of age. This study aimed to assess the real-world efficacy and safety of BOT in a paediatric cohort with EO refractory to standard therapies.

We conducted a retrospective analysis of electronic medical records from children with EO followed at our Centre through July 2025. Primary outcomes included clinical remission (absence of EO-related symptoms), endoscopic remission (Endoscopic Reference Score for EO [EREFS] = 0), and histological remission (<15 eosinophils/high-power field).

Seventeen children were treated with BOT 0.5 mg twice daily, initiated after a median of 16 months from diagnosis (IQR: 11–28.5). Prior therapies included PPIs (17/17, 100%), coupled with elimination diets (4/17, 24%), or TSC (4/17, 24%). All patients underwent a baseline endoscopy before BOT initiation, showing a median EREFS of 3 (IQR: 2–3). BOT was administered alongside PPI therapy in 11/17 (65%) patients. After 3 months, clinical remission was achieved in 11/17 (65%) children. Concomitant PPI therapy was not significantly associated with clinical remission [OR 0.87 (0.11-7.1 CI 95%), p=1]. Eight patients underwent repeat endoscopy after a median of 11.5 months (IQR: 6.75–16.75); 6/8 (75%) were in endoscopic remission, and 7/8 (87.5%) achieved histological remission. Eosinophil counts significantly decreased from baseline [median 30 (IQR: 15–50) to 6 (IQR: 6–9); p = 0.03]. Among the four patients who had previously failed TSC therapy, three achieved clinical, endoscopic, and histological remission. After a median follow-up of 12.5 months (IQR: 6.25–21), 11/17 (64.7%) remained on BOT therapy (Figure 1), and 9/11 (82%) were in clinical remission. No adverse events were reported.

BOT was a safe and effective treatment option for EO in patients who had not responded to previous standard therapies, including off-label TSC.

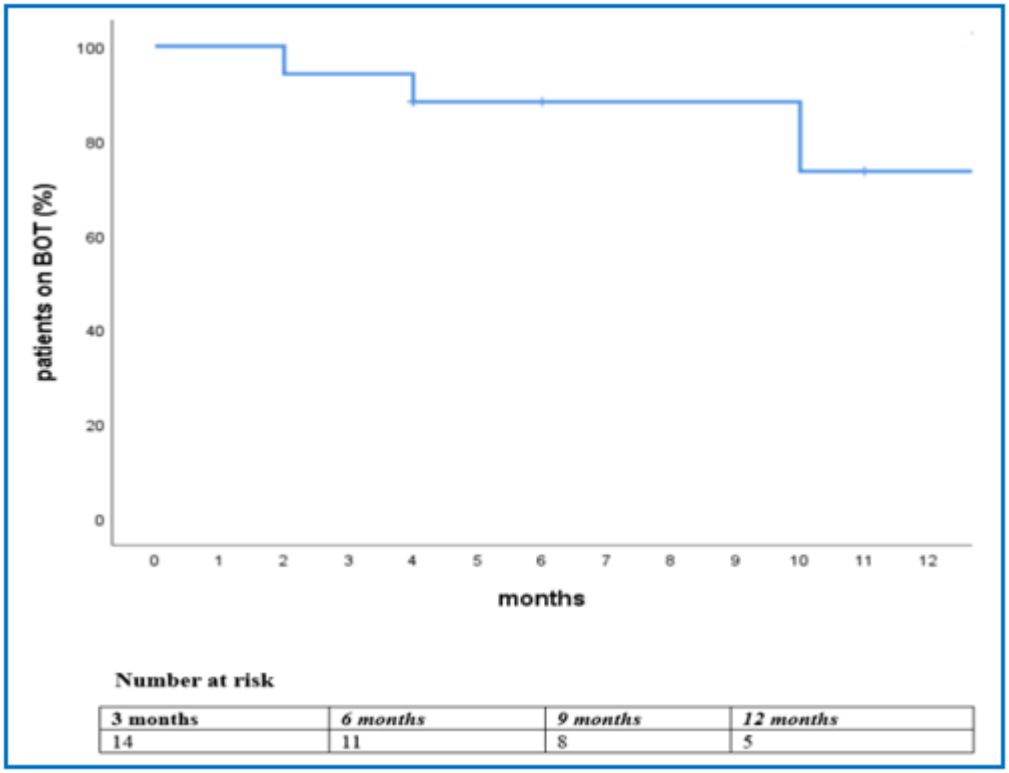

Figure 1 - Budesonide orodispersible tablets (BOT) durability in a paediatric EO cohort

References

1. Straumann A, Lucendo AJ, Miehlke S, et al. Budesonide orodispersible tablets maintain remission in a randomized, placebo-controlled trial of patients with eosinophilic esophagitis. Gastroenterology 2020;159(5): 1672–85.e5.
2. Lucendo AJ, Miehlke S, Schlag C, et al; International EOS-1 Study Group. Efficacy of Budesonide Orodispersible Tablets as Induction Therapy for Eosinophilic Esophagitis in a Randomized Placebo-Controlled Trial. Gastroenterology. 2019 Jul;157(1):74-86.e15.

OC60

Comparative Effectiveness of Oral Dispersible Budesonide (Jorveza) versus Conventional Therapies in Paediatric Eosinophilic Oesophagitis

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LEICESTER ROYAL INFIRMARY

Eosinophilic esophagitis(EOE), a chronic inflammatory condition, has become a leading cause of children presenting with dysphagia. British Society of Gastroenterology (BSG) and British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) joint consensus guidelines from 2022 suggests Topical steroids are effective for inducing histological and clinical remission in eosinophilic oesophagitis.

We conducted a retrospective review of Histology samples sent for assessment of EOE, and correlated it with Clinic letters, patient records, endoscopy findings both macroscopic and microscopic evidence to evaluate the different treatment modalities offered and the effectiveness of orodispersible budesonide(Jorveza) in comparison to conventional therapies as dietary restriction and proton pump inhibitors.

The demographic data suggests a mean age of 11 years, median age of 11.5 years with a male to female ratio of 2:1. Between January 2023 and January 2025 a total of 44 Endoscopy assessments were carried out with indications being either suspected EOE (n=25) or reassessment for EOE(n=19). 16 out of the 25 had a histological confirmation of EOE.

A total of 35 EOE cases identified, 28 of these children were treated with orodispersible budesonide (Jorveza) as first line with 21 cases of combined treatment with PPI. In 7 cases Jorveza alone was given, and 4 children had Exclusion diet

Our findings suggest that, Both the Jorveza only (100%) and the Jorveza +PPI Combination group(85%) had a higher clinical response rate in comparison to the exclusion diet alone with Clinical resolution of 75%. The PPI only group had a poor response rate of 33% in comparison to the groups, but only 3 children were on isolated PPIs in our cohort.

85% of children (30/35) were able to successfully complete Jorveza course, the common causes for inability to complete were identified as either taste of the medication or unable to follow instructions as children with special educational needs.

The Endoscopic responses of the children post induction treatment was difficult to interpret as many(14/35) have not had a repeat endoscopy post treatment and were subjected to further maintenance treatment or switch in the treatment based on clinical symptoms alone. Clinical resolution of symptoms has not translated well into endoscopic resolution of symptoms. 82%(29/35) have reported symptoms resolution while endoscopic resolution was only evidenced in about 38%(8/21). We have also found that endoscopic assessment performed while on Jorveza demonstrated a higher resolution (60%) in compared with children who were off Jorveza treatment(50%).These findings highlights the importance of endoscopic evaluation as a guide for EOE surveillance and to guide further treatment pathways.

Key Summary of findings			
Treatment group	Total	Clinical response	Endoscopic response
PPI only	3	**⅓ = 33%**	0/1 = 0%
Jorveza	7	**7/7 = 100%**	⅔ = 66%
Jorveza + PPI	21	**18/21 = 85%**	5/13 = 38%
Exclusion diet	4	**¾ = 75%**	¼ = 25%

References

Dhar A, Haboubi HN, Attwood SE, et al. Gut 2022;71:1459–1487.

OC61

Orodispersible Budesonide (ODB) may have a wider role in the management of non-eosinophilic oesophagitis (EoE) oesophageal strictures

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Orodispersible Budesonide (ODB) 'Jorveza' is a topical glucocorticoid receptor agonist indicated for the management of eosinophilic oesophagitis (EoE), a benign atopic inflammatory disorder of the oesophagus. It up-regulates anti-inflammatory agents such as IL-10 and annexin-1, and eosinophilia is reduced through IL-5 and eotaxin-3 inhibition, leading to decreased inflammation[1], and induces histological remission. ODB has also shown promise in managing post radio-frequency ablation strictures[2] and other inflammatory oesophageal conditions, although only licensed for EoE.

We have used ODB in 11-cases of non-eosinophilic oesophageal disease with dysphagia symptoms and no physiological evidence of reflux on 24-hour pH studies or major motility disorder on high resolution manometry. The treatment regimen included ODB 1mg taken twice daily for 12-weeks.

We assessed clinical, endoscopic, and histological improvement. Following the 12-week course, all patients experienced an improvement in one, two or all parameters (Table 1).

81.8% of patients showed symptomatic resolution (54.5% displaying a complete improvement, 27.3% displaying a partial improvement) and 18.2% showing no symptomatic response.

Of the patients that received a follow-up endoscopy, 80% showed complete endoscopic resolution and 20% displayed partial endoscopic response.

Histologically, of the three patients that received a follow-up biopsy, two displayed a complete histological response, and one achieved a partial response.

In summary, ODB is an efficacious drug utilised in the management of eosinophilic oesophagitis with a good safety profile. The promising clinical, endoscopic and histological responses observed in this group of patients suggest that ODB may have a broader therapeutic role beyond its current license.
Further research is needed to validate and build on this experience.
(Table 1)

ID	Age and Gender	Indications for ODB	Symptoms None/Moderate/Severe	Endoscopy before ODB None/ Moderate/Severe	Histologicay before ODB None/ Moderate/Severe	Clinical improvement 1/2/3	Endoscopic improvement 1/2/3	Histological improvement 1/2/3
1	64M	Post-RFA stricture	Dysphagia	Barrett's oesophagus with stricture at the GOJ	Severe esophagitis, cellular atypia following RFA	3	3	3
2	45F	Post-RFA stricture	Dysphagia, mild odynophagia	Oesophagitis in lower 1/3	*No biopsy*	1	3	*No biopsy*
3	71F	Esophagitis Dissecans Superficialis (Sloughing esophagitis)	Dysphagia	Grade A oesophagitis	*No biopsy*	3	*No follow-up*	*No biopsy*
4	58F	Esophagitis Dissecans Superficialis (Sloughing esophagitis)	Dysphagia	Severe oesophageal scarring; very narrow stricture	*No biopsy*	3	3	*No biopsy*
5	89F	Oesophageal lichen planus	Dysphagia, aspiration	*No endoscopy*	Lymphocytic infiltration	1	*No endoscopy*	2 - Reduced infiltration
6	76F	Inflammatory stricture (? Reflux related) – not responsive to PPI	Dysphagia, vomiting	Grade C oesophagitis	*No biopsy*	3	3	*No biopsy*
7	87M	LO	Dysphagia	*No endoscopy*		2	*No endoscopy*	*No follow-up*
8	50M	Inflammatory stricture (? Reflux related) – not responsive to PPI	Dysphagia	Grade D oesophagitis, inflammatory stricture	*No biopsy*	2	2	*No follow-up*
9	58F	Inflammatory stricture (? Reflux related) – not responsive to PPI	Dysphagia	Rings in distal oesophagus (sign of LOE)	*No biopsy*	2	2	*No follow-up*
10	63M	LO, stricture	Dysphagia	*No endoscopy*	Lymphocytosis	3	*No endoscopy*	*No follow-up*
11	66M	LO, stricture due to schatzki ring	Dysphagia	*No endoscopy*	Lymphocytosis	3	*No endoscopy*	3

References

1.Greuter T, Hirano I, Dellon ES. Emerging therapies for eosinophilic esophagitis. The Journal of Allergy and Clinical Immunology [Internet]. 2020 Jan 1 [cited 2022 Jan 1];145(1):38–45. Available from: https://pubmed.ncbi.nlm.nih.gov/31705907/
2.Wang WL, Tsai YN, Hsu MH, Lin JT, Wang HP, Lee CT. Administration of oral prednisolone to prevent esophageal stricture after balloon-type radiofrequency ablation for ultralong-segment esophageal neoplasia. Gastrointestinal Endoscopy. 2024 Aug;100(2):192–9.

OC62

Eosinophilic Oesophagitis in a Welsh centre: A first look at the epidemiology and clinical spectrum

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Eosinophilic Oesophagitis (EoE), a chronic inflammatory disease of the oesophagus (1), is rising in the paediatric population (2). There is increasing knowledge surrounding EoE and changing international guidelines (3). UK paediatric guidance however, has only recently been published (2). This study is the first in Wales to define paediatric EoE epidemiology and evaluate current management.

All paediatric patients with EoE seen in a tertiary centre between January 2020- June 2025 were included. Patients were identified from a specific clinical code.

Data was retrospectively collected from electronic patient records and recorded and analysed in Excel. Prevalence (using 2024 dataset) and incidence data was calculated using published population size data by year from StatsWales(4).

Patients diagnosed with EoE had clinical symptoms and a post-endoscopy histology report of >15 eosinophils/hpf. Patients with a high clinical suspicion of EoE and a borderline oesophageal mucosal eosinophilia were included if they were subsequently clinically diagnosed. Atopy refers to patients with a history of asthma, eczema or rhino-conjunctivitis. Transitioned patients refer to those who are ≥16 years old and have been referred to adult gastroenterologists.

92 patients were seen between 2020-2025 and were diagnosed over a 15-year period, between November 2010-May 2025. 78% (n=72) were male, mean age at diagnosis was 10 years old (range 1-16 years old). 51% (n=47) had an atopic history.

Local prevalence is 9.57 cases per 100,000 inhabitants; the table shows incidence (4).

Table Showing Incidience of EoE in Paediatric Population By Year

Year	Total Paediatric Population	Number of Patients diagnosed	Incidence per 100 000
2019	458567	14	3.05
2020	458384	4	0.87
2021	455861	8	1.75
2022	458111	13	2.84
2023	460289	9	1.96
2024	459583	12	2.61

From the date of referral to diagnostic endoscopy, the mean number of weeks was 9.4 (range 0-60 weeks). 68% (n=63) diagnostic endoscopies took 6 biopsies.

Dysphagia was the prevailing (n=65) presenting complaint, then food bolus obstruction (n=43) and vomiting (n=33). 7% (n=6) of patients had stricturing disease, 3 were treated with endoscopic dilatation.

Within 3 months of diagnosis, 50% of (n=46) patients were taking a proton pump inhibitor (PPI), 59% (n=54) were taking swallowed topical steroids (STS), 27% (n=25) took both. 9% (n=8) of patients were treated with diet.

67% (n=62) had ≥1 further endoscopy post-diagnosis, of these, 56% (n=35) had evidence of remission. 34% (n=12) of patients achieved remission on combination PPI and STS, 23% (n=8) on STS and 20% (n=7) on PPI.

37 patients were transitioned to adult care, 73% (n=27) have been seen by adult services since.

This is the first time a Welsh paediatric EoE cohort has been described. Our data showed similarities to published data, for example, male predominance (2) and dysphagia being the leading presenting complaint (5).

The incidence and prevalence of EoE in our cohort is significantly lower than published literature (6). Atopy rates in our cohort are also lower than observed elsewhere (7).

Further work is needed to raise awareness of EoE in Wales. The next step is to combine data with other Welsh centres to establish a pan-Wales pathway for EoE. Closer collaboration between different specialists is needed to identify children at risk of developing EoE.

References

1. Attwood SE, Smyrk TC, Demeester TR, Jones JB. Esophageal eosinophilia with dysphagia. A distinct clinicopathologic syndrome. Dig Dis Sci. 1993;38(1):109-16.
2. Dhar A, Haboubi HN, Attwood SE, Auth MKH, Dunn JM, Sweis R, et al. British Society of Gastroenterology (BSG) and British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) joint consensus guidelines on the diagnosis and management of eosinophilic oesophagitis in children and adults. Gut. 2022;71(8):1459-87.
3. Rank MA, Sharaf RN, Furuta GT, Aceves SS, Greenhawt M, Spergel JM, et al. Technical Review on the Management of Eosinophilic Esophagitis: A Report From the AGA Institute and the Joint Task Force on Allergy-Immunology Practice Parameters. Gastroenterology. 2020;158(6):1789-810.e15.
4. Welsh Government. Population estimates by local authority, year, sex and age [Internet]. StatsWales; 2025 [cited 2025 Oct 30]. Available from: https://stats.gov.wales/en-GB/82d9faea-b515-41cd-aedb-8f4594f66ce5
5. Shillitoe B, Lee JC, Hussien M, Beintaris I, Stothard M, Johnston M, et al. Clinical spectrum of paediatric and adult eosinophilic oesophagitis in the North East of England from 2016 to 2019. Frontline Gastroenterology. 2022;13(3):231-6.
6. Navarro P, Arias Á, Arias-González L, Laserna-Mendieta EJ, Ruiz-Ponce M, Lucendo AJ. Systematic review with meta-analysis: the growing incidence and prevalence of eosinophilic oesophagitis in children and adults in population-based studies. Aliment Pharmacol Ther. 2019;49(9):1116-25.
7. Ancellin M, Ricolfi-Waligova L, Clerc-Urmès I, Schweitzer C, Maudinas R, Bonneton M, et al. Management of eosinophilic esophagitis in children according to atopic status: A retrospective cohort in northeast of France. Archives de Pédiatrie. 2020;27(3):122-7.

OC63

Dupilumab in highly refractory Eosinophilic Esophagitis in children.

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Eosinophilic Oesophagitis (EOE) has several recognised conventional treatments. More recently dupilumab (anti IL-4 and IL-13) has been shown to an effective treatment for EoE for children and adults. There is a paucity of data on the efficacy of dupilumab in the treatment of refractory EoE or with associated non-EoE EGID. In this study we aimed to identify indication and efficacy of dupilumab in multi-treatment refractory EoE in children.

We conducted a retrospective review of patients with eosinophilic oesophagitis (EoE) refractory to conventional therapies who received dupilumab for a minimum of three months at our specialized centre. Clinical (PEESS vers. 2) and histological responses were evaluated at 3 and 6 months following treatment initiation.

Four male patients (mean age 13.5 years) were included; three had isolated eosinophilic oesophagitis (EoE), and one had concomitant eosinophilic colitis. Abdominal pain was the predominant symptom (100%), followed by dysphagia, vomiting, and regurgitation (75%), and food impaction (50%). The primary indication for initiating dupilumab was refractory disease despite multiple conventional treatments, including corticosteroids. Two patients (50%) developed adrenal insufficiency secondary to prolonged corticosteroid use. None of the patients achieved clinical or histological remission prior to starting dupilumab. Following dupilumab therapy, two patients (50%) demonstrated both clinical improvement and histological remission at 3 and 6 months respectively. One patient (25%) showed partial clinical response without histological remission within six months of treatment, leading to cessation of steroids and initiation of an elemental diet.

Table 1. Dupilumab outcomes in children with Refractory EoE

Patient	Age	Sex	Diagnosis	Diet	PPI	Steroids	Refractory to steroids disease	Adrenal suppression	Response at 3 months of Dupilumab	Response at 6 months of Dupilumab
A	13y	M	EoE	1	1	1	1	1	awaiting assessment	awaiting assessment
B	16y	M	EoE	1	1	1	1	1	remission	remission
C	16y	M	EoE and EGID	1	1	1	1	0	remission	remission
D	9y	M	EoE	1	1	1	1	0	partial	Active disease

0:No, 1:Yes

Dupilumab is licensed by not remunerated in the UK for children over the age of 1. Due to the requirement for local funding, its use is restricted. Approval has been gained at our site for those who have displayed refractory EoE or who have significant side-effects to treatment. This small study shows that dupilumab can be an effective treatment for this cohort and should be considered by funding bodies for use more widely in the UK.

OC64

Coeliac Disease treatment may not be associated with linear catch-up growth in the modern era.

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Historically, Coeliac Disease has been considered as an important cause of linear growth faltering in children, and effective treatment has been associated with linear catch-up growth. However, with modern, readily available diagnostics tests, and increased awareness, Coeliac is being diagnosed at an earlier stage in the disease course. Hence, we wondered if effective treatment of Coeliac would still be associated with linear catch-up growth.

We did a retrospective analysis of routine clinical data captured in electronic patient records of patients with an identified diagnosis of Coeliac Disease at a single centre. We extracted baseline demographic and clinical data, and anthropometric and laboratory data at 12, and 24 months after diagnosis. We focussed on height-for-age Z-score as a standardised index of linear growth, and the change in HAZ from diagnosis to 2 years post diagnosis (dHAZ-2y) as an index of catch-up growth. Data were fully anonymised and no ethical approval was required. Standard non-parametric testing, paired t-tests, and linear regression analyses were undertaken in Prism.

50 patients were included in the analysis. There was a modest degree of growth faltering at diagnosis, as the population mean HAZ was -0.45 (95% CI: -0.85 - -0.05). Across the population as a whole, there was no evidence of significant change in HAZ from diagnosis to 1, or 2 years, post-diagnosis. dHAZ-2y was inversely associated with baseline HAZ ($Y = -0.29*X + 0.08$; $R^2 = 0.18$; $p = 0.004$), suggesting regression to the mean over time. Considering patients who had normalised IgA-TTG at 1 year (n=27), versus those with persistently elevated IgA-TTG (n=13), there was no significant difference in terms of dHAZ-2y.

There is evidence of a modest degree of growth faltering at diagnosis, but we failed to identify a significant degree of linear catch-up growth during treatment of newly-diagnosed Coeliac Disease regardless of normalisation of IgA-TTG.

OC65

Anti-tissue transglutaminase antibodies in non-coeliac children: outcomes in a single tertiary centre.

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Coeliac disease is an autoimmune disorder occurring in genetically susceptible individuals, caused by an abnormal response to gluten[1]. This causes crypt hyperplasia, villous atrophy and epithelial lymphocyte invasion in the small intestine[1]. Diagnosis can be made on bloods if IgA tissue transglutaminase (TTG) is over ten times the upper limit of normal with a positive endomysial antibody (EMA) on a second sample, or on duodenal biopsy in those with lower titres[2].

There is limited literature regarding outcomes for patients with raised TTG who are not subsequently found to have coeliac disease. European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) suggests these children are considered at risk of future coeliac disease and recommend clinical and laboratory monitoring[2]. IgA TTG is also known to be associated with other autoimmune conditions including inflammatory bowel disease (IBD), autoimmune liver disease, thyroid disease, type 1 diabetes and with gastrointestinal infection[2].

We aimed to evaluate alternative causes for raised TTG in patients investigated for coeliac disease in a single tertiary centre and to develop departmental guidelines for management of future cases.

Patients undergoing TTG testing under Paediatric Gastroenterology between 2023-2025 were retrospectively identified from the electronic records system. Data was collected on age, symptoms at presentation, history or family history of autoimmunity, infection markers, outcome of endoscopy and subsequent diagnosis.

41 patients (25 female, 16 male) had an abnormal TTG result. 21/41 (51%) had a TTG level over ten times the upper limit of normal therefore met no biopsy criteria and were diagnosed with coeliac disease. 20/41 (49%) patients required endoscopy, with 5/20 still awaiting endoscopy. 4/15 (27%) of patients who underwent an endoscopy were diagnosed with coeliac disease on histology, 11/15 (73%) were not found to have coeliac disease on histology.

Of those with negative endoscopy, 3/11 (27%) were diagnosed with alternative gastrointestinal pathology (2 with IBD and 1 with helicobacter pylori). 3/11 (27%) patients had existing autoimmune disease (1 with hypothyroidism, 1 with type 1 diabetes and 1 with juvenile idiopathic arthritis). 5/11(45%) had a family history of autoimmune disease (3/5 family history of coeliac disease). 7/11 (64%) were EMA positive, which would indicate potential coeliac disease as per the ESPGHAN guidelines. 5/11 (45%) of patients started a gluten free diet after being reviewed in clinic. Limitations of the study included small patient numbers due to difficulty capturing patients with raised TTG values without coeliac disease from the electronic records system.

The majority of children with raised TTG will go on to be diagnosed with coeliac disease, but of those with a negative endoscopy, alternative pathology such as IBD or autoimmune disease should be considered. Literature is limited on long term outcomes for patients with an unexplained raised TTG; we would suggest these children are followed as per ESPGHAN guidelines and repeat endoscopy considered. A departmental guideline is under development currently. Larger studies of patients with raised TTG with negative duodenal biopsy would be helpful to provide more information on outcomes for this group of patients.

References

1 - Mubarak A, Spierings E et al. Children with celiac disease and high tTGA are genetically and phenotypically different. World Journal of Gastroenterology 2012 7:19 (41): 7114-7120.
2 - https://www.espghan.org/knowledge-center/publications/Gastroenterology/2019_ESPGHAN_guidelines_for_diagnosing_coeliac_disease. 2020.

OC66

Exploring the barriers to dietary adherence in Children and Young People with Coeliac Disease

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Coeliac disease (CD) is an autoimmune condition, and its management is strict adherence to a gluten-free diet (GFD) (1). There are multiple factors that can affect adherence. This study aims to quantitatively evaluate the barriers to GFD adherence to enable targeted intervention and service development in identified domains.

A questionnaire study was conducted with 60 participants with confirmed coeliac disease identified through the Paediatric Gastroenterology Service. Participants were divided into two groups based on age: 8–12 years (n=26) and 13–17 years (n=34). Participants completed measures assessing adherence to a gluten-free diet and the impact of potential psychosocial and practical barriers. Correlational analyses were used to explore associations between individual barriers and adherence scores within each age group.
Difficulty when travelling and eating out was a prominent domain in both groups, achieving the highest scores in the 13–17 years and the second and third highest in the 8–12 years (Figures 1 and 2). Whilst Coeliac UK offers gluten-free restaurant accreditation (2), options can often be limited, leading to a lack of desire to eat out. In the 13+ patient group, travel was the most influential barrier to GFD adherence, which could limit social development and independence compared to their peers (3). To address this, interventions would need to focus on the hospitality industry to improve education and gluten-free options, which could be aided by further research and lobbying.

Interestingly, the highest scoring barrier to adherence in the 8-12 years age group was ‘wanting to eat food with gluten in.' This is most likely due to the burden of buying and preparing a GFD falling on caretakers, whereas the desire for a non-GFD is more burdensome on the child themselves. This could signal a lack of understanding, so interventions would need to focus on education, both of children with CD as well as their peers.

Overall, this data shows that the majority of the barriers to GFD adherence are practical, based on the availability and cost of a GFD. On average, shopping for a GFD costs 35% more compared to a non-GFD (4). This limits further intervention, as changes to the food landscape on a national scale would be required to increase options and decrease costs associated with a GFD. One potential solution could be the reintroduction (5) of gluten-free prescriptions to ensure access to gluten-free necessities.

In conclusion, this study has shown that whilst adherence to a GFD is multi-factorial, external factors are the most burdensome, which requires further research and potential involvement from restaurants and supermarkets. Within the scope of paediatric gastroenterology, further education and signposting to resources could be key in helping to address these barriers.

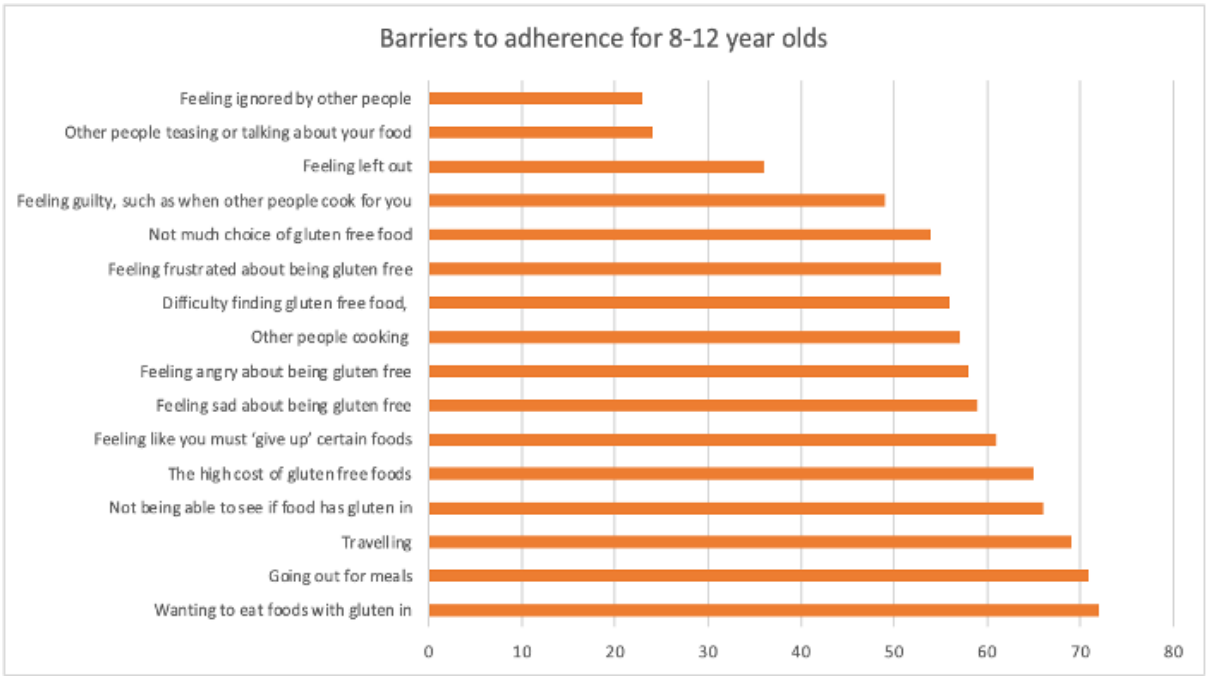

Figure 1 (above) shows the scores for barriers to adherence for 8–12-year-olds

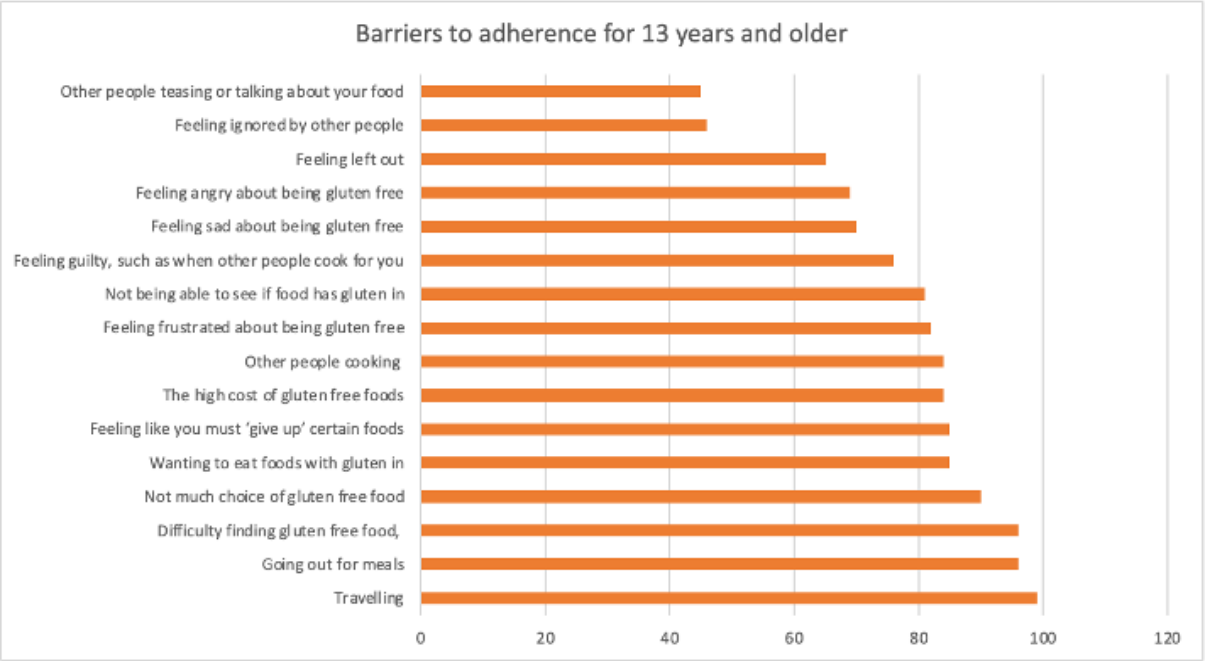

Figure 2 (above) shows the scores for barriers to adherence for those 13 years and older

References

1. Hill P, Austin A, Forsyth J, Holmes G. British Society of Gastroenterology guidelines on the diagnosis and management of coeliac disease. Gut. 2014;64(4):691-692.
2. Coeliac UK. Eating out [Internet]. Available from: https://www.coeliac.org.uk/information-and-support/living-gluten-free/the-gluten-free-diet/eating-out/
3. MacCulloch K, Rashid M. Factors affecting adherence to a gluten-free diet in children with celiac disease. *Paediatr Child Health.* 2014;19(6):305-309. doi:10.1093/pch/19.6.305
4. Coeliac UK. New Coeliac UK report sheds light on cost, access & availability of gf food [Internet]. 26 June 2024. Available from: https://www.coeliac.org.uk/about-us/media-centre/news/new-coeliac-uk-report-sheds-light-on-cost-access-and/?set=true&type=rfst - needs citation
5. West Yorkshire Health & Care Partnership. Treatments paid for by the NHS [Internet]. West Yorkshire (UK): West Yorkshire Health & Care Partnership; 2024 Feb 28. Available from: https://www.wypartnership.co.uk/our-priorities/improving-planned-care/our-west-yorkshire-and-harrogate-commissioning-policies/treatments-paid

OC67

Patients with suspected coeliac disease undergoing endoscopy: are we following ESPGHAN Guidelines?

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ESPGHAN 2020 guidelines permit a no-biopsy diagnosis of coeliac disease in children when tissue transglutaminase IgA (TTG-IgA) is ≥10× the local upper limit of normal (ULN), endomysial antibodies (EMA) are positive, total IgA is sufficient, the child is <18 years and consuming gluten and families agree to this pathway (1). Real-world uptake varies and laboratory ULN differences materially alter eligibility.

A retrospective review was conducted of 80 paediatric patients who underwent endoscopic evaluation for suspected coeliac disease over 6 years (2020 to November 2025) at a single tertiary centre. Data was collected for eligibility for ESPGHAN no-biopsy pathway. This included age, sex, TTG-IgA, EMA, IgA deficiency markers, endoscopy/histology, diet status at testing/scope, diagnosis, and management. No-biopsy eligibility was defined as: age <18 y, TTG-IgA ≥70 U/mL (≥10× ULN), EMA positive, no IgA deficiency, and on a gluten containing diet at testing/scope. Modified Marsh classification was used to grade the severity of intestinal damage seen on biopsy. This was categorised into stages 0, 1, 2, and 3, with the most severe forms (3a, 3b, and 3c) being consistent with coeliac disease.

Coeliac disease was diagnosed in patients with histology-proven enteropathy (Marsh type ≥2) or in those with Marsh type 1 changes accompanied by elevated TTG and initiation of a gluten-free diet.

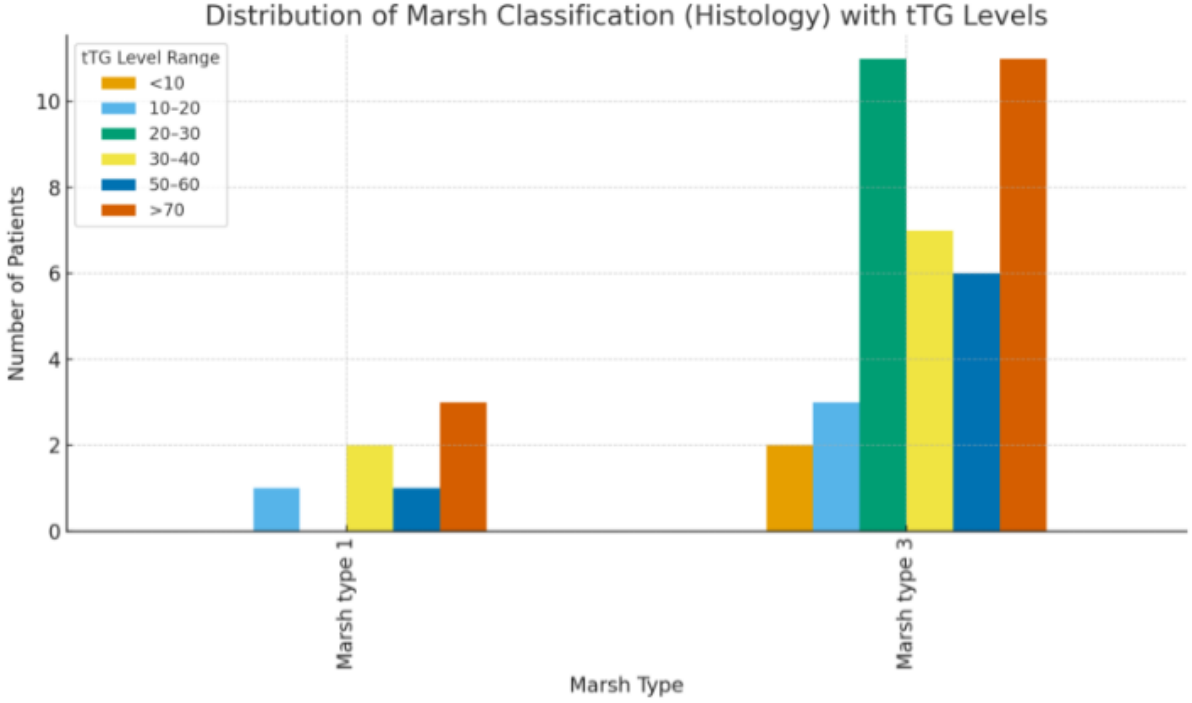
Among the 80 children evaluated, 10 (12%) fulfilled strict ESPGHAN no-biopsy criteria. 2 of these patients were also being evaluated for inflammatory bowel disease so warranted endoscopic evaluation. 1 of the patient's parents wanted endoscopic evaluation despite raised TTG IgA levels . IgA deficiency was present in 4 patients (5%); however, EMA-IgG was only performed in 3 of the 4 patients (2 IgG positive, 1 IgG-negative)

EMA was not measured in 15 patients (24%) with elevated TTG, limiting assessment of eligibility for biopsy avoidance. There was one patient with a TTG of 1.18 whose biopsy confirmed coeliac disease. Among the 80 patients evaluated, coeliac disease was diagnosed in 62 patients. 6 patients diagnosed with coeliac disease had Marsh type 1 changes on histology, elevated TTGs and were started on a gluten-free diet.

10 (12%) patients required gluten challenges prior to endoscopy 8 of whom were diagnosed with coeliac disease and started on gluten free diets.

Marsh type changes were identified on histology in 24 patients despite macroscopically normal endoscopic findings.

Graph showing patients with higher TTG titres were more likely to have histology changes (Marsh type 3 changes).



A total of 12% of patients fulfilled the ESPGHAN coeliac disease no-biopsy diagnostic criteria but nonetheless underwent endoscopy, representing procedures that might have been avoidable. EMA testing was omitted in 24% of cases, limiting adherence to the no-biopsy diagnostic pathway. This quality improvement project has highlighted areas for optimizing patient selection for endoscopy. As a result, all suspected coeliac disease cases are now discussed in our endoscopy MDT, and more stringent criteria have been implemented to improve diagnostic efficiency and compliance with ESPGHAN guidance.

References

Husby S, Koletzko S, Korponay-Szabó I, et al. European Society Paediatric Gastroenterology, Hepatology and Nutrition guidelines for diagnosing coeliac disease 2020. J Pediatr Gastroenterol Nutr 2020;70(1):141–156.

OC68

Age-Related Barriers to Gluten-Free Diet Adherence in Children and Young People with Coeliac Disease: Implications for Integrated Psychological Care

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Maintaining strict adherence to a gluten-free diet is the only effective treatment for Coeliac Disease (CD). However, maintaining consistent adherence can be challenging for many Children and Young People (CYP), particularly as they become increasingly independent[1]. Adherence is known to be influenced by a range of practical, psychological and social factors[2]. Understanding these barriers within paediatric populations can inform tailored medical, dietetic and psychological support. Although there are national guidelines for the management of CD, these do not yet fully integrate psychological care for CYP.

A questionnaire study was conducted with 60 CYP diagnosed with CD attending clinics within a Paediatric Gastroenterology Service. CYP were divided into two age groups: 8–12 years and 13–17 years. Participants completed self-report measures assessing adherence to a gluten-free diet and the impact of a range of potential barriers, including psychological, social and practical. Correlational analyses were conducted with each age group to explore associations between barriers and adherence scores.

Statistical analyses showed there were differences in the key barriers associated with adherence across the two age groups, and the extent to which these impacted the CYP. In younger children (8–12 years), adherence was significantly associated with practical barriers. Poorer adherence was significantly associated with practical barriers, particularly the high cost of gluten-free foods and limited availability or choice. In contrast, among adolescents (13–17 years), poorer adherence was significantly associated with psychological and social barriers. Those reporting poorer adherence described greater feelings of frustration, sadness and exclusion, and reported being more affected by others' comments or discussions about food. This group appeared more influenced by peer relationships and emotional factors surrounding dietary restrictions.

These findings suggest there is a developmental shift in the factors influencing adherence to a gluten-free diet in CYP. While practical barriers influence adherence in younger children, psychological and social factors play an increasingly significant role during adolescence. These differences have implications for service delivery, suggesting that psychology support should be both routinely available and tailored to the CYP's development.

Integrating psychological assessment and support into paediatric CD services is therefore essential to support the evolving developmental needs of CYP. For younger children, family-based support focused on practical management may improve adherence, whereas adolescents may benefit more from interventions targeting emotional coping, social inclusion and self-management skills. A multidisciplinary model embedding routine psychological input alongside medical and dietetic care could enhance adherence and wellbeing, thereby optimising long-term outcomes. Although current guidelines emphasise dietetic and medical follow-up, structured psychological intervention remains an area for development. Our findings provide support for integrating age-appropriate psychological support as a routine component of paediatric CD services.

References

1 Czaja-Bulsa G, Bulsa M. Adherence to gluten-free diet in children with celiac disease. Nutrients. 2018 Oct 4;10(10):1424.
2 White LE, Bannerman E, Gillett PM. Coeliac disease and the gluten-free diet: a review of the burdens; factors associated with adherence and impact on health-related quality of life, with specific focus on adolescence. J. Hum. Nutr. Diet. 2016 Oct;29(5):593-606.

OC69

"Glad to know I'm not alone in this experience of throwing up"; experience of Tree of Life Groups for Children with Coeliac Disease and their Parents

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Coeliac Disease (CD) is an autoimmune condition that currently can only be managed through strict adherence to a gluten-free diet. For young people, this restriction can substantially affect social functioning, participation, and psychological wellbeing. Research has shown that young people with CD may experience anxiety, embarrassment, isolation, and stigma associated with their dietary needs (Ho et al., 2020; Olsson et al., 2009). These challenges can make it difficult for young people to enjoy social activities involving food and may contribute to reduced self-esteem and social confidence. Despite the known psychosocial impact of CD, there are limited group-based interventions that specifically support young people and their families in managing the emotional and social consequences of living with the condition.

The current project aimed to assess whether families would engage with a *Tree of Life* (Ncube, 2006) group intervention and to evaluate its impact on young people's wellbeing, feelings of isolation, and parental wellbeing. The *Tree of Life* approach, grounded in narrative therapy principles, uses a metaphor of a tree to explore participants' strengths, values, and support networks, fostering connection and resilience within a group setting.

Three *Tree of Life* groups were delivered for young people aged 8–15 years, accompanied by two parent support sessions. In total, 32 young people (19 female, 13 male) and 15 parents (12 female, 3 male) took part. Participants qualitative feedback surveys immediately following the groups to capture participants' experiences and reflections.

Feedback from both young people and parents was overwhelmingly positive. All young people (100%) reported that they enjoyed taking part in the sessions, found them useful, and would recommend them to others. Parents also unanimously endorsed the usefulness of the sessions and expressed a desire for future groups. Participants particularly valued the opportunity to meet others with CD, share experiences, and exchange practical information such as recommendations for safe places to eat. Young people highlighted the benefit of forming friendships with peers who understood their experiences and expressed that the groups helped them feel less isolated and more confident managing CD in social contexts. Parents appreciated the opportunity to share their own experiences, connect with others caring for children with CD, and learn more about the condition and its management.

The *Tree of Life* groups were well received and demonstrated a positive impact on young people's self-image, wellbeing, and sense of connection. Both young people and caregivers described the sessions as empowering, supportive, and informative. Preliminary findings suggest that narrative-based group interventions such as *Tree of Life* may provide an effective, low-cost, and engaging way to support the psychosocial wellbeing of young people living with Coeliac Disease and their families. Further evaluation with larger and more diverse samples could strengthen the evidence base for the integration of such approaches into routine clinical support for chronic health conditions in young people.

References

Ho, W. H., Atkinson, E. L., & David, A. L. (2022). Examining the psychosocial well-being of children and adolescents with coeliac disease. *Journal of Pediatric Gastroenterology and Nutrition*, *76*(1). https://doi.org/10.1097/mpg.0000000000003652
Ncube, N. (2006). The tree of life project. *International Journal of Narrative Therapy & Community Work*, *2006*(1), 3-16.
Olsson, C., Lyon, P., Hörnell, A., Ivarsson, A., & Sydner, Y. M. (2009). Food that makes you different: The stigma experienced by adolescents with celiac disease. *Qualitative Health Research*, *19*(7), 976–984. https://doi.org/10.1177/1049732309338722

OC70

The National BSPGHAN GI Bleeding Survey – The State of Play in UK Paediatric Bleeding Services

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Acute paediatric GI bleeding is a rare but serious presentation and can be associated with significant morbidity and mortality. Previous prospective surveys have attempted to establish incidence and specific clinical data regarding GI bleeding[(1)]. Data regarding the configuration and delivery of GI bleeding services on a national basis are lacking. This survey aimed to establish how services are delivered, number of cases managed and frequency of morbidity and mortality with purpose of informing the development of a national GI bleeding practice framework. Units were invited to complete an online survey through the British Society for Paediatric Gastroenterology (BSPGHAN) then by directly contacting units to contribute. There were 20 responses from 17 centres indicating 57% survey coverage based on there being approximately 30 centres in the UK[(2)]. 15/17 of centres managed acute GI bleeding, of these 13/15 had gastroenterologists managing bleeding 24/7. In some centres, bleeding patients were managed by the surgical team or had direct input from adult services out-of-hours. The number of whole-time-equivalent consultants providing services varied considerably from 1 to 9 with a median of 5. 5/18 centres routinely used the Sheffield scoring system, 8/18 used the BSPGHAN bleeding pathway and the majority used a local guideline. 14/18 had access to adult support with some having formalised agreements but most on an informal basis. Interventional radiology (IR) support was highly variable with only one centre having 24/7 paediatric IR access but the majority had potential access to adult IR on-call. Equipment access was robust, with most centres having a dedicated GI bleeding trolley/kit (16/18) and near ubiquitous access to haemospray (17/18), endoclips (16/18) and band ligators (15/18). 13/18 of centres had Sengstaken-Blakemore tubes available for refractory bleeding. The annual case volume for acute GI bleeding interventions showed significant variation between centres (median=3.5, range=0-24), classifying it as a low-volume procedure in many settings. Reported clinical outcomes were favourable with the majority of centres reporting no mortality or significant morbidity due to acute bleeding in the last 12 months. Considering departmental confidence in managing bleeding, 72% of centres reported excellent or very good confidence in-hours compared to 28% excellent or very good out-of-hours. 7/20 centres had simulation or up-skilling sessions. This is the first project to survey acute paediatric GI bleeding services in the UK. These preliminary data indicate there is significant heterogeneity in how services are configured across the country particularly in terms of adult, surgical and IR support. Risk scores and national pathways are not universally used indicating there is scope to improve their utility. Case volume is generally low and morbidity and mortality is rare. Establishment of a prospective national bleeding registry could improve resource provision and inform efforts to standardise services.

Figure 1. Map of the UK with responding centres, green centres provide acute manage of GI bleeding and blue centres provide gastroenterology services but not bleeding management.

References

1. Thorn N, Vallorani M, Kirupananthan R, et al. P20 Emergenci: a UK prospective survey of severe GI bleeding (requiring upper GI endoscopy) and emergency endoscopy in under 16s. *Frontline Gastroenterology* 2021;12:A22-A23.
2. Royal College for Paediatrics and Child Health/British Society for Paediatric Gastroenterology, Hepatology and Nutrition. The paediatric gastroenterology, hepatology and nutrition UK national census 2021. 2021.

OC71

Endoscopic Resolution Clips to Repair Iatrogenic Caecal Perforation in Acute severe Ulcerative Colitis

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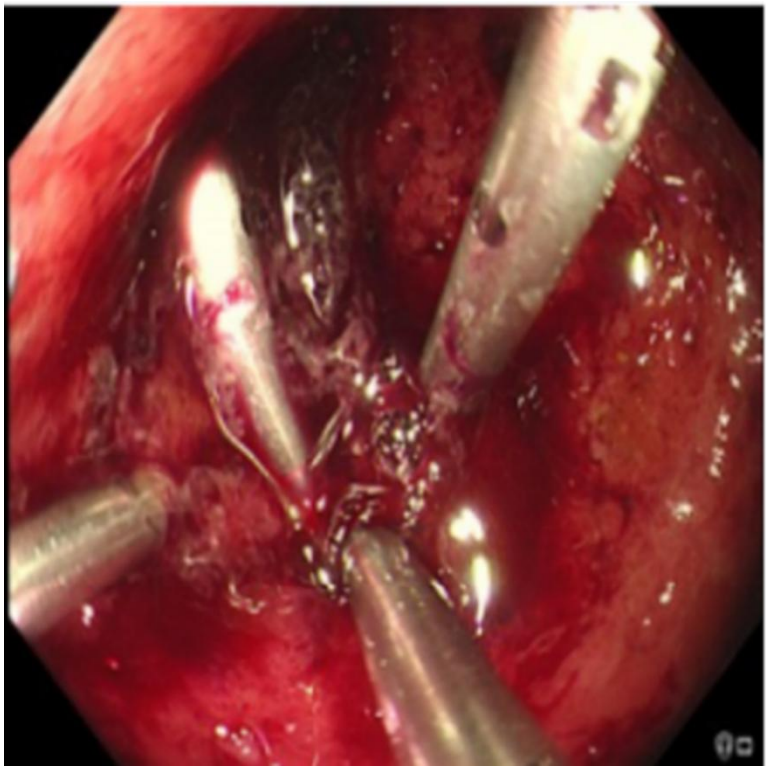
Colonoscopy is an essential tool for the initial assessment of Inflammatory Bowel Disease in children. Main complications include bleeding, infection and perforation. The literature around complications in Paediatric endoscopy is sparse. The estimated rates of perforation in children are 0.01% to 0.13% for all endoscopies and 1% for interventional procedures. It carries a significant morbidity and mortality.

CASE REPORT A 9 year-old boy presented to the Paediatric Gastroenterology clinic with 2 years history of intermittent lower abdominal pain, loose stools with blood and tenesmus. His weight was on 50 —75th centile and height on 25-50th centile. He did not have any features of extraintestinal involvement. There was family history of coeliac disease in Mum and half siblings. There was no history suggestive of Ehler Danlos or Epidermolysis bullosa. There were no risk factors from an anaesthetic point of view identified in clinic. There was no significant past medical history. Physical examination had been unremarkable with a normal soft abdomen with no tenderness or palapable mass. Full Blood Count had shown thrombocytosis (705 x 109/L) and elevated erythrocyte sedimentation rate of 31mm/hr. Other blood tests including Urea and Electrolyte, Liver Function Test, albumin (40g/l), coeliac screen were unremarkable. Faecal calprotectin was elevated at 1422mg/kg The patient underwent a diagnostic UGI Endoscopy and Ileocolonoscopy under general anaesthesia using a flexi laryngeal mask airway . Upper GI endoscopy revealed small polyp less than 0.5 cm at the distal end of the oesophagus, mild nodularity in the antrum and lax gastroesophageal junction. Ileocolonoscopy showed severe patchy colitis worse in the ascending and transverse colon with relatively spared rectum and patchy erythema in the terminal ileum. There were deep seated ulcers with slough and easy friability worse in the caecum. Caecal perforation was noted immediately after caecal biopsy. The patient was subsequently intubated and ventilated. 7 Bostons resolution clips were applied to close the mucosal defect (Figure 1) A contrast study was performed after the clips were applied (on table) which confirmed bowel continuity and no evidence of pneumoperitoneum. Post operatively, he was kept nil by mouth and started on Total Parenteral Nutrition . On day 6 post procedure, CT abdomen and pelvis with contrast was performed which did not demonstrate any evidence of residual post-operative complications such as leakage, fistula or peritonitis. A presumptive diagnosis of Ulcerative colitis (UC) with backwash ileitis (E4S1) was made. The patient was started on Anti-TNF α treatment (Infliximab 10 mg/kg) on an accelerated regimen 0,1 and 5 weeks . He was discharged on day 10 without any complications. He has been subsequently followed up in clinic and is doing well.

CONCLUSION Iatrogenic perforation during high risk paediatric colonoscopy can be managed using endoscopic clips , even in patients with Ulcerative colitis, thus avoiding the need for surgery.



References

1. Thakkar K, El-Serag HB, Gilger M. Complications of pediatric colonoscopy: a five-year multicenter experience. Clin Gastroenterol Hepatol. 2008 May;6(5):515-20.
2. Hsu EK, Chugh P, Mamula P. Incidence of perforation in pediatric GI endoscopy and colonoscopy: an 11-year experience. Gastrointest Endosc. 2013 Jun;77(6):960-6.

OC72

Avoidant/restrictive food intake disorder and paediatric feeding disorder in a tertiary paediatric centre – a service evaluation

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Avoidant/restrictive food intake disorder (ARFID) is characterized by restricted food intake and limited variation of diet, often resulting in suboptimal nutrition and poor growth. Despite being considered a new diagnosis (emerging from the Diagnostic and Statistical Manual of Mental Disorders, 5th edition) it's prevalence in the paediatric population is increasing, with some studies suggesting it affects 1 in every 5-20 children[1] Paediatric feeding disorder (PFD) is a similar disorder which is considered to overlap some aspects of ARFID, and work has been done to distinguish the two from each other[2]

We retrospectively reviewed medical records of all patients diagnosed with ARFID within the last 10 years at our paediatric tertiary hospital based in the UK, to see if they currently fulfil the ARFID diagnostic criteria, or whose symptoms are more aligned with PFD. We also reviewed any potential vitamin and trace metal deficiencies at the time of diagnosis (copper, zinc, selenium, vitamins A, E, D, and B12 + folate) and then exploring any comorbidities these patient groups may have, specifically neurodivergent (ADHD, ASD, Anxiety and sensory processing difficulties)

We reviewed the medical records of 269 patients in total, 220 diagnosed with ARFID and 49 PFD. 80(36%) of patients diagnosed with ARFID suffered from 1 or more vitamin deficiency at diagnosis, with 13(27%) patients with PFD suffering the same. Interestingly, within our patient cohort we found a high number of patients diagnosed with neurodivergent conditions, particularly Autistic Spectrum Disorder (ASD) and sensory processing difficulties. This was more prevalent in the ARFID cohort compared to those with PFD, with ASD diagnosis found in 105(48%) of patients and sensory processing difficulties found in 90(41%) of patients. However, both ARFID and PFD demonstrated cohorts of patients who suffered from 1 or more neurodivergent condition; ARFID 31(14%) PFD 14(29%). Interestingly, 47 patients in total required Percutaneous Endoscopic Gastrostomy (PEG) for ongoing nutrition management due to the severity of their condition.

Our service evaluation provided insightful data regarding the management of these patient groups, and areas we can support them more comprehensively (nutrition/vitamin/trace metals) at diagnosis. One area to pay particular attention to is neurodivergence, especially in ARFID where this seems to play a more direct role in dietary management. Further studies are needed to explore these factors in more detail.

	ARFID	**PFD**
Number of patients	220	49
Patients with 1 or more vitamin deficiencies	80	13
Copper	7	0
Zinc	1	0
Selenium	4	0
Vitamin A	32	2
Vitamin E	3	1
Vitamin D	33	10
B12	0	0
Folic acid	0	0
Autism	105	14
ADHD	9	1
Sensory processing difficulties	90	25
Anxiety	28	3
2 or more of the above conditions	31	14

References

1. Smyth M, Hudson L D. The presentation of avoidant restrictive food intake disorder (ARFID) in children with complex backgrounds. Paediatrics and Child Health 2025; 35(9).
2. Estrem H, Pederson J, Dodrill P, Romeo C, Thompson K, Thomas J, Zucker N, Noel R, Zickgraf H, Menzel J, Lukens C, Goday P, MacLaughlin S, Sharp W. A US-Based Consensus on Diagnostic Overlap and Distinction for Pediatric Feeding Disorder and Avoidant/Restrictive Food Intake Disorder. International Journal of Eating Disorders 2025; 58.

OC73

Single centre evaluation of multi-chamber bags as home parenteral nutrition in children with intestinal failure. Patient characteristics.

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Title: 'Single centre evaluation of multi-chamber bags as home parenteral nutrition in children with intestinal failure. Patient characteristics'

Background: Paediatric home PN (HPN) in the UK often utilises formulations compounded for individual patients. Multi-chamber bags (MCBs) are pre-made parenteral nutrition (PN) bags that have been successfully used as paediatric HPN in our institution (1). Models of MCB use include MCB-only (MCB-O) and a combination of MCBs plus compounded PN (hybrid). This is a re-audit of our HPN cohort to clarify patient characteristics associated with successful use of MCBs.

Aims: To evaluate patient characteristics associated with successful MCB use in an HPN cohort.

Methods: Clinical audit approval was obtained. HPN prescriptions and patient notes were assessed 1/1/2019 to 31/12/2024 for total PN days, MCB days, MCB model, patient diagnosis, actions to mitigate risk of electrolyte or nutritional deficiency whilst using MCBs (including use of enteral sodium), PN sodium content prior to first MCB prescription, adverse effects from MCB use and percentage of energy requirement received via PN when first initiated on MCBs.

Results:

MCB use in HPN cohort

	2019	2020	2021	2022	2023	2024
All PN days	6609	7238	6405	7133	7493	7967
MCB days	0	291	257	536	712	1258
% PN days as MCB	0%	4%	4%	8%	10%	16%
Active patients	27	26	23	25	24	27
Patients switched from compounded to hybrid/ MCB-O	0	0	0	4	3	6
Patients switched from hybrid/MCB-O to compounded	0	1	2	1	0	0

Forty-five patients received HPN, 17 received MCBs. Four patients received 2 MCB-containing courses. There were nine MCB-O courses, three hybrid courses and two holiday-only MCB courses. MCB-O acceptance was 83% for short bowel syndrome (SBS) diagnosis, 33% for pseudo-obstruction and 50% for enteropathy. 67% of patients with pseudo-obstruction diagnosis received hybrid model. Median sodium content of PN before first use of MCBs was 5mmol/kg/day (range 2.5-9). Anticipatory mitigation of deficiencies associated with MCBs included starting enteral sodium chloride supplements or dioralyte (30% of MCB patients), enteral micronutrient supplements and increasing electrolytes or micronutrients in compounded PN. The median proportion of energy requirements from PN was 56% for MCB-O (range 48-120) and 81% (range 39-91) for hybrid model.

Four ADRs contributed to PN model change or cessation of change; two involved loss of enteral tolerance, one of unclear origin unlikely due to MCB content and one was a holiday trial that wasn't viable long term. There were 10 other ADRs that did not require PN model change; 70% involved blood abnormalities, primarily low serum Vitamin B12, Vitamin A or Selenium, which resolved with additional supplementation.

Conclusions: MCBs comprised 16% of PN days in 2024. MCB-O model was used extensively in SBS whereas pseudo-obstruction often used hybrid model. The median sodium content of PN prior to MCB use was 5mmol/kg/day. Patients receiving around half their energy needs from PN successfully switched to MCB-O model, whereas hybrid model was utilised for higher PN energy dependence. This helps identify patients for whom MCBs may be used successfully in the future.

References

1. Phipps, A et al. Single centre evaluation of multi-chamber bags as home parenteral nutrition in children with intestinal failure. Clinical Nutrition ESPEN, Volume 68, 826.

OC74

A national survey examining the use of multi-chamber bags (MCBs) in paediatric home parenteral nutrition (HPN)

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MCBs are commercially available HPN preparation, licenced 'standardised bags' for use in both the adult and paediatric population. MCBs are used routinely in the adult population, but less commonly in paediatrics. The national framework for HPN commissioned by NHS England recommends that MCBs should be considered as a first line option in the paediatric population, unless otherwise clinically indicated[1]. Currently, no patients requiring HPN at our major centre are prescribed MCBs, largely due to insufficient micronutrient provision. Large patient numbers, along with increased pressure on the pharmacy compounding units[2], demonstrate the need for further consideration for the use of MCBs routinely in clinical practice, whilst ensuring that care can still be delivered safely and effectively.

The aim of this national survey was to understand the current use of MCBs in the UK and identify common barriers for implementing their use. Data was collected on the current use of MCB at other paediatric HPN centres in the UK and determine their experience of this.

An electronic survey was sent via email to dietitians working at all 21 paediatric HPN centres across the UK in January 2024. Answers were anonymised.

15/21 centres responded (71% response rate), of which 13% are currently using MCBs. 47% reported they intended to move towards the routine use of MCBs in the future. Six patients from two centres in total are on MCBs. No child <10kg were prescribed an MCB. No centre reported changing to an MCB when approaching transition to adult services. 33% responded on whether micronutrients were added to MCBs prior to delivery, although only 13% were using MCBS so likely respondents were conflating answers with inpatient use of PN. 3/15 (20%) respondents reported micronutrients being added to MCBs prior to delivery to patients home whilst 2/15 (13%) reported enteral supplementation was provided.

Whilst few centres are currently using MCBs in practice, a total of 60% report futures plans to implement these for paediatric HPN patients where clinically indicated. Children with a weight >10kg are likely to be favourable candidates. Also, careful consideration should be given to a plausible micronutrient plan. Industry needs to also play a role in providing MCBs which are more tailored to the paediatric population. This survey was limited in that respondents are likely to be conflating HPN with inpatient PN despite clear signposting on each question.

The evidence for use of MCBs to reduce burden on aseptic units is growing. UK centres should play an active role in supporting patients transition to MCBs where appropriate.

References

1. Commissioning statement. Parenteral nutrition for the treatment of adults and children with Type 2 and Type 3 intestinal failure requiring home parenteral support [Internet]. Available from: https://www.england.nhs.uk/wp-content/uploads/2023/10/2267-hpn-commissioning-statement.pdf.
2. Transforming NHS Pharmacy Aseptic Services in England A national report for the Department of Health and Social Care by Lord Carter of Coles Contents [Internet]. Available from:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/931195/aseptic-pharmacy.pdf.

OC75

DGAT1 Deficiency in the context of multiple IgE-mediated food allergies – A Unique Challenge

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A six-month-old first male infant (fourth child) born at term gestation following a low-risk pregnancy to non-consanguineous parents of mixed European/Black African ethnic descent was retrieved to a tertiary paediatric centre aged six months with severe weight loss, malnutrition, and oedema. On admission he had profound electrolyte disturbance (Calcium 0.79mmol/L, phosphate 0.32mmol/L, potassium 2.2mmol/L, sodium 116mmol/L, Mg 0.46mmol/L, zinc 4.3umol/L), hypoalbuminaemia <10g/L and deranged INR 6.9. He had a widespread erythematous rash and lower limb fixed flexion deformity. Admission weight was 4.6kg, <0.4th centile (birth weight 4.16kg, 75th centile).
Whole genome sequencing revealed that the patient is compound heterozygous for two pathogenic *DGAT1* nonsense variants (table 1)

Gene	Zygosity	Inheritence	HGVS description	Genomic coordinates	Classification
DGAT1	Heterozygous	Maternal	NM_012079.6:c.255C>Gp.(Tyr85*)	Chr8(GRCh38):g.144321354G>C	Pathogenic
DGAT1	Heterozygous	Paternal	NM_012079.6:c.647C>Gp.(Ser216*)	Chr8(GRCh38):g.144318290G>C	Pathogenic

Management included intravenous electrolyte replacement and antibiotics. The coagulopathy corrected with blood products. He was placed nil-by-mouth and given total parenteral nutrition. MRI brain revealed changes consistent with malnutrition. Echocardiogram was normal. OGD and colonoscopy demonstrated normal macroscopic and histological findings.

Continuous nasogastric feeds of amino acid formula with 76 % long chain triglyceride concentration were cautiously introduced with subsequent improved stool output and skin integrity and albumin recovery.

Low-fat diet was introduced and the formula was changed to a low fat, whole protein, high (85%) medium-chain triglyceride preparation, but a significant eczema flare resulted in immediate switch back to the previous formula.

During food introduction the patient had several further reactions. Allergy testing revealed multiple sensitisations with positive specific-IgE to coconut (4.32 kUA/L), wheat (5.83 kUA/L), egg white (6.06 kUA/L), cow's milk (7.61kUA/L), hazelnut (0.99 kUA/L with positive primary component cor a9 of 1.16) as well as positive skin prick test to soya and beans.
Three weeks after full feeding, he had weight loss, diarrhoea and progressive hypoalbuminaemia. Modular feeds (carbohydrate, amino acid and vitamins and minerals) were initiated. Walnut oil for lipid provision was used as a substitute for coconut-oil based MCT due to aforementioned allergies. After three weeks of modular feeds, the albumin, stools and weight improved with stable serum lipids.

The *DGAT1* gene is located on chromosome 8 with highest expression in the small intestine.(1) It encodes a protein that functions as a metabolic enzyme with key roles in cellular diacylglycerol lipid metabolism, triglyceride synthesis, and adipose tissue formation.(2) *DGAT1 deficiency* is a rare autosomal recessive condition characterised by congenital diarrhoea, protein losing enteropathy and failure to thrive.(3) Literature describes 25 mutation sites related to *DGAT1* with a total of 31 cases reported worldwide, all presenting within the first 4 months of life and 62% in the neonatal period.(3)

To our knowledge, this a novel genetic variant and is the first reported in an individual of Eastern European and Black African descent. Additionally, the presence of significant IgE-mediated food allergies posed unique challenges in developing the requisite nutritional treatment plan and achieving clinical stability. The patient is now thriving at sixteen months of age (50th and 25th centile for weight and height respectively). The complexities of this case highlights the benefits of true multidisciplinary collaboration in managing patients with rare diseases.

References

1. Congenital diarrhoeal disorders: advances in this evolving web of inherited enteropathies;.Olivier Goulet et al, Nat Rev Gastroenterol Hepatol. 2015 May; 12(5): 293–302.Published online 2015 Mar 17. doi: 10.1038/nrgastro.2015.44; PMCID: PMC7599016 , NIHMSID: NIHMS1626209, PMID: 25782092
2. (Identification of a gene encoding an acyl CoA:diacylglycerol acyltransferase, a key enzyme in triacylglycerol synthesis, Robert V Farese Jr et al, Proc Natl Acad Sci U S A. 1998 Oct 27; 95(22): 13018–13023.; doi: 10.1073/pnas.95.22.13018; PMCID: PMC23692; PMID: 9789033.)
3. Case report: Diagnosis and treatment of DGAT1 deficiency-induced congenital diarrhoea in two cases and literature review, Front. Paediatr. 16 october 2023, Sec. Paedaitric Gastroenterology, Hepatology and Nutrition, volumw 11-2023, https://doi.org/10.3389/fped.2023.1253800) Xu Lingfen et al

OC76

ROUTINE SURVEILLANCE CXR IN CHILDREN ON HOME PARENTERAL NUTRITION (HPN) – UNNECESSARY RADIATION ?

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Objectives and Study: The 2018 ESPGHAN guidelines on paediatric HPN recommend a routine chest X-ray (CXR) every 12 months[1]. Regular imaging can expose children to increased radiation and adds to the financial burden of health care systems. This study evaluates if annual surveillance CXRs impact on patient central venous catheter (CVC) management.

Methods: 5-year retrospective data collection (2019–2023) from electronic records of all children (age 0-18) receiving HPN in an intestinal failure (IF) centre. All patients with a central venous catheter (CVC) in place for ≥ one year were included. Patient demographics (gender, age), underlying IF diagnosis, annual CXR reports, and corresponding CVC management were recorded.

Results: A total of 137 routine annual CXR were performed on 54 patients (62% female). IF phenotype was 49/137 (36%) short gut syndrome, 47/137 (34%) gut motility disorders, 30/137 (22%) mucosal disease, 7/137 (5%) haematological conditions, 1/137 (1%) post bone marrow transplantation (BMT), 1/137 (1%) immunological condition, 2/137 (1 %) neurodevelopmental disorder.

129/137 (94%) CXRs did not result in a CVC intervention. Only 3% of 137 x-rays, affecting 4 patients, had a CVC change carried out based on the CXR result. 1/4 children underwent CXR due to clinical symptoms (pain at CVC site) and 1/4 children had suspected cuff migration, which coincided with their annual surveillance image. Only 1/54 patients (0.7% of x-rays) underwent a CVC replacement as a direct outcome of the CXR findings (displaced CVC, 1/54 patients (1/137 x-rays) underwent a CVC repair after catheter blockage identified on annual CXR.

Conclusions: Routine annual chest X-rays may be unnecessary in asymptomatic patients on long-term PN and could be limited to symptomatic patients and to those during periods of rapid growth, when there is a higher risk CVC tip migration. Adopting a more selective approach could lower radiation exposure and alleviate the economic burden on healthcare providers.

References

1. Hill S, Ksiazyk J, Prell C, Tabbers M; ESPGHAN/ESPEN/ESPR/CSPEN working group on pediatric parenteral nutrition. ESPGHAN/ESPEN/ESPR/CSPEN guidelines on pediatric parenteral nutrition: Home parenteral nutrition. Clin Nutr. 2018 Dec;37(6 Pt B):2401-2408

OC77

Solivito-N shortage: how important are water-soluble vitamins?

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At a specialist paediatric centre, Solivito-N is the sole water-soluble vitamin product used in bespoke and standard parenteral nutrition (PN). In October 2023, there was a global shortage of Solivito-N.

Contracted PN suppliers started allocating 50% of usual allowance of Solivito-N for bespoke PN compounding and lipid syringe batch production. Consequently, supplies were depleting rapidly, and the Nutrition Support and Intestinal Failure Team (NSIFT) were forced to evaluate how water-soluble vitamins were prescribed for PN patients.

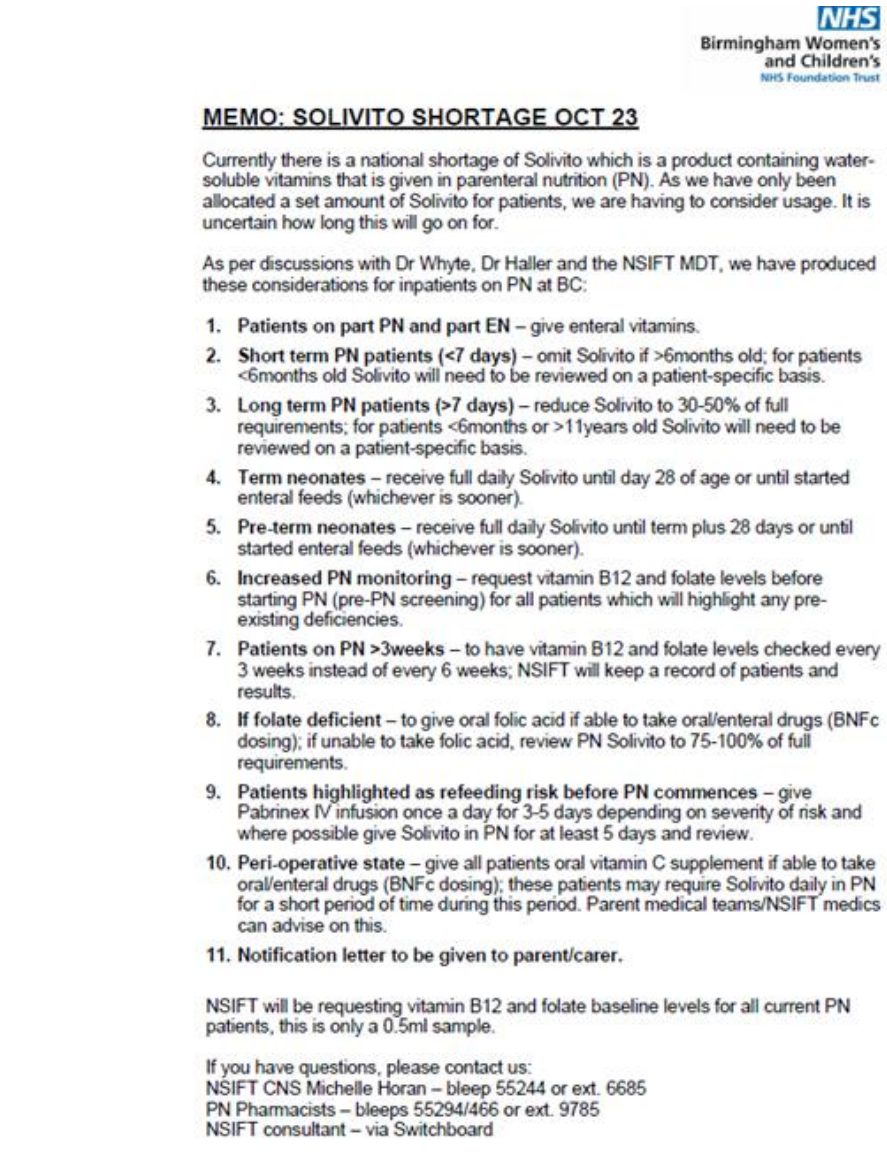
Alternative intravenous and enteral options for water soluble vitamins were assessed; other Trusts/suppliers were also consulted. A comparison of products was completed against guidelines, including a risk assessment of combination products versus current products used and on the Trust formulary. Actions required for PN patients were mapped out by NSIFT. Considerations included monitoring of water-soluble vitamin blood levels, frequency of patient reviews to ensure appropriate prescribing and management of bespoke versus standard PN to preserve stock.

A decision pathway was created (see image 1) and approved by all stakeholders and governance. Updates were sent to all clinical areas. The notification letter was formulated and approved for dissemination to parents/carers for PN patients.

An audit was conducted for four months, including total 89 PN patients, to record the Solivito-N decisions and to document the bloods results of vitamin B12 and folate monitoring. As vitamin C levels could not be monitored, high risk patients were prioritised for full dose.

Analysis from the audit highlighted that the actions implemented in response to the Solivito-N shortage were appropriate. The monitoring frequency allowed changes to be made to the vitamins provision efficiently and effectively, whilst working within the allocation of Solivito-N. NSIFT reviewed patients more frequently to ensure appropriate PN prescribing, and t he status of the shortage was discussed at the weekly NSIFT grand round meetings.

Image 1



NHS
Birmingham Women's and Children's
NHS Foundation Trust

MEMO: SOLIVITO SHORTAGE OCT 23

Currently there is a national shortage of Solivito which is a product containing water-soluble vitamins that is given in parenteral nutrition (PN). As we have only been allocated a set amount of Solivito for patients, we are having to consider usage. It is uncertain how long this will go on for.

As per discussions with Dr Whyte, Dr Haller and the NSIFT MDT, we have produced these considerations for inpatients on PN at BC:

1. **Patients on part PN and part EN** – give enteral vitamins.
2. **Short term PN patients (<7 days)** – omit Solivito if >6months old; for patients <6months old Solivito will need to be reviewed on a patient-specific basis.
3. **Long term PN patients (>7 days)** – reduce Solivito to 30-50% of full requirements; for patients <6months or >11years old Solivito will need to be reviewed on a patient-specific basis.
4. **Term neonates** – receive full daily Solivito until day 28 of age or until started enteral feeds (whichever is sooner).
5. **Pre-term neonates** – receive full daily Solivito until term plus 28 days or until started enteral feeds (whichever is sooner).
6. **Increased PN monitoring** – request vitamin B12 and folate levels before starting PN (pre-PN screening) for all patients which will highlight any pre-existing deficiencies.
7. **Patients on PN >3weeks** – to have vitamin B12 and folate levels checked every 3 weeks instead of every 6 weeks; NSIFT will keep a record of patients and results.
8. **If folate deficient** – to give oral folic acid if able to take oral/enteral drugs (BNFc dosing); if unable to take folic acid, review PN Solivito to 75-100% of full requirements.
9. **Patients highlighted as refeeding risk before PN commences** – give Pabrinex IV infusion once a day for 3-5 days depending on severity of risk and where possible give Solivito in PN for at least 5 days and review.
10. **Peri-operative state** – give all patients oral vitamin C supplement if able to take oral/enteral drugs (BNFc dosing); these patients may require Solivito daily in PN for a short period of time during this period. Parent medical teams/NSIFT medics can advise on this.
11. **Notification letter to be given to parent/carer.**

NSIFT will be requesting vitamin B12 and folate baseline levels for all current PN patients, this is only a 0.5ml sample.

If you have questions, please contact us:
NSIFT CNS Michelle Horan – bleep 55244 or ext. 6685
PN Pharmacists – bleeps 55294/466 or ext. 9785
NSIFT consultant – via Switchboard

OC78

An audit of 9 years of central line associated blood stream infection rates in a paediatric home parenteral nutrition cohort

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Background:
Home parenteral nutrition (HPN) is a mainstay of intestinal failure management. In the paediatric population parents will initially be trained to deliver this, with older children transitioning to administering this themselves where able. Ensuring children and families are trained and supported to minimise line infection is key in promoting good outcomes and preventing complications associated with HPN use. The NHS England HPN framework contract requests home PN centres to audit their central line associated bloodstream infection (CLABSI) rate. Our nutritional care team routinely reinforces this training. The British Intestinal failure alliance suggests that for patients using home parenteral nutrition 'Units should be aspiring to an adult/young people inpatient catheter related sepsis rate of less than 3/1000 catheter days and an outpatient one of less than 1/1000 catheter days.'[1] However it is unclear what a paediatric population should aspire to for a CLABSI rate as "Infants on parenteral nutrition have higher rates of catheter related sepsis."[1]

Aims:

1. To audit the CLABSI rate for the prior 9 years in a large hospital HPN cohort, where CLABSI is defined as a laboratory confirmed bloodstream infection where an eligible BSI organism is identified and a central line is present on the day of the BSI or within 48 hours before.
2. To audit the catheter-related sepsis rate for the prior 9 years in a large hospital Home PN cohort, where catheter-related sepsis was defined as a febrile episode, diagnosed clinically as CVC infection by the admitting consultant and treated with a complete course of intravenous antibiotics, with or without growth on blood culture.

Methods: A retrospective review of electronic notes for all patients who received HPN from 1st January 2016 to 31st December 2024. Notes were reviewed to establish when patients receiving HPN had developed CLABSIs on an outpatient basis. These records were used to generate the CLABSI rate per 1000 home PN days.

Results: 85 patients received home PN at some point during the 9-year period audited. CLABSI rates gradually fell from a low baseline, with some variations around the COVID-19 pandemic. The average CLABSI rate over the 9 years was 1.39 CLABSI per 1000 HPN days.

Year	CLABSI infection rate per 1000 HPN line days	Catheter related sepsis rate per 1000 HPN days
2016	0.36	1.99
2017	0.78	1.90
2018	0.72	1.64
2019	0.29	1.29
2020	0.49	0.78
2021	0.91	1.18
2022	0.88	1.59
2023	0.25	0.99
2024	0.70	1.16

Conclusions:
Our audit showed low levels of infections whichever measure was used, despite covering a paediatric population where line infections are known to occur more frequently. Continued use of a multidisciplinary care pathway for patients receiving home PN is crucial to keeping CLABSI rates low. A focus on CVC care, education and training, discharge planning and good hygiene practices enable CLABSI rates to be kept at a low level.

References

1. British Intestinal Failure Alliance (BIFA) position statement 2016. Home Parenteral Nutrition (HPN).

OC79

Real-world implementation of TPMT testing and metabolite-guided thiopurine therapy in paediatric inflammatory bowel disease: a contemporary single-centre analysis

Rose Alhaleem, Sian Copley
Royal Manchester Children's hospital

Thiopurine remain essential maintenance therapy in paediatric inflammatory bowel disease (IBD), yet clinical implementation of pharmacogenetic testing and therapeutic drug monitoring (TDM) varies widely despite guideline recommendations.[1,2]

Whilst TPMT enzyme activity predicts myelotoxicity risk, the optimal integration of TPMT results with serial metabolite monitoring for dose optimisation remains incompletely defined.[3] We evaluated our centre's approach to TPMT-guided therapy initiation, metabolite-based dose optimisation, and clinical outcomes.

We conducted retrospective analysis of paediatric IBD patients undergoing TPMT testing or receiving thiopurine therapy at a general centre between 2022-2025. We extracted TPMT activity levels, genotyping results, treatment data, serial monitoring, all 6-thioguanine nucleotide (6-TGN) and 6-methylmercaptopurine (6-MMP) measurements with corresponding dose adjustments, and adverse events. Clinical response was assessed by steroid-free remission at six months and biochemical markers.

One hundred seventy patients underwent TPMT testing. TPMT activity was normal in 129 patients (76%) whilst 41 (24%) demonstrated low or intermediate activity, notably higher than expected 10-11% heterozygote frequency.[2] Six patients with low TPMT underwent formal genotyping revealing *1/*3A (n=4), *1/*3C (n=1), and other heterozygous variants (n=1). Of tested patients, 100 subsequently received thiopurine therapy. Azathioprine (n=81) was initiated at median 1.5 mg/kg/day (range 0.5-2.5), while 6-mercaptopurine (n=19) at median 1.0 mg/kg/day (range 1.0-1.5). TPMT-guided dose reduction was systematically employed in 23 patients (23%). Combination therapy rates were high: 77% received 5-aminosalicylic acid, 52% anti-tumour necrosis factor biologics, and 67% concurrent corticosteroids at initiation.

Metabolite monitoring was performed in our cohort with mean 5.3 measurements per patient. Initial 6-TGN levels were subtherapeutic (<230 pmol/8×10⁸ RBC) in 46%, therapeutic (230-450) in 52%, and supratherapeutic in 2%.[4,6] Metabolite results influenced clinical management in 33% of episodes, leading to dose escalation, reduction, or identification of preferential shunting.[5] Haematological monitoring completion was excellent early (84-93% at weeks 4-12) but declined to 67% by month 12.

Sixty Seven patients (67%) achieved steroid-free remission at six months, of which 35 patients were on concomitant biologics. Adverse event rate was 12%. Specific events included myelosuppression (6%), pancreatitis (4%), and rash (4%). Importantly, analysis of TPMT status in patients experiencing adverse events revealed that the majority (67%) had normal TPMT activity, emphasizing that normal TPMT does not eliminate toxicity risk and metabolite monitoring remains essential for all patients.[3] Three patients developed severe neutropenia requiring temporary cessation but successfully resumed therapy. Treatment was permanently discontinued in six patients (6%), considerably lower than literature-reported rates of 10-28% mainly due to patient preferences.

Our data demonstrate that systematic pre-treatment TPMT testing combined with genotype-guided dosing, proactive metabolite monitoring, and responsive dose optimisation achieves superior clinical outcomes with lower adverse event rates. The high rate of low TPMT activity (24%) in our tested population warrants investigation and may reflect appropriate risk-stratified testing practices.[2] The substantial proportion requiring dose adjustment based on metabolites (33%) validates routine TDM utility beyond TPMT testing alone.[5] Our findings support integrated pharmacogenetic and metabolite-guided thiopurine therapy in paediatric IBD.

References

1. Relling MV, Schwab M, Whirl-Carrillo M, et al. Clinical Pharmacogenetics Implementation Consortium guideline for thiopurine dosing based on TPMT and NUDT15 genotypes: 2018 update. Clin Pharmacol Ther 2019; 105: 1095-105.
2. Kennedy AM, Griffiths AM, Muise AM, et al. Landscape of TPMT and NUDT15 pharmacogenetic variation in a cohort of Canadian pediatric inflammatory bowel disease patients. Inflamm Bowel Dis 2024; 30: 2418-27.
3. Coelho T, Andreoletti G, Ashton J, et al. Genes implicated in thiopurine-induced toxicity: comparing TPMT enzyme activity with clinical phenotype and exome data in a paediatric IBD cohort. Sci Rep 2016; 6: 34658.
4. Spencer E, Norris E, William C et al. The impact of thiopurine metabolite monitoring on the durability of thiopurine monotherapy in pediatric IBD. Inflamm Bowel Dis 2019; 25: 142-9.
5. Deben DS, Winkens B, van Moorsel SAW, et al. Early therapeutic drug monitoring helps to identify inflammatory bowel disease patients with a high risk to fail thiopurine treatment. Br J Clin Pharmacol 2024; 90: 3296-307.
6. Ooi CY, Bohane TD, Lee D, et al. Thiopurine metabolite monitoring in paediatric inflammatory bowel disease. Aliment Pharmacol Ther 2007; 25: 941-7.

OC80

Usefulness of age-banded patient information leaflets to support healthcare transition for young people with Inflammatory Bowel Disease

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The increasing incidence of Inflammatory Bowel Disease (IBD) in adolescents translates into an increasing cohort requiring healthcare transition. Between 2021-2022 12.5 per 100,000 in the UK were diagnosed with IBD [2]. Disease specific education is recognised and recommended as an important pillar of delivering developmentally appropriate healthcare (DAH) and effective transition [1].

To improve cohort knowledge age-specific information leaflets were developed for patients aged 14, 15 and 16+, each contained materials scaled for developmental appropriateness. These were distributed to YP's diagnosed with IBD who were involved with the transition process. The document included QR codes linking to additional online resources from Crohn's and Colitis UK, such as smoking, alcohol, sexual health and healthy lifestyle. In line with national guidance for young people to be involved in their transition process [3], they were involved in reviewing these leaflets to gauge the YP understanding of their disease, adolescent health and the transition process.

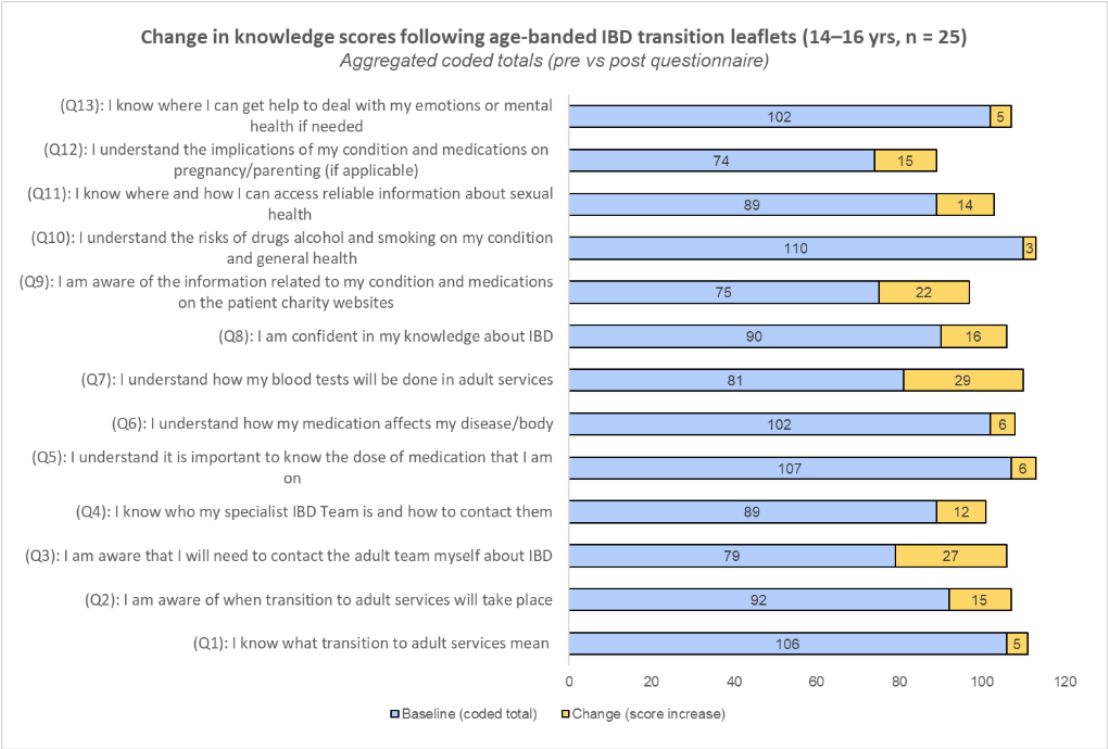
To assess effectiveness of the information leaflets and measure the change in understanding, an anonymous questionnaire was designed, which measured 13 key metrics related to IBD knowledge, adolescent health and healthcare transition, using Likert style format (coded as 1-5). Questionnaires were distributed pre, then post receipt of reading the supplied information to assess the impact on baseline knowledge and understanding.

25 completed responses were received. Overall, there was an improvement in the coded score across each question (Figure 1), data was aggregated as age linkage was not available at the time of analysis. Varying levels of improvement were noted in each question. The mean coded total score at baseline was 93.8, with the post leaflet response being totalled at 106.8, denoting a 13-point (14%) increase.

The lowest baseline scores were observed for Q12 (74), Q9 (75) and Q3 (79), while the highest pre-intervention scores were noted for Q10 (110), Q5 (107), Q1 (106). The greatest improvements in scores were seen for Q7 (+29), Q3 (+27) and Q9 (+22), These items had lower baseline scores compared with others, contributing to the greater observed change. In contrast, less significant changes were seen in questions that already had relatively high baseline scores Q10 (+3), Q1 (+5) and Q13 (+5), each had above average baseline scores, consistent with ceiling effects.

This study demonstrated that the information leaflets positively influenced young people's knowledge of IBD, adolescent health, and healthcare transition. Baseline responses identified areas requiring additional support. Future research exploring young people's views on the content, design, and alternative formats for information delivery would be valuable.

Figure 1



References

[1] Brooks AJ, Smith PJ, Cohen R, Collins P, Douds A, Forbes V, et al. UK guideline on transition of adolescent and young persons with chronic digestive diseases from paediatric to adult care. Gut. 2017;66:988–1000 [Abstract]
[2] Henderson P. Compounding prevalence: the continued rise in paediatric IBD – a worrying trend. European Crohn's and Colitis Organisation; 2024. 19(4). [Article]
[3] National Institute for Health and Care Excellence (NICE). Transition from children's to adults' services for young people using health or social care services. [Internet]. London: NICE; 2016 Feb 24 [cited 2025 Oct 30]. Available from: https://www.nice.org.uk/guidance/ng43

OC81

Prolonged secondary adrenal suppression in paediatric inflammatory bowel disease patients – evaluation of management and identification of prognostic factors.

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Secondary adrenal suppression is a well-established complication of high dose corticosteroid use in paediatric inflammatory bowel disease (PIBD) patients. At our institution standard practice is an initial screening with a morning cortisol at the end of the steroid course. If suppressed below 250nmol/L, hydrocortisone replacement is initiated. Cortisol levels 250-400 would lead to a repeat at 28 days. After a period of on replacement, determined by the endocrine department, a short synachthen test (SST) is performed to assess for ongoing adrenal suppression. Only if normal is replacement therapy stopped. This study aims to evaluate a single centre's experience with this management, as well as to identify factors that may be associated with prolonged periods of adrenal insufficiency.

Paediatric patients with both PIBD and evidence of Adrenal suppression under the care of a single major centre between 2017-2022 were identified using the endocrine department's database of all patients undergoing an SST, due to an initially low morning cortisol during this period, and then cross referencing them with a PIBD database. From review of the electronic patient records (EPR) age, IBD subtype, duration of steroid courses, first cortisol level, result of SST, total length of hydrocortisone replacement and results of any subsequent SSTs was collated

Between 2017-2022, 435 children aged between 0-18 years, were treated for IBD at this centre. Nineteen children (4.3%) were identified with the need for hydrocortisone replacement therapy and then at least one subsequent SST during this period. Diagnoses were UC 36.8% (n=7), Crohn's 52.6% (n=10) and IBDU 10.5% (n=2). Adrenal suppression was still present in 52.6% (n=10) of children by the time of their first SST, therefore requiring ongoing hydrocortisone treatment and a further SST. Median steroid course duration prior to first cortisol was 7 months, and median steroid replacement therapy was for 17 months; the longest duration of steroid replacement was 49.5 months. Pearson's correlation was performed between the length of hydrocortisone replacement and the following factors: duration of high dose steroid course ($p=0.24$), age ($p=0.14$) and initial suppressed cortisol level ($p=0.14$) None were statistically significant. Comparison of Crohn's vs UC groups was dichotomised around the mean hydrocortisone duration ($>$ or $<$ 20 months) and was also not significant different (Chi-test, $p=0.8$)

The results show that a significant number of children continue to require steroid replacement therapy by their first check SST. That a very wide range of duration is seen indicating unpredictable recovery.

This reinforces the importance of identifying factors that may contribute to children requiring longer courses of steroid replacement to best tailor their follow up reviews. Our lack of statistically significant results highlights the need for a larger cohort of PIBD patients with adrenal insufficiency to further evaluate for this. That around 25% of the group had a normal SST by 6 months, suggests that this may be a target timescale for the first SST.

OC82

A retrospective audit of referral and diagnostic timelines in IBD paediatric patients compared to the IBD Standards UK guidelines.

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The number of paediatric patients diagnosed with IBD has doubled in the UK in the last 10 years[1]. Patients are likely to experience delays in both diagnosis and treatment, associated with an increased risk of complications[2]. The IBD Standards UK guidelines[3] recommend that:

1. Patients who are referred with suspected IBD should be seen within four weeks.
2. Endoscopic assessment should be accessible within four weeks from initial tertiary care presentation.

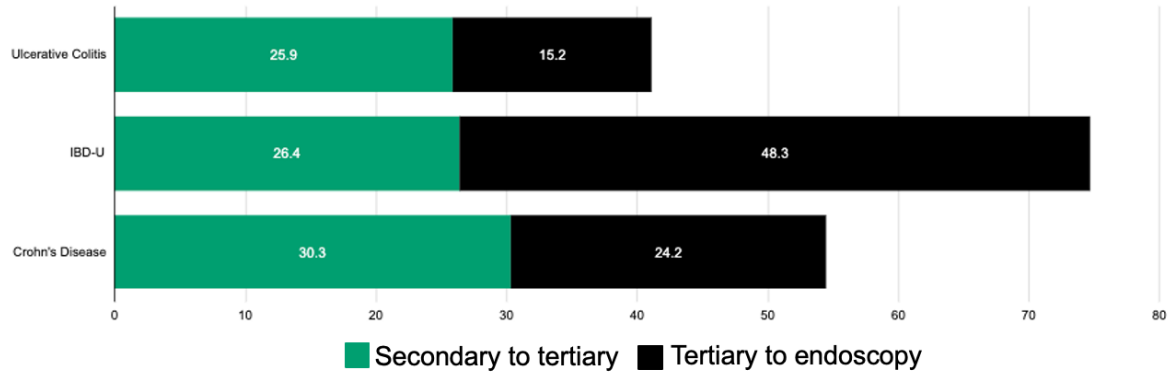
This retrospective audit assessed how effectively a tertiary hospital in England met these guidelines.

A selection of paediatric patients diagnosed with IBD between January 2020 and May 2025 (approximately 20% of patients diagnosed during this time) were identified using Trust databases; patients were excluded if diagnosed abroad, privately, or at a different hospital. The following was recorded for each patient: age, sex, IBD subtype, remission status at one year, whether they presented to A&E with symptoms, and the dates of the GP referral, presentation to secondary and tertiary care, and endoscopy date.

81 paediatric patients were included in the audit: 49 male and 32 female. The average age at diagnosis was 11.5 years. 54 patients were diagnosed with Crohn's Disease (CD), 15 with Ulcerative Colitis (UC), and 12 with inflammatory bowel disease unclassified (IBD-U). For all IBD subtypes, 30% of patients presented to A&E before diagnosis. Most patients experienced symptoms for less than 6 months before GP presentation (52% in CD, 60% in UC, and 50% in IBD-U). Patients with CD were most likely to experience symptoms for 1-2 years before presentation (11% in CD, 7% in UC, 8% in IBD-U). The average number of days between a GP referral and a secondary care appointment was 49.1 in CD, 15.5 in UC, and 122.6 in IBD-U. The average number of days between tertiary care appointment and endoscopic investigation was 24.2 days in CD, 15.2 days in UC, and 48.3 days in IBD-U. 55% of the patients were in remission at one-year post-diagnosis.

At this tertiary centre, paediatric patients with IBD wait less than 4 weeks between secondary care referral to tertiary care assessment and then onwards to endoscopy, meeting the IBD Standards UK guidelines. However, paediatric IBD patients experience a delay from primary care (GP) referral, with the delay most profound in IBD-U and least in UC. This may be because UC symptoms typically include blood in the stool, which prompts more urgent assessment. Patients without obvious alarming symptoms such as blood in stools likely experience symptoms for months prior to presentation and referral, due to symptom overlap with an alternative diagnosis such as IBS.

Figure 1: Average number of days from secondary to tertiary care, and tertiary care to endoscopy in paediatric IBD patients.



References

1. Green Z, Ashton J J, Rodrigues A., *et al*. Sustained Increase in Paediatric IBD Incidence Across the South-West UK Over 10 Years. Inflammatory Bowel Diseases 2024; 30(12), 2271-2279.
2. Jayasooriya N, Baillie S, Blackwell J., *et al*. Systematic review with meta-analysis: Time to diagnosis and the impact of delayed diagnosis on clinical outcomes in IBD. Alimentary Pharmacology and Therapeutics, 2023; 57(6), 635-652.
3. IBD UK. IBD Standards Core Statements, 2009; 1-4. Available from: https://ibduk.org/ibd-standards.

OC83

Patients with very-early onset Inflammatory bowel disease achieve similar outcomes to older children, however, receive more intensive dosing regimens – a case-controlled study

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Patients with very-early onset inflammatory bowel disease (VEOIBD) have been reported to have decreased response rate to infliximab. Younger children have unique drug pharmacokinetics, which risks insufficient drug exposure. We aim to assess infliximab dosing regimens and outcomes in children with VEOIBD compared to older children in a centre routinely using protocol-based proactive therapeutic drug monitoring (TDM).

We analysed a prospectively identified cohort of patients with VEOIBD diagnosed between January 1, 2018, and June 30, 2025, at a single tertiary centre. Patients requiring infliximab were matched by sex, IBD phenotype, and infliximab initiation date with controls aged 6–10 and ≥11 years. Data were retrospectively obtained from electronic medical records, including phenotypic details; disease activity scores, inflammatory markers at baseline, week 12, and week 52; infliximab dose, frequency, and trough levels for doses 1–7; current regimens, antibodies and adverse events.

Fifteen patients with VEOIBD commenced infliximab (8/15 [53%] male, median [IQR] age at diagnosis 4.2 [1.5-5.0] years, 6/15 (40%) monogenic disease) and were compared to 30 matched controls (6-10 year group, 7/15 [46.7%] male, median age at diagnosis 8.4 [7.4-9.5] years; 11+ group (8/15 [53%] male, median [IQR] age at diagnosis 12.2 [10.9-13.7] years). The median [IQR] length of follow-up was comparable between groups (VEOIBD: 2.9 [1.6-4.4] years, 6-10 group 3.3 [2.9-4.1] years, 11+ group 3.2 [1.7-5.5] years, p=0.74). Dose 3 trough levels were lower in the VEOIBD group (VEOIBD median 14.2 versus control 19.7, p=0.045). There was a trend towards a shorter interval between dose 3 and 4 (VEOIBD 6.4 weeks vs controls 8.0 weeks, p=0.055) and the requirement for dose/interval escalation immediately post-induction (VEOIBD 8/15 vs 8/30, p=0.07). Through the study, patients with VEOIBD had higher median [IQR] doses (VEOIBD 10 [10.0-12.5] mg/kg vs Controls 10 [10.0-10.0] mg/kg, p=0.01) and shorter median [IQR] dosing interval (VEOIBD 4.0 [3.6-4.0] weekly vs Controls 6.0 [4.0-6.0] weekly. The proportion of patients with moderate to severe disease compared to those in remission or mild disease was similar between the groups at baseline, 12 weeks, and 52 weeks ($p = 0.60$, $p = 0.52$, $p = 0.22$, respectively). Faecal calprotectin (μg/g stool) at each time point was similar between groups (Baseline VEOIBD 1800 vs Controls 1701, p=0.83; Week 12 VEOIBD 492 vs 332, p=0.68; Week 52 VEOIBD 420 vs 228).

In our cohort, patients with VEOIBD had comparable outcomes to matched controls with later onset IBD, however, required more intensive dosing up to year 3. Pharmacokinetic studies may support the hypothesis of more rapid drug clearance in VEOIBD and the use of dosing based on body surface area should be further explored.

OC84

Substantial Cost Benefit of Switching from Intravenous to Subcutaneous Infliximab in Adolescent Inflammatory Bowel Disease

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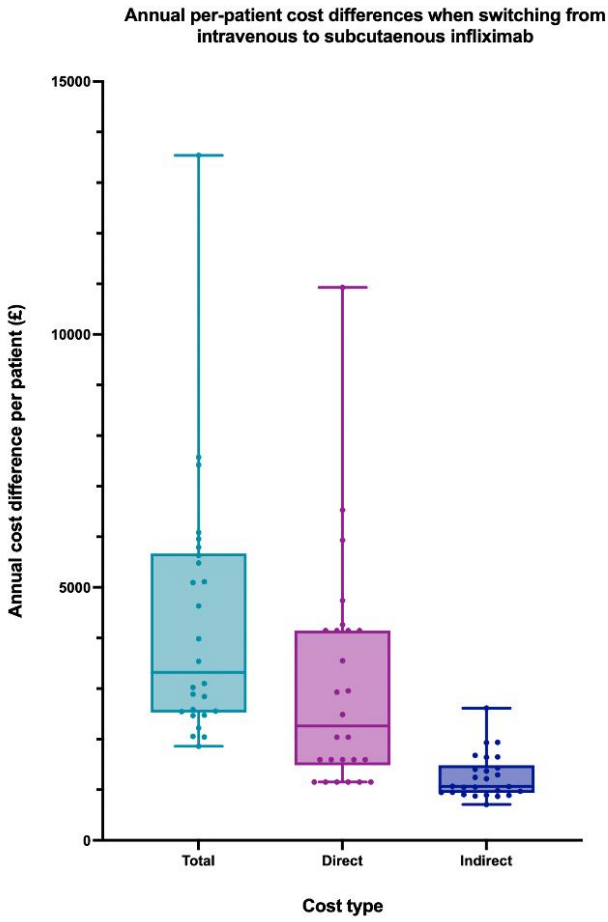
Switching from intravenous infliximab (IV-IFX) to subcutaneous infliximab (SC-IFX) has been shown to increase infliximab trough levels, reduce immunogenicity and be broadly cost-neutral in adult inflammatory bowel disease (IBD).[1,2] However, evidence in adolescent IBD remains limited. This on-going quality improvement project (QIP) aims to evaluate the economic, environmental and clinical outcomes of switching adolescents with IBD from IV-IFX to SC-IFX.

In this prospective, single-centre QIP, adolescents (aged 16-17) with IBD receiving IV-IFX maintenance therapy for ≥ 3 months were offered switching to 120mg SC-IFX every-other-week.[3] A Trust-specific economic model compared direct and indirect costs of IV-IFX and SC-IFX, covering NHS, Trust and family costs. Environmental impact was estimated based on travel-related greenhouse gas emissions (GHGs). Patients who agreed to switch were scheduled for clinical assessments at baseline and weeks 4, 8, 16, 24 and 52 post-switch. Patient satisfaction surveys were scheduled for 16 and 52 weeks post-switch.

Economic modelling based on 26 eligible switching patients estimated a total annual per-patient saving of £3318.92 with SC-IFX. The annual direct saving per-patient was £2262.80, representing an approximate 35% cost reduction to the healthcare system. Median per-patient annual travel-related GHGs from IV-IFX was an estimated 27.5 kgCO2e, expected to be negligible with home-administered SC-IFX.

Between February and May 2025, five male adolescents (median age 17.3 years), all with Crohn's disease, were switched. All three patients in disease remission at baseline maintained remission at week 4. One patient with refractory disease did not regain response by week 8, while the remainder continued SC-IFX with no adverse events. Median infliximab trough levels increased by 3.4 mg/mL at week 4.

SC-IFX substantially reduces healthcare and patient costs, as well as travel-related GHGs, in adolescent IBD within our Trust. Preliminary findings suggest that SC-IFX is well-tolerated in adolescents with early signs of clinical benefit. Full 52-week data and larger studies are required to confirm long-term safety, efficacy and sustainability.



References

1. Papamichael K, Lin S, Moore M, Papaioannou G, Sattler L, Cheifetz AS. Infliximab in inflammatory bowel disease. *Therapeutic Advances in Chronic Disease.* 2019. doi:10.1177/2040622319838443.
2. Schreiber S, Ben-Horin S, Leszczyszyn J, Dudkowiak R, Lahat A, Gawdis-Wojnarska B, et al. Randomized Controlled Trial: Subcutaneous vs Intravenous Infliximab CT-P13 Maintenance in Inflammatory Bowel Disease. *Gastroenterology.* 2021. doi:10.1053/j.gastro.2021.02.068.
3. National Institute for Health and Care Excellence. *Remsima (infliximab biosimilar) for subcutaneous injection for managing Crohn's disease and ulcerative colitis*. https://www.nice.org.uk/advice/es35/chapter/Product-overview

OC85

Acute drug hypersensitivity reactions to infliximab in paediatric IBD patients: a single centre experience

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Infliximab (IFX) is an anti-TNF monoclonal, IgG2a antibody (TNF-alpha) used in the treatment of paediatric inflammatory bowel disease (IBD). There is a 5-23% risk of Drug Hypersensitivity Reactions (DHR) to IFX infusion in IBD patients.[1] Potential DHR include anaphylaxis, cytokine release syndrome, and serum sickness through host antibody to infliximab responses.[2, 3, 4] For those with severe reactions – options include avoidance, change of drug or desensitisation.[5,6] Research has shown that premedication is not effective in reducing rate of infusion reactions due to IFX.[7]

A retrospective cohort review identified paediatric IBD patients treated with infliximab over an 8 year period. Each case had a DHR during an infusion. The total paediatric IBD cohort of 352 patients over that time included 160 patients treated with IFX. 13 (8%) had an acute drug reactions (see Table 1). 7 patients reacted during their induction regime; 3 patients had >10 previous infusions. Standard induction regime of 0, 2 and 6 weeks was used in 12 patients, 1 patient was accelerated 0, 1 and 4 weeks. Doses (in mg/kg) ranged from 5 (3), 10 (7) to 20 (3) and frequency (in weeks) from 4 (1), 6 (2) to 8 (3). 10 patients were on co-existing IBD medication including azathioprine (8), allopurinol (2), 5-ASA (2) and methotrexate (1). Anti-infliximab levels were raised in 2 patients at >200 and 147.4ng/ml. Infliximab levels were low (<5mcg/ml) in 5 patients. Intravenous (IV) hydrocortisone was given as a pre-medication in 8 patients. Reaction symptoms included rash (10), itchiness (3), facial swelling (2), nausea/vomiting (2) and respiratory compromise (7) including documented oxygen desaturation (3). Acute treatment included antihistamine (11), Intramuscular (IM) adrenaline (5) and IV hydrocortisone (1). 5 patients required overnight admission for monitoring. Mast Cell Tryptase (MCT) levels were checked in 8 patients; only 1 was mildly raised (19ug/L at baseline, 23ug/L at 4 hours). 5 patients were referred to allergy clinic for follow-up. All 13 patients were switched to adalimumab for ongoing management of their IBD.

We have identified significant drug reactions in 13 (8%) of our paediatric IBD patients treated with IFX. Half of these reactions involved respiratory compromise although only a third received IM adrenaline. It is yet to be analysed which type of DHR is involved- a Type 1-DHR or other Type 2-4 DHR. This may reflect involvement of trained immunity pathways alongside conventional hypersensitivity mechanisms.[8] More research is needed on this matter and on appropriate risk assessments and management algorithms for this patient group.

Table 1: Patient characteristics (n=13)

Characteristic	**n (%)**
Gender	
Male	5 (38)
Female	8 (62)
Diagnosis	
Crohn's disease	7 (54)
Ulcerative Colitis	6 (46)
Age (years)	
Mean	11
Range	5 to 16
History of atopy	
Personal history	8 (62)
Asthma	5 (38)
Eczema	4 (31)
Hayfever	7 (54)
IgE mediated food allergy	1 (8)
Family history	7 (54)
Drug allergy	3 (23)

References

1. Lichtenstein L, Ron Y, Kivity S. Infliximab-Related Infusion Reactions: Systematic Review. J Crohns Colitis. 2015 Sep;9(9):806-15.
2. Dharmaraj R, Lemon TP, Elmaoued R. Infusion Reactions to Infliximab in Pediatric Patients with Inflammatory Bowel Disease. *Children.* 2024; 11(11):1366.
3. Jutel M, Agache I, Zemelka-Wiacek M. Nomenclature of allergic diseases and hypersensitivity reactions: Adapted to modern needs: An EAACI position paper. Allergy. 2023; 78: 2851-2874.
4. National Institute for Health and Care Excellence (NICE). Anaphylaxis: assessment and referral after emergency treatment. CG134. Overview | Anaphylaxis: assessment and referral after emergency treatment | Guidance | NICE
5. National Institute for Health and Care Excellence (NICE). Drug allergy: diagnosis and management. CG183. Overview | Drug allergy: diagnosis and management | Guidance | NICE
6. Madrigal-Burgaleta R, Guzman-Melendez MA, Alvarez-Cuesta E. Drug allergy desensitization is not a unique recipe. Curr Opin Allergy Clin Immunol. 2022 Jun 1;22(3):167-174.
7. Cullen M, Green Z, Morris K. OC4 Discontinuation of premedication for infliximab infusions is well-tolerated, without adverse events, and cost-saving in paediatric inflammatory bowel disease Frontline Gastroenterology 2025;**16:**A3.
8. Martín-Cruz, L. and Palomares, O. (2025), Allergen-Specific Immunotherapy and Trained Immunity. Allergy, 80: 677-689.

OC86

Very early onset inflammatory bowel disease -a tertiary centre's experience.

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Very Early-onset Inflammatory bowel Disease (VEOIBD) refers to children diagnosed with IBD before 6 years of age and comprises 3-15% of all paediatric IBD patients.[1] Within this group, a small cohort of patients have a monogenic cause for their IBD (0-33%).[2] The paediatric IBD Porto group of European Society of Paediatric Gastroenterology, Hepatology and Nutrition suggests careful consideration of symptoms and suggestions of monogenic causes in patients below the age of 6 years and genetic testing regardless in those under 2 years.[2] We reviewed the demographics, investigations and outcomes of our patients diagnosed with VEOIBD at our centre.

Twenty-seven patients diagnosed with VEOIBD between the years of 2014 and 2024 were identified at our tertiary centre. 12 were white British, 7 Pakistani and 8 were of other ethnic background. The average age at diagnosis was 45.3 months. 6 patients were under 2 years old when symptoms started. Where documented, 33.3% of patients had a family history of consanguinity and 58.3% had a family history of inflammatory bowel disease.

On reviewing the presenting symptoms,19 patients presented with bloody diarrhoea. Others were investigated for chronic diarrhoea, perianal abscess, abdominal pain and faltering growth. Average time from symptoms to diagnosis was 7.1 months. Of the 27 patients, 6 did not have faecal calprotectin checked, 3 had a faecal calprotectin of <500 and 18 had a faecal calprotectin of >500.

In all patients, diagnosis was confirmed with endoscopy and histology. We reviewed investigations undertaken for causes of monogenic IBD. 19 (70%) patients had genetic testing sent, 8 did not. Of those genetic tests sent, 5 were under 2 years old. 3 patients had mutations, 2 of these were unrelated to IBD and 1 found a variant in the STXB3 gene which was not significant on functional testing. 2 patients still have results pending. Of the 8 where genetic testing was not sent, 3 were due to issues with consent or parental refusal including 1 patient who was younger than 2 years old. 1 patient is a new diagnosis, and genetic consent is awaited.

Immunology testing was undertaken in 20 (74. %) patients, whilst 7 (26%) patients did not have immunology testing done. In those who had the tests, no immunological cause was found.

At the time of review, 13 (48%) patients remain on biologic treatment, 7 (26%) are on Azathioprine or an aminosalicylates and 7 (26%) have been able to discontinue all medication. 4 (15%) patients failed to respond to any medical treatment including biologic therapy and underwent colectomy.

Our data reflects that VEOIBD is rare and response to treatment is variable with some having aggressive disease. Genetic testing was considered in all patients under 2 years of age, with only 1 patient not having testing secondary to issues with parental consent rather than clinician decision. Immunology investigations were undertaken in all patients under 2 years. None of our patients have any significant findings on genetic or immunological testing. The variability in outcomes is interesting and is an area for further study and consideration.

References

1. Heyman MB, Kirschner BS, Gold BD, et al. Children with early-onset inflammatory bowel disease (IBD): analysis of a pediatric IBD consortium registry. J Pediatr. 2005;146:35–40
2. Uhlig HH, Charbit-Henrion F, Kotlarz D, et al. Clinical Genomics for the Diagnosis of Monogenic Forms of Inflammatory Bowel Disease: A Position Paper From the Paediatric IBD Porto Group of European Society of Paediatric Gastroenterology, Hepatology and Nutrition. J Pediatr Gastroenterol Nutr. 2021 Mar 1; 72(3):456-473

OC87

Patient information leaflets – Gastroenterology endoscopic procedures in children. Designing patient information leaflets for Paediatric endoscopy: A user-centred approach.

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Sheffield Children's NHS Foundation Trust

Background

An increasing attention to the quality of paediatric endoscopic services, led to the development of paediatric specific endoscopy quality standards in the joint NASPGHAN and ESPGHAN guidelines. Two quality standards emphasise the importance of providing accurate, accessible information to patients and their families to facilitate informed consent and promote patient centred care.

Our primary objective was to create up-to-date information leaflets on gastrointestinal endoscopic procedures, with the aim of improving understanding of the procedures' intended benefits and risks. Ultimately, we sought to develop leaflets that could serve as model for all paediatric endoscopy centres.

Methods

This work was conducted following a user-centred design approach. Existing leaflets from Sheffield's Children's NHS Foundation Trust were reviewed and updated in line with current evidence and guidelines, while new ones were created where needed. The revised materials were proofread and refined through iterative review by the paediatric gastroenterology team, including doctors, specialist and endoscopy nurses.

The finalised relevant information leaflets were distributed to children and their families on the day of their endoscopic procedure. Participants completed a standardised questionnaire assessing their baseline knowledge of the procedure. Responses were recorded on a five-point Likert scale ("Strongly disagree" to "Strongly agree"). After receiving the relevant leaflet, participants completed the same questionnaire to evaluate any change in understanding. Improvement was defined as an increase of at least one point on the Likert scale.

Results

15 patients answered the questionnaires. Of these, 40% underwent a gastroscopy, 20% underwent a colonoscopy, 20% had a gastroscopy associated to a pH study, 7% had a polypectomy, a percutaneous endoscopic gastrostomy or a change of Corflo PEG to a balloon button PEG. Nearly half of the questionnaires were answered by parents, 20% were filled in by the child only, and one third by both.

The Table 1 shows improvements in understanding after having read the information leaflet. The greatest improvement was observed in knowing what to expect after the procedure. Over half of respondents showed increased understanding of what an endoscopy is, how the procedure is performed, the main risks, and why and how to have a bowel preparation. In contrast, fewer children reported feeling more prepared for the procedure, while 45% of parents felt more confident explaining it to their child.

Questions	**Improvement ≥1 point increase, %**
I know what an endoscopy is	47
I know how the procedure is performed	53
I know why and how I/my child needs a bowel preparation for colonoscopy	50
I know the main risks of the procedure	53
I know what to expect after the procedure	67
I feel prepared for the procedure	14
I feel more confident explaining the procedure to my child/young person	45

Table 1. Understanding improvement for each assessed question.

Conclusion

The leaflets significantly enhanced understanding among patients and families. This improvement was observed among patients and parents who had already received verbal explanations about the procedure and had provided informed consent. This highlights the value of written educational resources in reinforcing comprehension and supporting informed decision-making.

References

1. Lightdale JR, Walsh CM, Narula P, et al. Pediatric Endoscopy Quality Improvement Network Quality Standards and Indicators for Pediatric Endoscopy Facilities: A Joint NASPGHAN/ESPGHAN Guideline. J Pediatr Gastroenterol Nutr [Internet]. mars 2022 [cité 26 sept 2025];74(S1). Disponible sur: https://onlinelibrary.wiley.com/doi/10.1097/MPG.0000000000003263
2. Lightdale JR, Walsh CM, Oliva S, et al. Pediatric Endoscopy Quality Improvement Network Quality Standards and Indicators for Pediatric Endoscopic Procedures: A Joint NASPGHAN/ESPGHAN Guideline. J Pediatr Gastroenterol Nutr [Internet]. mars 2022 [cité 29 oct 2025];74(S1). Disponible sur: https://onlinelibrary.wiley.com/doi/10.1097/MPG.0000000000003264

OC88

Accessibility of Helicobacter pylori Diagnosis and Treatment Guidelines for Paediatric Patients in Primary Care Settings: A Simulated Search Evaluation

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Accurate testing and treatment guidance for Helicobacter pylori (H. pylori) in children is vital to prevent unnecessary investigations and promote antimicrobial stewardship.[1,2] Anecdotal feedback from general practitioners (GPs) suggests that current paediatric recommendations are difficult to locate across various online sources. There is also a heavy reliance on NICE as a source of clinical information in primary care settings. However, these have yet to be updated with specific guidance on the testing and treatment of H. pylori in children.[3] This service evaluation examined how easily the latest ESPGHAN/NASPGHAN guidelines can be accessed through common online channels used in primary care, to identify areas for improvement.

A website audit and simulated-search method were used without GP sampling. Fifteen resources (including NICE, BNFC, NHS Scotland, BSPGHAN, and five local guidelines) were reviewed for accuracy and clarity of H. pylori diagnostic indications and treatment. Five GP-style searches (e.g., “H. pylori treatment in children guidelines in the UK”) were entered into Google and Bing. The top ten results were evaluated for authority and accuracy. Two reviewers conducted 30 timed searches to simulate GP behaviour, recording the sources, time taken to locate the correct resource, and the content.

Authoritative guidance (ESPGHAN/NASPGHAN Guideline) appeared within the top three Google results in 10% of queries and in 90% for Bing. Only 2/15 audited sites had accurate, up-to-date regimens that matched 2024 ESPGHAN recommendations. The average time for reviewers to locate the precise resource was 90 seconds. Barriers included a lack of NICE guidance specifically for children, inconsistent wording, and unclear navigation.

In conclusion, access to information on H. pylori diagnosis and treatment remains inconsistent. Clearer signposting within GP systems, an update to NICE guidance, and search engine optimisation could improve usability and support antimicrobial stewardship, thereby ensuring children receive the highest standard of care.

References

1. Homan M, Jones NL, Bontems P, Carroll MW, Czinn SJ, Gold BD, et al. Updated joint ESPGHAN/NASPGHAN guidelines for management of Helicobacter pylori infection in children and adolescents (2023). Journal of Paediatric Gastroenterology and Nutrition. 2024 Aug 15;79(3):758–85.2.
2. Aguilera Matos I, Diaz Oliva SE, Escobedo AA, Villa Jiménez OM, Velazco Villaurrutia Y del C. Helicobacter pylori infection in children. BMJ Paediatrics Open. 2020 Aug;4(1):e000679.
3. McCartney M, Connolly K, Sullivan F, Heneghan C, Yu E, Hendry B, et al. Where do UK clinicians find information at the point of care? A pragmatic, exploratory study. BMC Primary Care. 2024 Oct 23;25(1).

OC89

Review of Children with Helicobacter pylori Infection in South-West London

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Helicobacter pylori (Hp) infects approximately 50% on the global population (1). It remains the leading cause of peptic ulcer disease and chronic gastritis and also has associations with gastric cancer (2). ESPGHAN/NASPGHAN guidelines recommend targeted testing, eradication therapy, and mandatory post-treatment re-testing (3). Compliance to these recommendations, particularly with respect to targeted testing and re-testing, varies across centres. South-West London (SWL) has a heterogenous population, in this audit we explored factors associated with infection and concordance of management to guidelines.

We aimed to:

1. Assess the demographic of patients presenting with positive Hp in SWL
2. Evaluate adherence to ESPGHAN/NASPGHAN guidelines
3. Identify areas for improvement in management

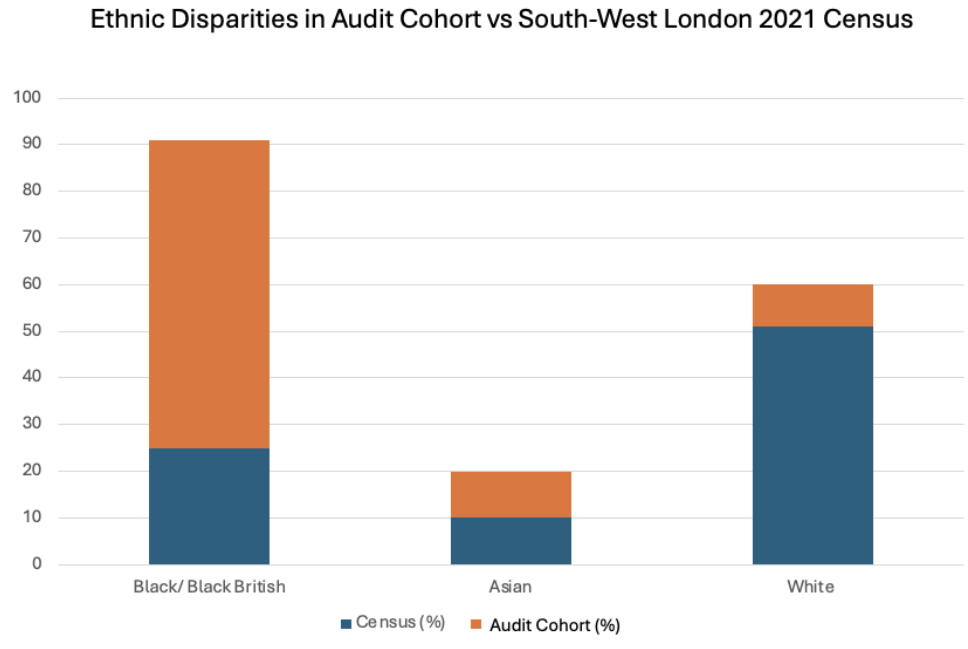
An audit was conduct on paediatrics patients (<18years at the time of testing), with a confirmed diagnosis of Hp. Data was collected from electronic patient care records and laboratory databases, from the last 2 years. Extracted variables included age, gender, ethnicity, weight percentile, diagnostic modality, treatment regimen and re-testing rates. Management was compared against ESPGHAN/NASPGHAN guidelines (3). Associations between categorical variables and Hp prevalence were assessed using Chi-square goodness of fit test, with $p < 0.05$ considered statistically significant.

A total of 113 patients were identified with confirmed Hp infection. Ethnic distribution, where documented, revealed 66% Black/ Black British, 10% Asian, and 9% White. Statistical analysis revealed that the affected ethnic proportions were statistically significant *($\chi^2 = 115.63$, df =4, $p< 0.001$)*. Weight percentiles also varied, 30% of those with documented weight were obese, 12% were overweight and 56% were in the healthy range. Statistical analysis revealed this as a statistically significant result ($\chi^2 = 57.73$, df= 3, $p< 0.001$).

Regarding management, 65% of patients received correct treatment as per ESPGHAN/NASPGHAN guidelines (omeprazole, amoxicillin, clarithromycin/ metronidazole). However, 56% of patients had no documented re-testing after treatment, and only 18% achieved confirmed eradication. Among those who underwent an oesophago-gastro-duodenoscopy (OGD), none had the recommended 6 or more biopsies retrieved.

The collected data highlights notable ethnic disparities in Hp prevalence in SWL, despite the recent 2021 census illustrating an ethnic distribution of 51% White and 25% Black/ Black British in this area as shown in Figure 1. This demonstrates an over-representation of Black ethnicity with Hp, calculated as statistically significant ($\chi^2 = 86.81$, df= 4, $p< 0.001$), aligning with existing literature (4). It also demonstrated that 40% of paediatric cases with confirmed Hp are overweight, in accordance with prior studies (5). While initial management largely aligned with ESPHGAN/NASPGHAN guidelines, we identified a lack of appropriate follow up and re-testing in the 6-8 weeks period post treatment (2). This increases the risk of missed treatment failure and persistent infections, which contributes to a rise in antibiotic resistance and long-term gastric complications.

This audit highlighted the need for improved awareness of the ESPGHAN/NASPGHAN guidelines in both primary and tertiary care. Ethnic disparities for infections were also noted and may suggest a higher index of suspicion of infection in these groups.



References

1. Hassan MN. Global prevalence of Helicobacter pylori and its effect on human health. Pure and Applied Biology. 2020 Mar 10;9(1).
2. Hsieh H, Yang HB, Sheu BS, Yang YJ. Atrophic gastritis in Helicobacter pylori-infected children. Helicobacter. 2022 Jun;27(3):e12885.
3. Homan M, Jones NL, Bontems P, Carroll MW, Czinn SJ, Gold BD, et al. Updated joint ESPGHAN/NASPGHAN guidelines for management of *Helicobacter pylori* infection in children and adolescents (2023). J Pediatr Gastroenterol Nutr. 2024 Sep 15;79(3):758–85.
4. Brown HT, Epplein M, Tang H, Garman K. Abstract PO-183: Racial disparities in *Helicobacter pylori* infection: A systematic review and retrospective study. Cancer Epidemiology, Biomarkers & Prevention. 2022 Jan 1;31(1_Supplement):PO-183-PO-183.
5. Suki M, Leibovici Weissman Y, Boltin D, Itskoviz D, Tsadok Perets T, Comaneshter D, et al. Helicobacter pylori infection is positively associated with an increased BMI, irrespective of socioeconomic status and other confounders: a cohort study. Eur J Gastroenterol Hepatol. 2018 Feb;30(2):143–8.

OC90

Assessment of compliance with NASPGHAN guidelines for omeprazole use in children with reflux disease.

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Proton pump inhibitors (PPIs) are frequently prescribed in paediatrics for symptoms suggestive of gastroesophageal reflux disease (GERD). Despite their therapeutic role, concerns remain regarding overuse, prolonged duration, and deviation from established guidelines. North American Society for Paediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) 2018 guidelines suggest dietary and lifestyle modifications before pharmacological treatment, limiting omeprazole use to 4–8 weeks before reassessment, and referral to a paediatric gastroenterologist when symptoms persist or complications are suspected. This study aimed to assess compliance with these guidelines within a hospital trust in England.

A retrospective review was conducted on 50 randomly selected paediatric patients who attended outpatient clinics and were prescribed omeprazole. Data were collected from electronic records with support from junior medical and pharmacy teams. Information included patient age, sex, clinical indication, duration and repetition of prescriptions, whether dietary modification was trialled before initiation, and whether the prescription was made by a gastroenterologist or another subspecialty. Patients receiving omeprazole for gastroprotection (e.g., with steroid or NSAID therapy) were analysed separately. Those prescribed omeprazole for reflux symptoms were divided into two groups: Group A (infants) and Group B (children). One patient was excluded due to death.

Only 12.2% of prescriptions of patients included (n=6) were made by paediatric gastroenterologists, while 87.8% originated from other subspecialties. Among all prescriptions, 54% (n=27) were for reflux-related symptoms and 46% (n=22) for gastroprotective purposes. Of those prescribed omeprazole for reflux, 48% were in Group A and 52% in Group B. Complex comorbidities (genetic, metabolic, or cardiac) were present in 53.8% of Group A and 71.4% of Group B.

Dietary or lifestyle modification prior to omeprazole use was attempted in 76.9% of Group A and 57.1% of Group B. Only 7.6% of Group A and 35% of Group B were referred to a gastroenterologist for further assessment. Of the 27 patients prescribed omeprazole for reflux, 44.4% (n=12) had objectively confirmed reflux through OGD, pH impedance, or laryngoscopic evaluation, while 55.6% were treated empirically based on symptoms. Among those with confirmed reflux, 80% had attempted dietary modification before starting omeprazole. Two-thirds (66.7%) of all reflux patients received omeprazole for longer than 8 weeks with no clear discontinuation plan.

Our findings highlight partial compliance with NASPGHAN guidelines for paediatric reflux management, particularly treatment duration. Referral rates for persistent or complex reflux were low, indicating gaps in practice. Educational initiatives and structured outpatient resources (e.g., guideline-based brochures and checklists) are recommended to promote appropriate omeprazole use and reinforce non-pharmacological strategies. We suggest implementing these educational resources and reaudit after 6 months. Further research is warranted to evaluate omeprazole prescribing for gastroprotection and develop updated UK-specific guidance consolidating paediatric omeprazole indications, including GERD, eosinophilic esophagitis, H. pylori infection, and gastric ulcer prevention.

Table 1. Summary of compliance with NASPGHAN 2018 guidelines.

Parameter	Group A (infants)	Group B (children)
Attempted dietary modification before PPI	76.9% (n=10/13)	57.1% (n=8/14)
Referral to gastroenterology	7.6% (n=1/13)	35.0% (n=5/14)
Objective confirmation of reflux	44.4% (n=12/27)*	
PPI duration ≤8 weeks	33.3% (n=9/27)*	

* Data not broken down by age group.

References

1. Rosen R, Vandenplas Y, Singendonk M, et al. Pediatric gastroesophageal reflux clinical practice guidelines: Joint recommendations of NASPGHAN and ESPGHAN. J Pediatr Gastroenterol Nutr. 2018;66(3):516–554.
2. Vandenplas Y, Rudolph CD, Di Lorenzo C, et al. Pediatric gastroesophageal reflux clinical practice guidelines: Joint recommendations of NASPGHAN and ESPGHAN. J Pediatr Gastroenterol Nutr. 2009;49(4):498–547.

OC91

Efficacy and safety of non-pharmacological treatments for paediatric functional constipation: a systematic review and meta-analysis

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Functional constipation (FC) is a common condition in children that can significantly affect their quality of life and often requires long-term management. Given the multifactorial nature of FC, treatment should be personalised and include both non-pharmacological and pharmacological approaches (1-3). This review analyses the efficacy and safety of non-pharmacological interventions in the management of childhood FC. Electronic searches were conducted in PubMed, MEDLINE, Embase, and PsycINFO up to March 2025 for randomised controlled trials (RCTs) including children aged 0-18 years with FC and treated with non-pharmacological interventions, compared to placebo, no treatment or any other intervention. Primary outcomes were treatment success, defecation frequency and withdrawals due to adverse events. The certainty of the evidence was assessed using the GRADE framework. We included a total of 93 RCTs, comprising 7,787 children (50.4% female). We investigated 47 interventions, including dietary, psycho-educational, physiotherapy, complementary and alternative medicine, and electrical stimulation. Abdominal transcutaneous electrical stimulation (ATES) combined with pelvic floor muscle exercises (PFME) probably improves treatment success and defecation frequency compared with PFME alone (RR 1.75, 95% CI 1.25 to 2.44; MD 1.85, 95% CI 1.28 to 2.43; moderate certainty). Percutaneous tibial nerve stimulation (PTNS) associated to PFME may improve treatment success (RR 1.73, 95% CI 1.08 to 2.77; low certainty) and probably increase defecation frequency (MD 1.82, 95% CI 0.82 to 2.82; moderate certainty). Behavioural therapy combined with PEG may not improve treatment success (RR 0.83, 95% CI 0.62 to 1.12; low certainty) and probably reduces defecation frequency (MD -1.80, 95% CI -2.88 to -0.72; moderate certainty). It is uncertain if there is any difference in defecation frequency when probiotics are added to laxatives compared to laxatives alone (MD: 0.12, 95% CI -0.09 to 0.34; low certainty). Cow's milk free diet (CMFD) in addition to PEG may improve defecation frequency when compared to normal diet in addition to PEG (RR: 1.34, 95% CI 1.15 to 1.57; low certainty). Some non-pharmacological treatments for childhood FC demonstrate beneficial effects and may be considered as part of management. Future RCTs should focus on improving methodological rigor.

References

1. Pijpers MA, Bongers ME, Benninga MA, Berger MY. Functional constipation in children: a systematic review on prognosis and predictive factors. J Pediatr Gastroenterol Nutr. 2010;50(3):256–68.
2. Vriesman MH, Rajindrajith S, Koppen IJN, van Etten-Jamaludin FS, van Dijk M, Devanarayana NM, et al. Quality of Life in Children with Functional Constipation: A Systematic Review and Meta-Analysis. J Pediatr. 2019;214:141–50.
3. Koppen IJN, van Wassenaer EA, Barendsen RW, Brand PL, Benninga MA. Adherence to Polyethylene Glycol Treatment in Children with Functional Constipation Is Associated with Parental Illness Perceptions, Satisfaction with Treatment, and Perceived Treatment Convenience. J Pediatr. 2018;199:132–9.e1.

OC92

Embedding psychology into a tertiary gastroenterology service: A year-long retrospective study of referrals

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Psychological support has become increasingly recognized as a key component in improving outcomes in paediatric gastroenterology, complementing medical treatments. The biopsychosocial model provides a foundation for integrating psychological care, yet the demand for such services often exceeds availability [1]. In response to this need, a tertiary paediatric gastroenterology service successfully secured funding for a full-time embedded clinical psychologist (1.0 FTE) starting in September 2022. This transition from general paediatric psychology input to specialised care has led to the development of group interventions, a stepped-care model, and an increase in referrals. The team has also expanded to include an Assistant Psychologist (0.6 FTE) and Trainee Clinical Psychologists.

This study aims to provide a retrospective analysis of referrals to the embedded psychology service between April 2024 and March 2025, examining conditions treated, reasons for referral, waiting times, and outcomes. A total of 155 children and young people (CYP) were referred, with 86% being outpatients. The most common conditions included Disorders of Gut-Brain Interaction (42%), Inflammatory Bowel Disease (32%), and Constipation/Toileting Difficulties (13%).

For inpatient referrals, all were seen within 2 days. Outpatient referrals were scheduled for a telephone consultation with a member of the psychology team within an average of 24 days. These consultations allowed for a detailed discussion, the development of a working formulation, and a plan for support. The most common initial intervention was a group intervention (65%), followed by individual support through waitlists, priority interventions, or the Assistant Psychologist pathway (20%). Wait times for interventions ranged from 0 to 252 days, with an average wait of 68 days.

Of the 121 referrals closed to psychology, 64 (53%) received intervention(s) and were discharged as planned. The remaining cases were closed at various stages due to reasons such as no longer requiring support, being referred to other services, or withdrawal (47%). Thirty-four CYP remained open to the service, either continuing interventions or on the waitlist.

The data highlights the growing demand for psychological support and the benefits of embedding psychology within paediatric gastroenterology teams. This integration has allowed for a more efficient response to referrals, with many CYP accessing support more quickly than before. The stepped-care model has facilitated group interventions and low-intensity pathways, ensuring those who need individual support can be seen sooner.

While the findings from this single-site study may not be generalizable to other services or populations, the results strongly suggest that embedding psychology within gastroenterology teams is beneficial. The study also highlights the need for continued support for referrals to appropriate services and further exploration of barriers to engagement with psychological interventions.

References

1. Wong E, Heuschkel R, Lindsay C et al. The growing gap between demand and availability of clinical psychology in Paediatric Gastroenterology: a retrospective analysis of clinical routine care. European Journal of Pediatrics. 2021 Apr;180(4):1307-12.

OC93

Diagnostic difficulties in neonatal cholestasis: Cystic biliary atresia mimicking choledochal cyst on imaging

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A term female neonate (birth weight 3.5 kg) with an antenatally suspected ovarian cyst presented with jaundice, pale stools, and hepatomegaly. Postnatal ultrasound revealed a 6.4 cm cystic lesion in the porta hepatis region, ruling out the prenatal diagnosis. A tubular anechoic structure adjacent to the cyst could not be clearly identified as either a collapsed gallbladder or dilated biliary duct. Laboratory investigations showed conjugated hyperbilirubinaemia with elevated AST, ALT, and total bilirubin levels. MRCP demonstrated a well-circumscribed cystic lesion at the porta hepatis with prominent intrahepatic ducts. Neither an extrahepatic duct nor a normal gallbladder structure was identified, which is unusual for a choledochal cyst and typically associated with biliary atresia. However, based on probability (choledochal cyst being more common), a presumptive diagnosis of choledochal cyst was made. A preoperative HIDA scan and liver biopsy were not performed, as imaging was deemed diagnostic. The infant underwent exploratory laparotomy at 44 days of age for planned cyst excision. An intraoperative cholangiogram revealed the cyst was associated with an obliterated extrahepatic biliary tree, confirming cystic biliary atresia. Kasai portoenterostomy was performed with excision of the fibrotic cyst and anastomosis of a Roux limb to the liver hilum. Postoperatively, the infant recovered well with gradual resolution of jaundice and normalisation of stool colour. Growth improved dramatically from the 9th centile pre-surgery to above the 75th centile by 26 weeks of age. Follow-up at 3 months showed stable liver function with no signs of cholangitis. This case highlights that cystic biliary atresia can mimic a choledochal cyst even with cyst sizes exceeding 2.5 cm. The absence of a visible gallbladder on MRCP should raise suspicion for biliary atresia. Retrospectively, HIDA scintigraphy and liver biopsy could have clarified the diagnosis preoperatively. Key learning points include cystic biliary atresia mimics choledochal cyst on ultrasound and MRCP; elevated transaminases and bilirubin with pale stools warrant urgent evaluation for biliary atresia regardless of cystic features; intraoperative adaptability is essential in paediatric hepatobiliary surgery; and additional diagnostics, including HIDA scan and liver biopsy, should be considered in ambiguous cases despite apparent diagnostic imaging.

References

- Schooler GR, Mavis A. Cystic biliary atresia: A distinct clinical entity that may mimic choledochal cyst. Radiol Case Rep. 2018;13(2):415-418.
- Chen YT, He X, Wang H, et al. Differentiation of cystic biliary atresia and choledochal cysts using prenatal ultrasonography. Ultrasonography. 2021;40(4):566-574.
- Chen YT, Gao MJ, et al. Comparative analysis of cystic biliary atresia and choledochal cysts: Clinical features and outcomes. Front Pediatr. 2022;10:947876.
- Kasahara M, Kudo M, Nishida M, et al. Choledochal cyst with or without biliary atresia in neonates and young infants: US differentiation. Radiology. 1998;209(2):465-469.
- Zhou L, Shan Q, Tian W, et al. Ultrasound-based differential diagnosis between cystic biliary atresia and choledochal cysts associated with different outcomes: five case reports. Medicine (Baltimore). 2019;98(8):e14641.
- Tanaka H, Sasaki H, Wada M, et al. Histological differentiation between prenatally diagnosed choledochal cyst and type I cystic biliary atresia using liver biopsy specimens. Eur J Pediatr Surg. 2007;17(1):19-23.
- Berrocal T, Luque R, Gámez M, et al. Scintigraphic features of choledochal cyst. J Nucl Med. 1989;30(5):622-628.

OC94

Using serum 7-alpha-hydroxy-4-cholesten-3-one (C4) levels to assist in screening and diagnosis of bile acid diarrhoea

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Bile acid diarrhoea (BAD) is characterised by increased bile acid loss and chronic lower gastrointestinal symptoms including cramping pain and diarrhoea. It is more commonly seen in the setting of ileal resection or disease but has overlapping features with conditions such as diarrhoea-prominent IBS (IBS-D) and may be underdiagnosed, with around 20% of adolescents with IBS-D thought to have BAD (1). Consideration of BAD is recommended in the management of IBS-D and testing for BAD is recommended in chronic diarrhoea (2).

BAD can be diagnosed using 75-selenium homotaurocholic acid test (SeHCAT) testing, but this involves a waiting list for the test, ionising radiation and several repeat nuclear medicine appointments. Studies have validated serum 7-alpha-hydroxy-4-cholesten-3-one (C4) as an alternative (increased serum C4 levels seen due to a compensatory increase in hepatic CYP7A1 activity) (3). This should be sent on a fasted sample but can use a combined biochemistry sample therefore does not require additional blood sampling. C4 may be falsely increased in liver dysfunction and with bile acid sequestrant use.

We aimed to evaluate utility of C4 in patients undergoing investigation for diarrhoea in a single tertiary centre. C4 testing was introduced on a trial basis.

C4 results were prospectively collected and data was collected on reason for request (IBS-D, known short bowel syndrome (SBS) or other), test result, liver function tests (LFTs), subsequent SeHCAT request and result, treatment initiated and outcome.
73 patients had C4 levels requested, 31/73 (42%) due to loose stool (probable IBS-D), 13/73 (18%) known short bowel syndrome), 29/73 (40%) other symptoms including constipation, abdominal pain. C4 results were grouped as < 50 (low/BAD unlikely), 50 – 142 (equivocal) and > 142 (high/BAD highly likely). 20/73 (27%) had equivocal or high C4 results. All with equivocal or high C4 had SeHCAT requested. To date 4 have had SeHCAT testing with 3 positive results (2 IBS-D, 1 SBS) and 1 negative (SBS). All patients with positive results started treatment with cholestyramine and have shown clinical improvement.

6 patients had deranged LFTs but no association was shown between this and C4 level (2 low, 3 equivocal, 1 high).

C4 is an easy and convenient screening test for BAD which can be used in combination with routine blood testing. Results largely correlated with SeHCAT results and therefore C4 could be used to guide trial of initiation of cholestyramine treatment without the need for SeHCAT testing. Results should be interpreted with caution in those with deranged LFTs although no association was seen in this study. Longer term follow up of this patient group is ongoing and larger studies are recommended to further evaluate the role of C4 testing.

References

1. *Camilleri M, Nurko S. Bile Acid Diarrhea in Adults and Adolescents. Neurogastroenterol Motil. 2022 Apr; Epub 2021 Nov*
2. *Vasant DH, Paine PA, Black CJ, British Society of Gastroenterology guidelines on the management of irritable bowel syndrome. Gut. 2021 Epub 2021*
3. *Gothe F, Beigel F, Rust C. Bile acid malabsorption assessed by 7 alpha-hydroxy-4-cholesten-3-one in pediatric inflammatory bowel disease: correlation to clinical and laboratory findings. J Crohns Colitis. 2014 Sep*

OC95

Gastric Ulcer in a 2.5-Month-Old Infant in Syria: Possible Role of Helicobacter pylori and Aspirin Exposure

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Background:
Gastric ulcers are uncommon in pediatric populations, with an incidence of 2–8% in children and extremely rare occurrence in early infancy. The primary etiologies include *Helicobacter pylori* infection and prolonged use of nonsteroidal anti-inflammatory drugs (NSAIDs). We present a rare case of a bleeding gastric ulcer in a 2.5-month-old infant with concurrent *H. pylori* infection, maternal aspirin/NSAID exposure during breastfeeding, and COVID-19 infection.

Case Presentation:
A 2.5-month-old male presented with severe pallor, recurrent hematemesis (post-breastfeeding), and melena for one week, despite maintaining normal weight gain. Hemoglobin was 3 g/dL, requiring transfusion. The infant's mother had contracted COVID-19 one month earlier, recovered within 5 days, but continued aspirin and other NSAIDs for a month during breastfeeding. Clinical examination revealed severe pallor but was otherwise unremarkable. Stool testing showed WBCs and RBCs; stool culture was negative. Upper gastrointestinal endoscopy revealed a bleeding gastric ulcer on the greater curvature. Biopsy demonstrated chronic gastritis, and *H. pylori* antigen was positive. Five days into hospitalization, the infant tested positive for COVID-19.

Treatment included intravenous omeprazole, diet modification, fluids, and subsequent triple therapy (*H. pylori* eradication regimen: proton pump inhibitor, clarithromycin, and amoxicillin for 14 days). COVID-19 was managed symptomatically. Clinical recovery was achieved, with normalization of hemoglobin and resolution of bleeding. Seven-month follow-up confirmed complete recovery and negative *H. pylori* stool antigen.

Discussion:
This case is notable for:

1. **Unusual age of onset** – gastric ulcers are extremely rare in infants under 3 months.
2. **Atypical ulcer location** – on the greater curvature, whereas most pediatric gastric ulcers occur on the lesser curvature.
3. **Multiple potential risk factors** – *H. pylori* infection, aspirin exposure via breast milk, low socioeconomic status, and concurrent COVID-19 infection.

H. pylori is a well-established cause of chronic gastritis and gastric ulceration, with increased prevalence in low-income regions and possible maternal–child transmission. Although most NSAIDs pose minimal risk to nursing infants, aspirin may be transmitted via breast milk in pharmacologically relevant amounts, particularly with chronic maternal use, potentially exacerbating gastric mucosal injury. The role of COVID-19 in ulcer pathogenesis remains unclear, though studies report a high prevalence of active ulcers among infected patients with gastrointestinal symptoms.

Conclusion:
Gastric ulceration, though rare in early infancy, should be considered in cases of upper gastrointestinal bleeding. This case underscores the importance of evaluating *H. pylori* infection even in very young infants and considering maternal medication history during breastfeeding. Early endoscopic diagnosis and targeted eradication therapy can result in complete recovery.

References

1. Martini N, Al haj Kaddour M, Baddoura M, Jarjanazi M, Mahmoud J. A case report of a gastric ulcer in a 2.5-month-old infant in Syria: Helicobacter pylori and Aspirin as possible causes. *SAGE Open Medical Case Reports*. 2024;12. doi:10.1177/2050313X241242932

OC96

"Microbiota–Neurotransmitter Crosstalk: Unlocking the Gut–Brain Axis for Novel Psychiatric Therapies"

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The human gut harbors a complex and diverse microbial ecosystem—collectively termed the gut microbiota—that exerts profound effects on host physiology, including brain function. This bidirectional communication, known as the gut–brain axis, integrates neural, immunological, and neuroendocrine pathways, enabling gut microbiota to modulate neurotransmitter synthesis and signaling. Disruption of this microbial balance, or dysbiosis, has been increasingly implicated in the pathogenesis of major neuropsychiatric disorders.

This review synthesizes current evidence linking gut microbiota to the regulation of four key neurotransmitter systems—tryptophan/serotonin, dopamine, gamma-aminobutyric acid (GABA), and glutamate—and their roles in four prevalent psychiatric conditions: schizophrenia, depression, generalized anxiety disorder (GAD), and autism spectrum disorder (ASD).

Emerging studies reveal that gut microbiota influence tryptophan metabolism and peripheral serotonin production via bacterial metabolites and immune modulation, thereby impacting mood and stress regulation. Similarly, certain taxa enhance dopamine synthesis or protect dopaminergic neurons, while others promote neuroinflammation and dopamine depletion. GABA production by Lactobacillus, Bifidobacterium, and other genera affects inhibitory signaling in the brain, with implications for anxiety, depression, and neurodegeneration. Furthermore, alterations in gut composition can shift glutamate–GABA balance, influencing synaptic plasticity and cognitive functions.

Clinical and preclinical data consistently demonstrate altered microbial signatures in neuropsychiatric disorders. In schizophrenia, dysbiosis correlates with neuroinflammatory pathways, neurotransmitter imbalances, and treatment-resistant psychosis. Depression is associated with reduced microbial diversity and shifts in serotonin- and dopamine-producing bacteria, contributing to HPA axis dysregulation. In GAD, decreased abundance of short-chain fatty acid–producing genera and impaired serotonin availability exacerbate anxiety symptoms. ASD presents with distinctive microbial patterns and comorbid gastrointestinal dysfunction, with evidence that microbiome-targeted interventions can improve behavioral and GI outcomes.

Therapeutic strategies targeting gut microbiota—such as probiotics, prebiotics, dietary modification, and fecal microbiota transplantation (FMT)—show promise in modulating neurotransmitter pathways and alleviating psychiatric symptoms. Notably, interventions like microbiota transfer therapy in ASD have demonstrated sustained improvements in both gastrointestinal and behavioral domains. However, mechanistic understanding remains incomplete, and inter-individual variability in microbiome composition poses a challenge for standardized therapies.

The gut–brain axis offers a compelling framework for understanding the interplay between microbial ecology and mental health. By elucidating the molecular mechanisms underlying microbiota–neurotransmitter–behavior relationships, this field may pave the way for novel, microbiome-based interventions that complement existing psychiatric treatments. Future research should focus on longitudinal, multi-omics approaches, personalized microbiota modulation, and integration of microbiome profiles into precision psychiatry.

Keywords: gut–brain axis, gut microbiota, neurotransmitters, mental disorders, dysbiosis, probiotics, psychobiotics, fecal microbiota transplantation

References

Mhanna, Amjad MD[a,b]; Martini, Nafiza MD[b,c,*]; Hmaydoosh, Ghefar MD[a,b]; Hamwi, George MD[a,b]; Jarjanazi, Mulham MD[d]; Zaifah, Ghaith MD[a,b]; Kazzazo, Reem MD[a,b]; Haji Mohamad, Aya MD[e,b]; Alshehabi, Zuheir PhD[f]. The correlation between gut microbiota and both neurotransmitters and mental disorders: A narrative review. Medicine 103(5):p e37114, February 02, 2024. | DOI: 10.1097/MD.0000000000037114

OC97

Oral probiotics for the treatment of infantile colic? A systematic review and meta-analysis

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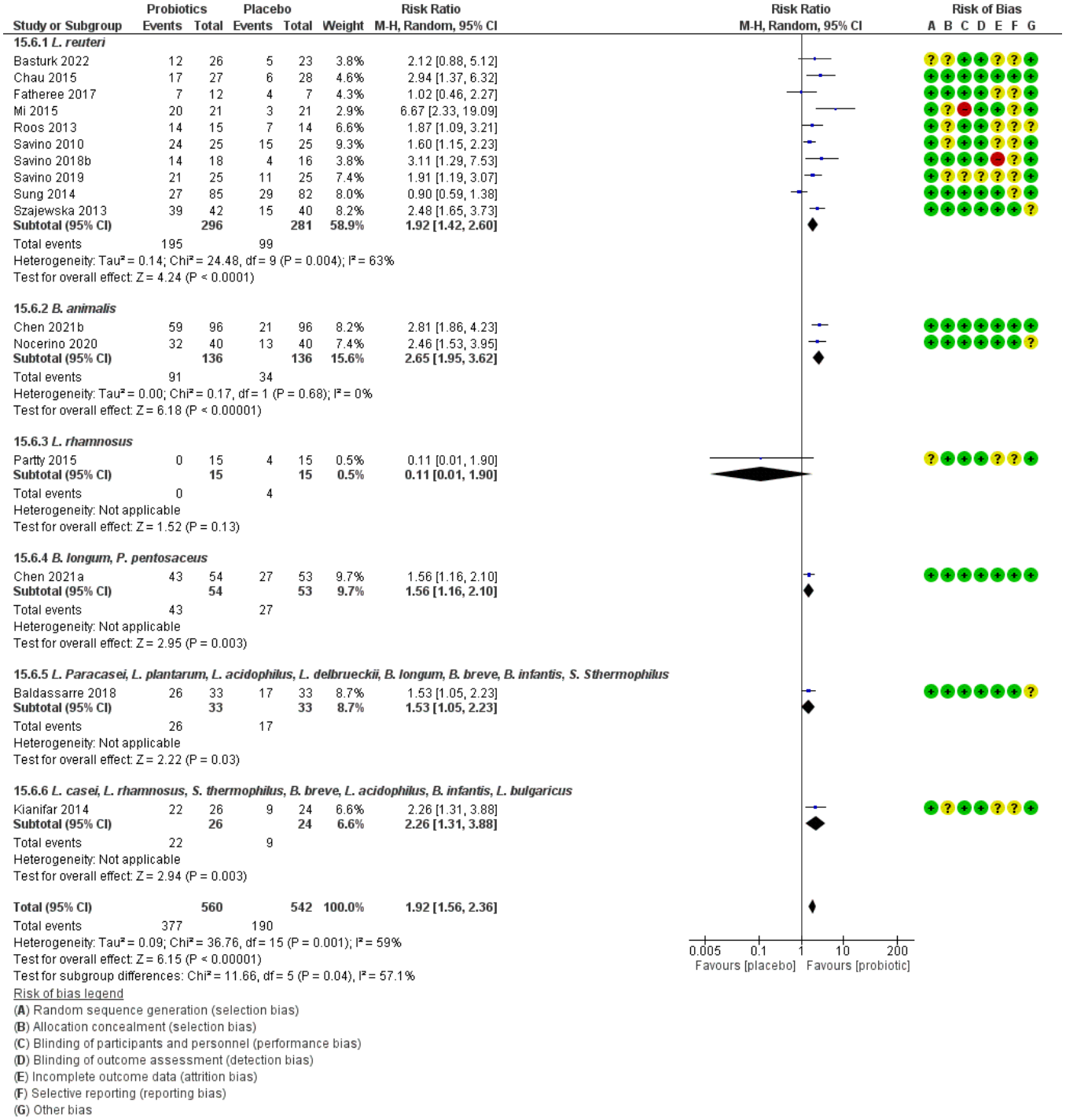
Infantile colic (IC) is a common condition characterised by excessive crying in the early months of life and has a substantial impact on the quality of life of caregivers. The objective of this study was to assess the safety and effects of probiotics for infantile colic.
We searched MEDLINE, EMBASE, Cochrane Library from inception to Jul 2024. RCTs comparing probiotics to any control in infant with colic were considered. The primary outcomes were treatment success, crying time, the number of cases of IC, and withdrawals due to adverse events. RoB 1 and GRADE were used for risk of bias and certainty of the evidence assessment.
There were 45 RCTs (n=3475) eligible for inclusion. Bifidobacterium animalis is more effective than placebo in achieving treatment success (relative risk [RR] 2.65, 95%CI 1.95 to 3.62, high certainty). Lactobacillus reuteri; mixture of Bifidobacterium longum and Pediococcus pentosaceus; and a synbiotic probiotic mixture of 7 strains maybe more effective than placebo in achieving treatment success with low certainty of evidence. B. animalis may lead to less crying time compared to placebo (MD -36.04 min/day, 95% CI, -29.39 to -42.68, low certainty) (Figure 1). Meta-regression indicated that treatment effect of probiotics compared to placebo decreased over time. Moderate-certainty evidence suggests probiotics probably increase treatment success in exclusively breastfed infants compared with placebo. (RR 2.05, 95%CI 1.70 to 2.46).
High, moderate and low certainty evidence across probiotic specimens and follow up times suggest efficacy in the treatment of infantile colic. Future research should explore their mechanisms within the microbiome.

Figure 1. Forest plot of treatment success, subgrouped by specific strain.



OC98

A Rare Case of Type II Ileal Atresia Presenting on Day One of Life possibly due to Intrauterine intussusception.

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Small intestinal atresia (SIA) in neonates is a relatively rare event with a reported prevalence of 1.6 per 10 000 births[1]. There are few clinical cases in literature that demonstrate relationship between intrauterine intussusceptions and ileal atresia. We report a similar case of a newborn who presented with intestinal atresia on day 1 of life. [2 ,3]

Intrauterine intussusception (also called antenatal intussusception) is a rare cause of congenital intestinal atresia, particularly ileal atresia. The proposed mechanisms include abnormal fetal peristalsis or vascular compromise leading to intussusception, which causes ischemia, necrosis, and resorption, ultimately resulting in atresia. The incidence of this latter cause of intestinal atresia has been described between 0.6% and 13% [4] or 25% of all ileal atresia. [5]

We describe the case of a female newborn who was born at 38+2 weeks of gestation by EMCS due to reduced foetal movements at a DGH. Baby was born poorly and needed resuscitation at birth with intubation and ventilation. Clinical examination at that time showed increasing abdominal distension and bilious vomiting. This led the team to perform an X-ray abdomen which showed dilated bowel loops pushed to the left side, free air in the abdomen(Falciform ligament sign) and no gas in the rectum. Baby was urgently transferred to a tertiary centre for surgical input. On Day 2 of life baby had a laparotomy with right hemicolectomy and ileostomy.

A diagnosis of type 2 ileal atresia was confirmed along with other findings of matted loops of terminal ileum, multiple (four) perforations and gross contamination of the peritoneal cavity. Following the intervention, baby started recovering and was extubated the day after. The bilious aspirates also started clearing up and reducing in amount. Baby was given support with PN and antibiotics and continued to improve.

The early presentation and the operative findings of type 2 ileal atresia with matted terminal ileal loops, multiple perforations, and gross peritoneal contamination strongly suggests a prenatal ischemic insult as the initiating event leading to the vascular compromise and resultant atresia. Among the recognized mechanisms, intrauterine intussusception is a well-documented cause of jejunoileal atresia, resulting from compromised mesenteric blood flow to the intussuscepted segment. This leads to ischemic necrosis, resorption of the affected bowel, and formation of blind ends connected by a fibrous cord, as seen in type 2 atresia. The presence of adhesions and perforations in this case likely reflects postnatal progression of injury in an already compromised segment. Recognition of intrauterine vascular events such as intussusception as potential causes of ileal atresia highlights the complex prenatal origin of neonatal intestinal obstruction and reinforces the importance of early diagnosis and prompt surgical intervention to prevent further bowel loss. Awareness of such intrauterine events is important, as early recognition and prompt surgical management are key to minimising bowel loss and improving neonatal outcomes. Also, cystic fibrosis remains an important co-morbid condition that must be excluded promptly in all newborns with intestinal atresia. Fast diagnosis and effective interdisciplinary team work are essential for a satisfying outcome.

References

1. Bianchi F, et al. Epidemiology of small intestinal atresia in Europe: a register-based study. Arch Dis Child Fetal Neonatal Ed. 2012;97:F183-8.
2. Joshi SB, Kinhal V, Desai M, Tilak, Choudhari FU. A Rare Case of Jejunal Atresia Due to Intrauterine Intussusception. J Clin Diagn Res. 2015 Sep;9(9):PD30-1. doi: 10.7860/JCDR/2015/14063.6566. Epub 2015 Sep 1. PMID: 26500958; PMCID: PMC4606287.
3. Sarin YK. Intrauterine intussusception causing ileal atresia. APSP J Case Rep. 2010 Jul;1(2):18. Epub 2010 Dec 1. PMID: 22953261; PMCID: PMC3417996.
4. de Luca U, Esposito C, Porreca A. Intrauterine intussusception as a cause of ileal atresia occurring late during pregnancy. Eur J Pediatr Surg. 1995 Apr;5(2):116-8. doi: 10.1055/s-2008-1066182. PMID: 7612581.
5. Komuro H, Hori T, Amagai T, Hirai M, Yotsumoto K, Urita Y, Gotoh C, Kaneko M. The etiologic role of intrauterine volvulus and intussusception in jejunoileal atresia. J Pediatr Surg. 2004 Dec;39(12):1812-4. doi: 10.1016/j.jpedsurg.2004.08.037. PMID: 15616938.

OC99

Effect of General Anaesthesia on gas and liquid reflux events on 24-hour pH-Impedance study in children

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Multichannel intraluminal impedance (MII) is a validated technique for assessing the movement of fluids, solids, and gas in the oesophagus and is routinely used alongside pH monitoring to characterise gastro-oesophageal reflux (GOR) events.[1] Anaesthesia is known to influence gastric and intestinal motility, potentially predisposing to transient increases in reflux activity.[2] Adult studies have demonstrated increased reflux events within minutes of anaesthetic induction and have identified aspiration of gastric contents as a major complication of anaesthesia.[3] A small retrospective paediatric study has reported increased GOR parameters, particularly during the first hour and up to six hours post-anaesthesia.[4] However, data exploring the impact of anaesthesia on gas reflux in children are lacking. This study aimed to evaluate the effect of general anaesthesia on acid, non-acid, and gas reflux parameters in paediatric 24-hour pH-impedance studies.

A retrospective review was undertaken of 100 consecutive 24-hour pH-impedance studies performed between July 2021 and March 2025. Fifty studies were conducted post-anaesthesia (24 following bronchoscopy and 26 following gastroscopy) and fifty without anaesthesia. Studies with a recording duration of less than 20 hours were excluded. Data were extracted from clinician reports for total reflux events, and for acid, weak acid, and non-acid reflux episodes. The number of gas reflux events during the first four hours of recording was quantified using Laborie software. Comparisons were made between the anaesthesia and non-anaesthesia groups using the Mann-Whitney U test, with a p-value of <0.05 considered statistically significant.

Analysis demonstrated a significant increase in total gas reflux events in the post-anaesthesia group compared to the non-anaesthesia group (84.17 vs 49.35, $p = 0.0039$), and in the first four hours of recording (21.36 vs 10.42, $p = 0.0030$). There was no significant difference in gas reflux between bronchoscopy and gastroscopy subgroups. Acid and non-acid reflux events did not differ significantly between the anaesthesia and non-anaesthesia groups.

These findings suggest that general anaesthesia is associated with a significant increase in gas reflux activity in children undergoing 24-hour pH-impedance studies. Gas reflux has been shown to influence symptom association and diagnostic interpretation, as the presence of gas boluses can increase the likelihood of a study being classified as positive for reflux-symptom correlation.[5] The observation that gas reflux increases after anaesthesia is relevant, particularly as pH-impedance catheters are frequently placed in theatre to improve tolerance in children. The presence of gas may also reflect aerophagia, which can mimic GER disease and lead to misinterpretation.[5]

A retrospective paediatric study showed increase in acid and non-acid reflux events following anaesthesia for first 4hrs in children over 1yr of age and not in infants.[2] This wasn't seen in our study.

While our study benefits from a well-defined cohort and consistent methodology, limitations include its retrospective design, modest sample size, and unaccounted confounding factors such as indication for study, baseline impedance, and premedications. As there are limited small studies, a large prospective study is warranted to confirm these findings and, if validated, adjustments in analysis and interpretation may be required to prevent false-positive results in children undergoing pH-impedance monitoring.

References

1.Loots CM, Benninga MA, Davidson GP, Omari TI. Addition of pH monitoring to impedance testing increases the yield of symptom association analysis in children. *J Pediatr Gastroenterol Nutr.* 2012;54(4):506–512.
2.Omari TI, Rommel N, Staunton E, et al. Effect of anesthesia and sedation on gastroesophageal reflux in children: a prospective study. *J Pediatr Gastroenterol Nutr.* 2011;53(2):154–158.
3.Reimer C, Bytzer P. Anesthesia and gastroesophageal reflux: implications for aspiration risk. *Anesth Analg.* 2005;101(3):627–633.
4.Ross JJ, Simpson R, Omari TI. The impact of general anesthesia on gastroesophageal reflux in children undergoing impedance-pH monitoring: a retrospective study. *Neurogastroenterol Motil.* 2019;31(12):e13723.
5.Wenzl TG, Moroder C, Trachterna M, Thomson M, Silny J. Esophageal pH monitoring and impedance measurement: assessment of reflux in infants and children. *Am J Gastroenterol.* 2002;97(6):1351–1357.

OC100

Gastro-intestinal Manifestations in DiGeorge Syndrome: A single centre experience

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To describe the spectrum, frequency, and clinical outcomes of GI manifestations in patients with genetically confirmed DiGeorge syndrome at a single tertiary care centre.

We retrospectively reviewed medical records of patients with confirmed DiGeorge syndrome followed at our centre from January 2010 to July 2025. Data collected included demographic details, genetic confirmation, GI symptoms, endoscopic/radiologic findings, motility study results (where performed), interventions, and outcomes.

Twenty patients (13 males, 7 females), all diagnosed within the first year of life, were included. Gastro-intestinal(GI) manifestations were observed in all patients (100%). Common presentations included gastroesophageal reflux disease (GORD) in 16 (80%), feeding difficulties in 13 (65%), and chronic constipation in 9 (45%). Structural anomalies were identified in 3 patients: oesophageal atresia in 2 (10%) and anorectal malformation in 1 (5%), all of whom underwent corrective surgery.

Nutritional compromise was documented in 15 patients (75%), often compounded by endocrine-related growth failure. Feeding team input played a key role in initiating and optimising nutritional support. All patients received multidisciplinary care involving gastroenterology, cardiology, immunology, and nutrition services.

Symptom resolution was achieved in only 7 patients (35%), while others had persistent but improved symptoms. Two patients underwent thymic transplantation.

GI manifestations are highly prevalent in children with DiGeorge syndrome and encompass both functional and structural disorders. Nutritional challenges are common, and targeted feeding support can significantly improve growth and quality of life. Early recognition and multidisciplinary management are essential to reduce morbidity and enhance long-term outcomes.

OC101

The Riddle of Normal Results (NR) in Children with Functional Chronic Constipation.

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Background: Children with troublesome chronic constipation +/- faecal incontinence (FCC) are investigated with a hierarchy of tests and screening questionnaires (bowel and quality of life scores – QoL).

Aim: to study patients with FCC who are referred to the service whose tests (Transit marker study – TMS; High Resolution Anorectal Manometry –HRAM) are normal.

Methods: A prospective maintained database was reviewed for patients in the service between September 2016 to October 2025. Standard evaluation includes: demographics, HRAM parameters (sphincter function, rectal sensation, recto-inhibitory reflex, endurance squeeze, dyssynergic defaecation) and questionnaires: St Marks Incontinence Scores (SMIC), Cleveland Constipation Scores (CCS), Paediatric Emotional Distress (PI-ED) and Paediatric QoL Inventory (PedsQoL). SPSS was used to perform statistical analysis: median, range, percentages, and Pearson correlation (p value of <0.05 as significant).

Results: In total 315 patients underwent awake HRAM and completed questionnaires. Patients with normal results (NR) [normal HRAM and TMS] = 13% (40/315). The demographics of the NR group: 63% males, age median of 10 – year old (range: 1-16) and 30% neurodiversity. Results for questionnaires: St Marks Incontinence Scores (SMIC), Cleveland Constipation Scores (CCS), Paediatric Emotional Distress (PI-ED) were classified as normal or abnormal.

Table 1: Outcome HRAM and TMS results versus PI-ED scores; **normal HRAM and TMS in bold**

	Normal HRAM Normal TMS	**Normal HRAM Abnormal TMS**	**Normal TMS Abnormal HRAM**	**Abnormal HRAM Abnormal TMS**	**TOTAL**
Normal PI-ED	32	1	94	84	211
Abnormal PI-ED	8	15	32	49	104
TOTAL	40	16	126	133	315

Conclusion

1. Normal HRAM and TMS provide objective reassurance for clinician, parents and patient.
2. Normal HRAM and TMS create a potential diagnostic void, which requires further evaluation. The bio-psycho-social model describes the contributions of three dimensions in ill health.
3. Objectively normal investigations are a potentially useful tool in advancing understanding, education and relationship between clinician, parent and patient.

OC102

Parent and Patient Reported Symptoms (Cleveland Constipation Score) Predict an Abnormal Transit Marker Study.

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Background: Constipation is a frequent cause of paediatric gastroenterology outpatient attendance (1,2). Subjective evidence using bowel scores such as the Cleveland Constipation Score (CCS) provides insight from the patient and parent about the degree of constipation. Transit maker studies (TMS) are often undertaken because they are useful, non-invasive and informative diagnostic tool in children with functional constipation (FC) (2-4).

Aim: We aim to compare subjective reporting using bowel questionnaire (CCS) with objective findings (using TMS).

Methods: A prospective maintained database was reviewed for patients in the service between September 2016- October 2025. Data regarding demographics, questionnaire (CCS) and TMS. SPSS was used to perform statistical analysis: median, range, percentages, and Pearson correlation (p value of <0.05 as significant).

Results: 440 patients completed the CCS questionnaire and underwent TMS. 56% males; median age 9-year-old (range 1- 27 years); 30% with neurodiversity. There were no significant differences between those with normal and abnormal TMS scores for demographics (sex, age), neurodiversity and bladder continence. Patients with abnormal TMS had worse CCS scores ($p<0.001$) (Table 1); specifically, they had infrequent bowel movements, difficulty when passing a bowel movement, incomplete and unsuccessful evacuation ($p<0.05$).

Table 1: Comparison of subjective score - Cleveland Constipation Score (CCS) and objective study - transit marker study (TMS)

MEASURES	**Normal TMS = 196** **M, ± *(range)***	**Abnormal TMS n = 244** **M, ± *(range)*** 29% STC; 71% RED	**Significance (p value)**
Sex	53% males	58%	NS
Age	M: 9 ± 3.83 *(1-18)*	M: 10 ± 3.57 *(1-18*)	NS
Duration of Symptoms (months)	M: 93 ± 50.11 *(6-264)*	M: 94 ± 48.40 *(4-3240)*	NS
Neurodiversity	28%	31%	NS
Urinary Incontinence **Double Incontinence**	43% 38%	39% 40%	NS
Cleveland Constipation Score CCS (Median +/- SD)	M: 14.91 ± 4.89 (1-30)	M: 17.12 ± 4.88 (7-29)	**p<0.001**

Key: M = Mean, ± Standard deviation, NS (not significant)

Conclusion

1. Subjective scores - Cleveland Constipation Score (CCS) correlate with objective transit maker studies (TMS).
2. The combination of TMS and CCS maybe useful if there is diagnostic uncertainty or concerns regarding parental reporting.
3. It remains to be seen to what extent the CCS can used as a radiation-free tool in the management of children with constipation.

References

1. Rybak A, Martinelli M, Thapar N et al. Colonic Function Investigations in Children: Review by the ESPGHAN Motility Working Group. JPGN, 74: (5), 681-692, 2022.
2. Papadopoulos M, Mutalib M, Nikaki N et al. Radiopaque marker colonic transit study in the pediatric population: BSPGHAN Motility Working Group consensus statement. NGM, 36: (5), 1-11, 2024.
3. Metcalf AM, Phillips SF, Zinsmeister AR, et al. Simplified assessment of segmental colonic transit. Gastroenterology, 92:40–7. 10, 1987.
4. Cook BJ, Lim E, Cook D, et al. Radionuclear transit to assess sites of delay in large bowel transit in children with chronic idiopathic constipation. J Pediatr Surg, 40:478–83, 2005.

OC103

Establishing a Gastroenterology Commercial Research Portfolio Specialising in Paediatric Inflammatory Bowel Disease, at a UK Specialist Paediatric NHS Foundation Trust.

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Backgrounds:
The incidence of paediatric inflammatory bowel disease (pIBD) is rising. There is an unmet need to understand disease causation and match disease phenotypes to efficacious drugs. Unfortunately, new drug trials in pIBD have lagged adults, as a consequence of which only two biologics are licensed for pIBD in a majority of countries. Some of the new generation biologics and oral small molecules are only available off-label on a case-by-case basis.
Sheffield Children's NHS Foundation Trust (SCH) has developed a growing portfolio of clinical research trials in commercial Clinical Trial Investigational Medicinal Product (CTIMP) trials in 2024. More than seven studies have opened or are in the later stages of set-up, leading the UK's paediatric gastroenterology IBD-specific research portfolio. Trials range from oral to intravenous medications for both Crohn's Disease and Ulcerative Colitis, sponsored by a range of pharmaceutical companies. SCH has accumulated many first patient recruitments in both the UK and Europe, whilst also maintaining its status as the lead paediatric IBD centre in the North of England.
Aims: Our aim is to perform a stakeholder analysis, involving the trust, research team, pharmaceutical company, patient and families, to understand the interplay of various factors, roadblocks and putative solutions in establishing an IBD research portfolio within SCH.
Methodology: A qualitative study design was utilised, whereby the study team members, principal investigator, and patients/families discussed the barriers and obstacles to initiation and management of an extensive portfolio of commercial IBD clinical trials within a specialist paediatric NHS trust.
Results and Conclusions:

Stakeholder	Obstacles	Solutions
Research team and Principal investigator	• Lack of prioritised research time for PI. • Overstretched clinical service requirements.	• Develop research mentors within trusts and integrated care boards (ICBs). • Contractual re-negotiations for protected research time.
NHS trust	• Prolonged waiting times for newly diagnosed and follow up patients. • Authorities not licensing new drugs in children, limiting options to 2 IBD treatments.	• Develop integrated clinical pathways to ensure research capacity allows for prompt diagnosis and follow up of trial participants.
Pharmaceutical company	• Research protocols not tailored to regional needs. • High volumes of blood required for central tests, based on adult volumes	• Greater collaboration needed with NHS Trusts allowing for protocol allowances in keeping with local needs. • Central laboratories to invest in child-specific blood processing equipment.
Patients and families	• Longer and more intense assessments required as part of trial vs standard of care. • Screen failures attributed to steroids obscuring symptoms in patients with severe disease who appear clinically improved.	• Highlight benefits of being part of research. Good communication with family from Informed consent to end of trial participation. • Reduce dependency on repeated endoscopic assessments. Utilise validated proxy markers, i.e. PUCAI, MINI index etc.

Future implications: It is hoped that other paediatric and adult services in the NHS, as well as healthcare services more globally, can exchange knowledge and experiences to improve the management of similar portfolios of complex commercial trials, to further enhance treatment and outcomes for children with this debilitating condition.

References
N/A

OC104

Multi-centre review of transitional care in young adults with paediatric-onset inflammatory bowel disease

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Inflammatory Bowel Disease (IBD) presenting in childhood and adolescence is often more aggressive and extensive, posing unique challenges on nutrition, development, and growth. Emerging evidence shows that one of the major determinants of disease burden and long-term outcomes in paediatric-onset IBD, is the necessity of nutritional surveillance. MDT-based structured transition programs should be integral to management of IBD in children, incorporating systematic evaluation of anthropometric and nutritional status.

The aim of this study is to assess the anthropometric profile and nutritional well-being of young adults with IBD. We assessed disease demographics, disease-specific parameters, prevalence of malnutrition (over-weight and under-weight), and micronutrient deficiencies.

A retrospective observational study conducted in 2 paediatric IBD centres in the UK and Northern Ireland. Descriptive data on cohort of IBD (CD, UC, IBD-U), anthropometry, and nutritional parameters was captured. Disease activity was determined by CRP, fecal calprotectin, and clinician's assessment. Anthropometric data (BMI, height, weight, and BMI percentiles) and biochemical nutritional markers (haemoglobin, ferritin, albumin, folate, vitamin D, and B12) were assessed. We used RCPCH definitions as UK data and based on derivation of Z scores using LMS growth data. All biochemical parameters and nutrient deficiencies were categorised according to national UKAS standards.

102 patients (59 males and 43 females), median age 17 (range 16-23), were recruited across the 2 centres. There were 29 (28.4%) CD, 57 (55.9%) UC, and 8 (7.8%) IBD-U. 17 (16.7%) patients had active disease, with 81 (79.4%) patients with inactive (quiescent) disease, which was determined at the last documented clinical assessment. 22 (21.6%) of patients were overweight or obese, and 9 (8.8%) were underweight, with the majority (63 (61.8%)) having normal BMIs (18.5-24.9).

Only 29/102 patients had up-to-date documentation of all nutritional parameters assessed. Micronutrient data was available for 75/102 for folate, 84/102 for ferritin, 58/102 for vitamin D, and 75/102 for vitamin B12. 19.6% had anaemia (Hb<120/130 g/L), 32.3% low/borderline ferritin, 32.4% folate insufficiency (< 4.4 µg/L), 28.4% vitamin D deficiency, 13.8% low B12, and 1% hypoalbuminemia. Among 61.8% with normal BMI, 86.8% of patients had at least one micronutrient deficiency.

Our findings confirm high prevalence of malnutrition (over- and underweight) and micronutrient deficiencies in young adults. The limits of weight-based assessments reconfirm that BMI alone does not capture nutritional compromise. Transition protocols should include IBD-specific screening methods (including biochemical surveillance for vitamin D, folate, and B12). This vulnerable cohort needs multidisciplinary programs that integrate self-management education and appropriate dietetic support to improve long-term outcomes. Our study further highlights the need for a national standardised consensus for consistent holistic practise.

OC105

Long-term follow up of real world data of children with inflammatory bowel disease (IBD) treated with Vedolizumab and Ustekinumab

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Vedolizumab and Ustekinumab were first approved by our trust for treatment of patients with Ulcerative Colitis (UC), Crohn's Disease (CD) and IBD-U in 2018, before blueteq approval. Our aim was to assess the longer-term efficacy and safety of these drugs in children.

This was an observational single centre cohort study. Data was collected from the electronic patient record platform Cerner millennium and analysed using excel.

	Vedolizumab	Ustekinumab
n	14	17
Median age at diagnosis(years)	8.1 (1-14)	9.8 (5-14)
Diagnosis n	UC: 10 IBD-U: 2 CD: 2	UC: 2 IBD-U: 1 CD: 14
Disease location (Paris classification) n	L3: 1 E2: 1 E4: 12	L1: 1 L2: 2 L3: 9 E4: 2
Disease duration prior to starting VDZ/UST (median)	41 months (12-146)	36 months (5-66)
Duration of anti-TNF prior to starting VDZ/UST (median)	15 months (5-54)	23 months (3-65)
Adverse events	0	1 Psoriasis 1 Acne

27 patients were studied in total. 23 patients were treated with Vedolizumab or Ustekinumab and 4 patients were treated with both. All patients had previously failed treatment with one or more anti TNFa medications and one had also failed treatment with a JAK2 inhibitor. All patients had an endoscopy prior to starting treatment.

Clinical remission was defined as PUCAI/PCDAI <= 10. This was achieved in 78.6% of Vedolizumab patients at 12 weeks and 56.3% of Ustekinumab patients at 8 weeks. For those that remained on treatment with Vedolizumab 100% were in remission from week 52 to 208. For those who remained on treatment with Ustekinumab 87.5% were in remission at week 52 and 100% from week 104 to 208.

Of the 14 patients that were treated with Vedolizumab, 4 (29%) experienced treatment failure. Of these two were due to primary non-response, one was due to secondary loss of response and one was due to poor control of psoriasis secondary to previous treatment with infliximab. These four patients were switched to Ustekinumab. The average amount of time these patients took Vedolizumab before treatment failure was 10.8 months.

Of the 17 patients that were treated with Ustekinumab, 10 (58.8%) experienced treatment failure. 5 of these (50%) primary and 5 (50%) secondary loss of response. Of these 10 patients 7 were switched to Upacitinib and 3 to Risankizumab.

Prior to treatment with Vedolizumab, patients had required on average 2.3 courses of steroids and during treatment no patients required steroids. No patients in the Vedolizumab treatment group had adrenal insufficiency.

Prior to treatment with Ustekinumab patients had required on average 1.1 courses of steroids and during treatment 4 patients required treatment with a course of steroids. One patient in the Ustekinumab group had adrenal insufficiency.

No patients taking Vedolizumab or Ustekinumab required surgery.

In children with IBD that have lost response to anti TNF treatment, both Vedolizumab and Ustekinumab are effective and safe, with remission rates higher than published data (1)(2). During treatment no patients required colectomy or long-term steroids.

References

1. Cohen S, Rolandsdotter H, Kolho KL, Turner D, Tzivinikos C, Bramuzzo M, et al. Effectiveness and Safety of Ustekinumab in Pediatric Ulcerative Colitis: A Multi-center Retrospective Study from the Pediatric IBD Porto Group of ESPGHAN. Pediatric Drugs [Internet]. 2024 May 23;26(5):609–17. Available from: https://doi.org/10.1007/s40272-024-00631-z
2. Singh N, Rabizadeh S, Jossen J, Pittman N, Check M, Hashemi G, et al. Multi-Center experience of vedolizumab effectiveness in pediatric inflammatory bowel disease. Inflammatory Bowel Diseases [Internet]. 2016 Aug 19;22(9):2121–6. Available from: https://doi.org/10.1097/mib.0000000000000865

OC106

Niemann Pick Type C associated inflammatory bowel disease: a paediatric case series from a single centre.

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Niemann-Pick C (NPC) is a neurovisceral lysosomal disorder resulting from autosomal recessive inheritance of pathogenic variants in *NPC1* or *NPC2*. The clinical association of NPC and inflammatory bowel disease (IBD) has been recognised over the last twenty years but remains poorly understood. While IBD clinically expressed as Crohn's disease (CD) is the predominant form and hypothesis of impaired autophagy and immune dysregulation as the underlying mechanism, identification and management of these patients remains unclear. We present a case series of five paediatric patients from a single UK metabolic centre who had IBD associated with NPC.

We conducted a retrospective review of patients from a single metabolic centre with a dual diagnosis of IBD and NPC. We reviewed biochemical, radiological and endoscopic results. We reviewed the clinical course of this cohort, both from a neurological and gastrointestinal perspective.

We identified five patients with NPC and IBD. All 5 patients were female, with mean age at diagnosis of IBD 6.2 (range 2-11y). NPC diagnosis preceded IBD in four patients by a mean of 4.6y (range 2-6y) at a mean age of 2.8y (4m-7y). All had typical NPC presentation with splenomegaly +/- hepatomegaly +/- jaundice. Neurological features emerged in this cohort over the same time period, recognised 2-7yrs following NPC diagnosis.

Presentation of IBD consisted of loose bowel motions, significant fistulating disease and large peri-anal skin tags. Four patients were receiving miglustat prior to diagnosis of IBD. Three patients were categorised as CD, and two as Very Early Onset (VEO-IBD) following endoscopic and histological assessment. All patients were diagnosed with severe fistulating disease. 4/5 patients had significantly large anal skin tags and 3/5 patients demonstrated labial / vulval disease. 4/5 patients were initiated on anti-aTNF therapy, but all patients required change of class / biologic. Three patients required colectomy. Two patients died at ages 2 and 17y.

This cohort of patients represent a specific phenotype of IBD at presentation: significant anal skin tag, severe rectosigmoid disease with fistulating disease and high number with vulval involvement. All patients were female, which may significant. The clinical course is severe and challenging, demonstrated by severe disease at presentation, biologic class switch and a high number of colectomy. In addition, the neurological decline in patients with NPC can add to difficult interpretation of clinical progression. The GI side-effects of miglustat can be confused with presentation of IBD.

Due to the rarity of NPC and the even lower incidence of IBD, the number of affected patients is small. However, when both conditions occur together, the disease presentation and progression tend to be particularly severe. This suggests that NPC may contribute to a distinct pathophysiological mechanism involving autophagy dysregulation and mucosal immune dysfunction.

As active inflammation can accelerate neurodegeneration in NPC, we recommend routine screening for IBD in NPC patients with GI signs or symptoms. Multidisciplinary management involving gastroenterologists, neurologists, and geneticists is crucial to optimise care. Further research is needed to clarify the mechanistic links between NPC, autophagy impairment, and intestinal inflammation, which may reveal novel therapeutic targets for these complex cases.

References

Schwerd T et al. Impaired antibacterial autophagy links granulomatous intestinal inflammation in Niemann–Pick disease type C1 and XIAP deficiency with NOD2 variants in Crohn's disease. Gut.2017;66:1060-1073.

Williams I, Pandey S, Haller W et al. Anti-TNF therapy for inflammatory bowel disease in patients with neurodegenerative Niemann-Pick disease Type C. Wellcome Open Res 2022;7:11.

OC107

Safety of accelerated infliximab infusions in children with inflammatory bowel disease: a retrospective cohort study

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Infliximab (IFX) is a widely used biologic agent in the management of paediatric inflammatory bowel disease (IBD) [1,2]. Standard infusion regimens typically require two to three hours per dose [3]. Evidence showed that accelerated IFX infusions administered over one hour are safe in adults with IBD and associated with an improved patient experience and more efficient use of healthcare resources [4-5]. Despite these advantages, supporting data in the paediatric population remains limited [6-10]. In the United Kingdom (UK), no studies have yet examined this approach.

Given the growing use of IFX in IBD, this study aimed to evaluate the safety of accelerated IFX infusions in children with IBD by analysing the frequency and nature of both acute and delayed infusion reactions (IR). The primary outcomes were to determine the incidence and type of IR during the maintenance phase, while the secondary aim was to generate local evidence to inform the safe and effective implementation of rapid IFX infusions in paediatric practice.

Following ethical approval from the local Research Governance and Ethics Committee, a retrospective cohort study was conducted at a tertiary paediatric centre in the South of England. In this hospital, patients who safely completed the induction phase at a standard rate were transitioned to the accelerated infusion protocol. All paediatric patients aged 2 to 18 years treated with IFX therapy, between August 2014 and August 2024, were considered eligible for this study. Data were extracted from medical records, including demographic characteristics, IBD subtype, number of accelerated infusions, use of pre-medication, concomitant immunomodulator therapy, and any documented IR. Descriptive and inferential statistical analyses were performed using IBM SPSS Statistics version 29, with statistical significance defined as $p < 0.05$.

Initially, 65 children were identified; four were excluded due to incomplete medical records. All 61 included patients progressed to receive accelerated IFX infusions after completion of the induction phase. The majority of patients (n=48) had Crohn's disease, 12 had ulcerative colitis, and 3 had IBD-unclassified. A total of 1,180 IFX infusions were administered at both the induction and maintenance phases. Of these, 977 were given at the accelerated rate.

No IR were reported during both the induction and maintenance phases. None of the patients required pre-medication, and the majority (n = 58, 95%) were on concomitant immunomodulator therapy, most commonly azathioprine. The main findings are summarised in Table 1.

Although limited by its retrospective, single-centre design, this study provides the first UK-based evidence supporting the safety of accelerated IFX infusions in children with IBD. The results align with existing international data and suggest that implementing shortened infusion protocols may improve patient experience and optimise service efficiency (6-10). Larger multicentre studies are recommended to confirm these findings and to evaluate potential differences in IR rates across demographic, clinical, and treatment-related subgroups.

Table 1. Main findings from the service evaluation of accelerated IFX infusions in paediatric IBD
This table presents the key results of the service evaluation assessing the safety of one-hour IFX infusions in children with IBD.

Variable	Category	N (%) or Range (Median)	Units / Notes
Gender	Female	22 (36)	
	Male	39 (64)	
IBD Phenotype	Crohn disease	48 (75)	
	Ulcerative colitis	12 (20)	
	Unclassified IBD	3 (5)	
Age at diagnosis, years		2-17 (11)	Range, (Median)
IFX infusions	Total Infusions	1180 (100)	Includes induction and maintenance phase
IFX protocol	Standard rate	183 (15)	induction phase
	Rapid rate	997 (85)	maintenance phase
IFX dose at induction	5 mg/kg	52(85)	
	10 mg/kg	9 (15)	
Infusion reactions	Induction phase	0 (0)	
	Maintenance phase	0 (0)	
Immunomodulator therapy	Azathioprine	51 (84)	
	Methotrexate	5 (8)	
	Mercaptopurine	2 (3)	
	None	3 (5)	

OC107 – Continued

References
1. Ng SC, Shi HY, Hamidi N. Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies. Lancet Gastroenterol Hepatol. 2017;390(10114):2769-78.
2. Kuenzig ME, Fung SG, Marderfeld L. Twenty-first century trends in the global epidemiology of pediatric-onset inflammatory bowel disease: systematic review. Gastroenterology. 2022;162(4):1147-59.
3. European Medicines Agency. Remicade: EPAR – Product information Internet].Availablefrom: https://www.ema.europa.eu/en/medicines/human/EPAR/remicade.
4. Neef HC, Riebschleger MP, Adler J. Meta-analysis: rapid infliximab infusions are safe. Aliment Pharmacol Ther. 2013;38(4):365-76.
5. Clare DF, Alexander FC, Mike S. Accelerated infliximab infusions are safe and well tolerated in patients with inflammatory bowel disease. Eur J Gastroenterol Hepatol. 2009;21(1):71-5.
6. Jagt JZ, Galestin SE, Claesen J. Safety of accelerated infliximab infusions in children with inflammatory bowel disease: a retrospective cohort study. J Pediatr Gastroenterol Nutr. 2023;77(3):373-80.
7. El-Matary W, Dykes DMH, Bauman L. Rapid infliximab infusion in children with inflammatory bowel disease: a multicenter North American experience. Inflamm Bowel Dis. 2017;23(12):2104-8.
8. Van Wassenaer EA, van Oosterhout JPM, Daams JG. Safety of Rapid Infliximab Infusions in Children: A Systematic Review. J Pediatr Gastroenterol Nutr. 2020 Sep;71(3):361-365.
9. Lev-Tzion R, Assa A, Yerushalmi B. Rapid infliximab infusion in children: a multicenter retrospective cohort study. *J Pediatr Gastroenterol Nutr.* 2017;65(5):e101-3.
10. Hutsell SQ, Wu M, Park KT. Frequency of severe infusion reactions associated with outpatient infusion of infliximab without premedications. *J Pediatr Gastroenterol Nutr.* 2017;65(4):430-1.

OC108

Tuberculosis in children with inflammatory bowel disease on anti tumor necrosis factor therapy: "Diagnostic Lessons from two cases"

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Tuberculosis (TB) is a recognised complication in adult patients with inflammatory bowel disease (IBD) receiving biologic treatment.[1] In contrast, paediatric cases are less commonly reported.[2,3] Despite this, children undergoing immunosuppressive treatment are at increased risk for severe and atypical presentations of TB.[4] Therefore, maintaining a high index of suspicion and ensuring early diagnostic evaluation is critical. We describe two paediatric patients with Crohn's disease who developed TB during biologic therapy.

The first case involves a 19-year-old female initially diagnosed with Budd Chiari syndrome and IBD unclassified (IBD-U) at age 5, later confirmed as Crohn's disease. She was treated with azathioprine and infliximab but later switched to adalimumab due to antibody formation. She had BCG vaccination as a baby and her pre-biologic QuantiFERON was negative. While visiting India at age 12, she developed fever, abdominal pain, and weight loss. Imaging revealed bilateral pulmonary nodules and sputum for acid fast bacilli was positive. She completed a 6-month treatment for pulmonary tuberculosis (3 months of intensive therapy with rifampicin, ethambutol, pyrazinamide and pyridoxine and 3 months of maintenance therapy with rifampicin and pyridoxine) and she made a full recovery. Her biologics were re-started after completing anti TB treatment. She later required change of biologics to Vedolizumab due to ongoing active inflammation of the colon. She has subsequently transitioned to adult services at age 17 on vedolizumab.

The second is an 11-year-old boy diagnosed with Crohn's disease at age 10. Initially treated with infliximab, he was switched to adalimumab due to allergic reaction. He did not receive BCG at birth (not recommended) however, his pre-infliximab QuantiFERON was negative. A year after diagnosis, after a trip to Poland, he presented with prolonged fever without classical tuberculosis symptoms. His biologic treatment was stopped. Initial investigations were inconclusive (normal chest X-ray and slightly raised inflammatory markers). Whole-body MRI and subsequent chest-CT revealed pulmonary consolidation. Despite broad-spectrum antibiotics and antifungals, fever persisted. His repeat QuantiFERON was indeterminate. He later developed anaemia, thrombocytopenia, and markedly elevated ferritin, suggestive of an immune-mediated response. Gastric washing for acid fast bacilli was positive, and his culture yielded rifampicin-sensitive mycobacterium tuberculosis. At this time, he had developed features of miliary TB on his chest X-ray. He was treated with intravenous steroids and intravenous anti-TB therapy (rifampicin, isoniazid, linezolid and levofloxacin) due to clinical severity. These were later switched to rifampicin, ethambutol, levofloxacin, pyrazinamide and pyridoxine, on account of persistent thrombocytopenia. He continued to make significant improvement and was discharged home on oral medications.

The risk of tuberculosis remains a serious clinical consideration in children with IBD on biologic treatment. To mitigate this risk, it is essential that all patients undergo appropriate TB screening prior to initiating biologic treatment, in line with the ESPGHAN guidelines. A high index of suspicion following travel to countries with elevated TB prevalence is essential, and appropriate precautions should be undertaken by families during such travels. The clinical presentation may be atypical and subtle and even an isolated fever should prompt consideration of TB in this vulnerable population.

References

1. Azevedo F C, Barros L L, Justus F F, et al. Active tuberculosis in inflammatory bowel disease patients: a case-control study. Therap Adv Gastroenterol. 2023 Jul 4;16.
2. Cruz A T, Karam L B, Orth R C, et al. Disseminated Tuberculosis in 2 Children with Inflammatory Bowel Disease Receiving Infliximab. Pediatric Infectious Disease Journal 33(7):779-781.
3. Telefon A H, Cil M K, Sonmez G, et al. Balancing effective treatments with potential threats: The Impact of biologic agent Use on tuberculosis development in Children with chronic inflammatory disorders. Int J Rheum Dis. 2025 Feb;28(2): e70145.
4. Parigi S, Licari A, Manti S, et al. Tuberculosis and TNF alpha inhibitors in children: how to manage a fine balance. Acta Biomed. 2020 Sep 15;91(11-S):e2020009.

OC109

The “Cross-Trust” histopathology multidisciplinary team: report of meeting outputs and impact on paediatric IBD patient management in a UK tertiary referral centre

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Paediatric inflammatory bowel disease (IBD) is increasing globally, particularly among adolescents and young adults (1,3). Complex cases, especially those approaching adult transition, benefit from multidisciplinary input, yet the impact of structured cross-speciality histopathology review remains underexplored. This service evaluation assessed the outputs and clinical impact of a novel “Cross-Trust” Histopathology MDT, designed to refine diagnosis, guide therapy, and support transition in complex paediatric IBD patients at a UK tertiary referral centre.

A retrospective review was conducted of eight biannual MDT meetings held between January 2021 and March 2024. Participants included paediatric gastroenterologists, adult IBD physicians, and specialist gastrointestinal histopathologists. Patients were referred for discussion due to diagnostic uncertainty, therapeutic complexity, or imminent transition. Extracted data included demographics, pre- and post-MDT diagnosis, therapeutic recommendations, surgical considerations, transition-related outcomes, and documentation in electronic health records. Primary outcomes were diagnostic reclassification, therapeutic modification, and transition-related decisions.

Twenty-seven patients were reviewed (mean age 17.2 years, range 14–21; 59% male). The predominant reason for referral was diagnostic clarification. Following MDT review, 11 patients (41%) had their diagnosis revised: seven patients initially labelled as IBDU favouring UC were reclassified as UC, one as CD, and three were found not to have IBD (disuse colitis, eosinophilic colitis, amebiasis). Sixteen patients (59%) retained their initial diagnosis. Diagnostic refinement was driven by detailed histopathological assessment, including crypt architecture, basal plasmacytosis, granulomas, and eosinophilic infiltration. Therapeutic recommendations were modified in three patients (11%), with two commencing or escalating biologics (infliximab, vedolizumab) and one receiving a non-biologic adjustment. No surgical referrals were made. Transition planning was altered in one patient, with immunology referral delaying transfer. Only three MDT outputs (11%) were recorded in the electronic health record.

In conclusion, the Cross-Trust Histopathology MDT improved diagnostic accuracy in 41% of complex cases, influenced therapy in selected patients, and prevented inappropriate immunosuppression in three non-IBD cases. Although documentation was limited, this model demonstrates the value of structured, cross-speciality review in optimising paediatric IBD management. Wider adoption, alongside improved recording processes, could enhance care consistency and outcomes across centres.

References

1. Benchimol EI, Fortinsky KJ, Gozdyra P, et al. Epidemiology of pediatric inflammatory bowel disease: a systematic review of international trends. Inflamm Bowel Dis 2011; 17: 423-439.
2. Thurgate LE, Lemberg DA, Day AS, Leach ST. An overview of inflammatory bowel disease unclassified in children. Inflamm Intest Dis 2019; 4: 97-103.
3. Sýkora J, Sýkora J, Pomahačová R, Kreslová M, et al. Current global trends in the incidence of pediatric-onset inflammatory bowel disease. World J Gastroenterol 2018; 24: 2741-2763.

OC110

Perceptions of transitional care in adolescents with inflammatory bowel disease: a service evaluation using the Mind the Gap questionnaire

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Transition from paediatric to adult healthcare is a critical phase for adolescents with chronic conditions, including inflammatory bowel disease (IBD) (1,2). Adolescents with IBD face unique challenges, including continuity disruptions, loss of established provider relationships, and increased responsibility for self-management (3). The *Mind the Gap* questionnaire assesses perceived quality of transitional care by comparing expectations of "best care" with perceptions of "current care," highlighting areas for improvement (4). This service evaluation assessed perceptions of transitional care among adolescents with IBD and their parents, and identified domains for service enhancement.

A retrospective, cross-sectional service evaluation was conducted at Sheffield Children's Hospital. Adolescents aged 14–18 years with IBD who had not yet transferred to adult services, along with their parents or carers, were invited to complete the *Mind the Gap* questionnaire. The tool evaluates three domains: management of the environment, provider characteristics, and process of care. Gap scores range from −7 (most satisfied) to 7 (least satisfied). Descriptive statistics, Cronbach's alpha, Friedman tests, and Mann–Whitney U tests were applied.

Of 35 families invited, 25 adolescents (71.4%) and 35 parents (100%) completed the survey. Median adolescent age was 15.7 years (range 14–18), 68% male; parents were predominantly mothers (88%), median age 40.3 years. Adolescents reported moderate satisfaction, with no significant differences between the three domains ($\chi^2(2) = 3.318$, $p = 0.190$). Parents expressed greatest dissatisfaction with management of the environment (mean gap = 1.16, median = 1.0) and highest satisfaction with provider characteristics (mean = 0.41, median = 0.23; $\chi^2(2) = 11.139$, $p = 0.004$). No significant differences were observed between overall adolescent and parent gap scores. Internal consistency was high (total scale $\alpha = 0.883$ for adolescents; $\alpha = 0.922$ for parents).

This first application of the Mind the Gap questionnaire in adolescents with IBD preparing for transition shows moderate satisfaction among adolescents, while parents highlighted environmental aspects as key areas for improvement. The findings support targeted interventions to optimise transitional care and better prepare adolescents for adult services. Future work should explore whether addressing these gaps improves long-term adherence, clinical outcomes, and patient satisfaction.

References

1. Campbell F, Biggs K, Aldiss SK, et al. Cochrane Database Syst Rev 2016; 4: CD009794.
2. Seydel A. J Spec Pediatr Nurs 2023; 28: e12414.
3. Wong LH, Chan FW, Wong FY, et al. J Adolesc Health 2010; 47: 540-546.
4. Shaw KL, Southwood TR, McDonagh JE; British Society of Paediatric and Adolescent Rheumatology. Child Care Health Dev 2007; 33: 380-388.

OC111

A case report on Infliximab related pneumonitis and hepatotoxicity in a paediatric patient with inflammatory bowel disease

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Infliximab, a chimeric monoclonal antibody targeting tumour necrosis factor-alpha (TNF-α), is widely used in inflammatory bowel disease (IBD). While effective, it carries the risk of uncommon but serious adverse effects, including pulmonary and hepatic injury. We report a rare paediatric case of suspected infliximab-related pneumonitis with concurrent hepatotoxicity.

A teenager diagnosed with IBD-unclassified was started on infliximab two months after diagnosis on an accelerated induction regimen due to recurrent flare-ups. Azathioprine was paused for hepatotoxicity but later reintroduced at a low dose, then discontinued for intolerance, after which mercaptopurine was started. The liver function tests subsequently normalised.

Six months later, during a routine infliximab infusion visit, the patient developed acute respiratory distress with hypoxaemia. Chest radiography revealed bilateral diffuse opacification, and CT thorax showed symmetrical consolidation of the lower lobes without cavitation or effusion. Bronchoalveolar lavage cultures were negative, including for mycobacterium tuberculosis. Despite prolonged intravenous antibiotics and antifungals, hypoxia persisted, and infection was excluded. Pulmonary function testing revealed severe restriction, gradually improving with corticosteroid therapy.

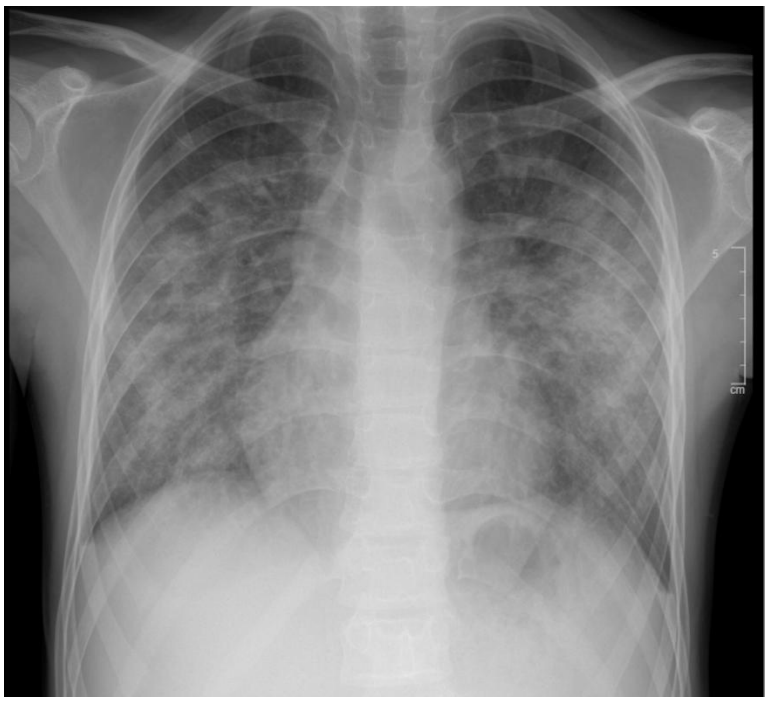
Given the lack of infectious aetiology, inflammatory or hypersensitivity pneumonitis secondary to infliximab was diagnosed. A lung biopsy was considered; however, the procedure was deferred as the patient was clinically unstable and required high-flow oxygen support.

The patient received three days of intravenous methylprednisolone followed by oral tapering prednisolone and prophylactic azithromycin. Infliximab was discontinued, and Vedolizumab initiated as a gut-selective alternative.

During admission, transaminase elevations and mild coagulopathy were noted. Abdominal ultrasound demonstrated a starry sky hepatic pattern. The tertiary hepatology team considered drug-induced liver injury but recommended a comprehensive workup to exclude other causes, including autoimmune, infectious, and metabolic aetiologies. All investigations were unremarkable, supporting a diagnosis of infliximab-related hepatotoxicity.

The mechanism of infliximab-associated hepatotoxicity is believed to involve autoimmune or immuno-allergic reactions rather than direct hepatocyte injury. According to LiverTox, Infliximab has been linked to several hepatic injury patterns—most commonly autoimmune-type hepatitis due to immune dysregulation and antibody formation, rather than intrinsic hepatotoxicity.[1] Similarly, pulmonary injury associated with TNF-α inhibitors is thought to result from drug-induced immune activation and hypersensitivity. This case highlights a rare but important dual complication of infliximab therapy in a paediatric patient—pneumonitis and hepatotoxicity—occurring in the absence of other identifiable causes. The temporal association, exclusion of infection, radiological findings, and favourable response to corticosteroids support the diagnosis.

Pulmonary complications of TNF-α inhibitors are uncommon but increasingly recognised. Recent pharmacovigilance data from the World Health Organization's VigiBase indicate that infliximab shows one of the strongest associations with drug-induced interstitial lung disease among biologic agents. [2] Moreover, detailed case reports document infliximab-induced pneumonitis and organising pneumonia in patients with IBD or other inflammatory conditions. [3, 4] In this patient, the clinical presentation, imaging features and rapid corticosteroid response are consistent with drug-induced pneumonitis rather than an infectious process. Early multidisciplinary intervention, prompt discontinuation of the offending agent, and the initiation of corticosteroid therapy were essential for recovery. Transitioning to a gut-selective biologic enabled continued IBD control while minimising risk of further systemic immune-mediated lung injury.



References

1. Infliximab. In: LiverTox: Clinical and Research Information on Drug-Induced Liver Injury [Internet]. Bethesda (MD): National Institute of Diabetes and Digestive and Kidney Diseases; 2012–. Available from: https://www.ncbi.nlm.nih.gov/books/NBK548203/
2. Minagi A, Nawa H, Goda M. Evaluation of interstitial lung disease complications caused by biologic agents using a spontaneous adverse drug reaction reporting database. Pharmacol Res Perspect 2025; 13: e70063.
3. Makkawy E A, Alanazi M T, Yehia M F. Infliximab-induced interstitial pneumonitis: a case report. Cureus 2023; 15: e40812.
4. Pham K, Wysham N. Infliximab-induced organising pneumonia resulting in persistent respiratory impairment. ACG Case Rep J 2025; 12: e01855.

LBA1

Retained Bravo pH Capsule in a Child: A Case Report

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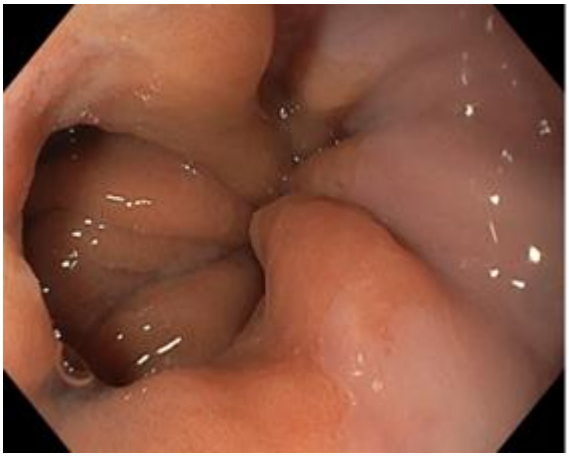
Background:
The Bravo wireless pH monitoring system is widely used and better tolerated to evaluate gastroesophageal reflux disease (GERD). This is particularly useful in older children and children with behavioural problems who are likely to pull out a conventional pH probe. No significant complications are reported, although short durations of chest pain can happen. Currently, no data exists on the risk of capsule retention in the pediatric population. We report a case of capsule retention in an 8-year-old child and successful retrieval after 140 days.
Case Presentation:
An 8-year-old boy with hypoxic–ischemic encephalopathy, four-limb cerebral palsy with dystonia, global developmental delay, refractory epilepsy, and gastrostomy feeding following redo fundoplication (for hiatus hernia) had a Bravo capsule inserted to assess ongoing reflux symptoms. 20 weeks later, an incidental chest X-ray revealed the capsule was retained in the lower chest. He did not have any new symptoms other than reflux-related. He was admitted electively for oesophagogastroduodenoscopy (OGD) and capsule retrieval. Endoscopy showed a normal oesophagus, an open gastroesophageal junction, and mild erythema in the gastric body. The capsule was not seen on initial examination, but on careful examination with fluoroscopy; it was identified within the hiatus. The capsule was successfully retrieved endoscopically under fluoroscopic guidance using a mobile image intensifier, without complication.
Discussion
The Bravo capsule typically detaches spontaneously within 5–7 days and is passed uneventfully. Often, older children report that they can feel when the capsule is dislodged, but this is not monitored. There is no need to retrieve the capsule once the study is completed. Some reported side effects are chest pain/dysphagia for a short period, but the risks of perforation or capsule retention are not reported.
Current practice suggests no indications to check if the capsule has dislodged or if the patient has passed the capsule. There are a few anecdotal case studies in the adult population of aspiration and retention, but these were noted following changes in hemodynamic status and compliant by the patient. However, there are no previous case reports in the paediatric population documented in the literature.
Given anatomical variations /motility issues, these may influence adherence, detachment, or migration of the capsule, complicating retrieval and interpretation of pH monitoring results. In patients with known behavioural or anatomical abnormalities, consideration should therefore be given to interval imaging, i.e. x-rays; to confirm capsule passage and prevent delayed recognition of retained or displaced devices.

Figure 1a) Top central – Bravo capsule – measuring 30mm in length; Figure 1b) Middle left – open gastro-oesophageal junction showing hiatus hernia; Figure 1c) Middle right – Bravo capsule attached to oesophageal mucosal lining;



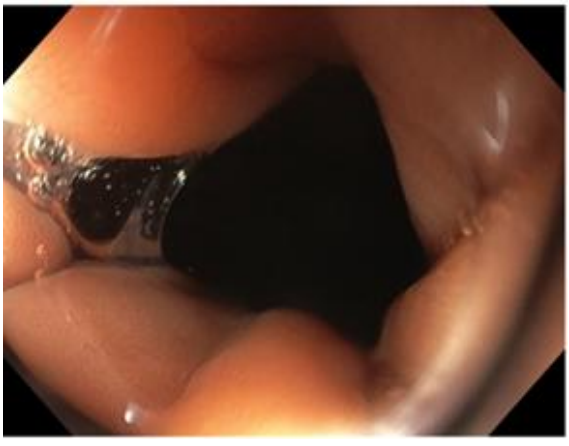


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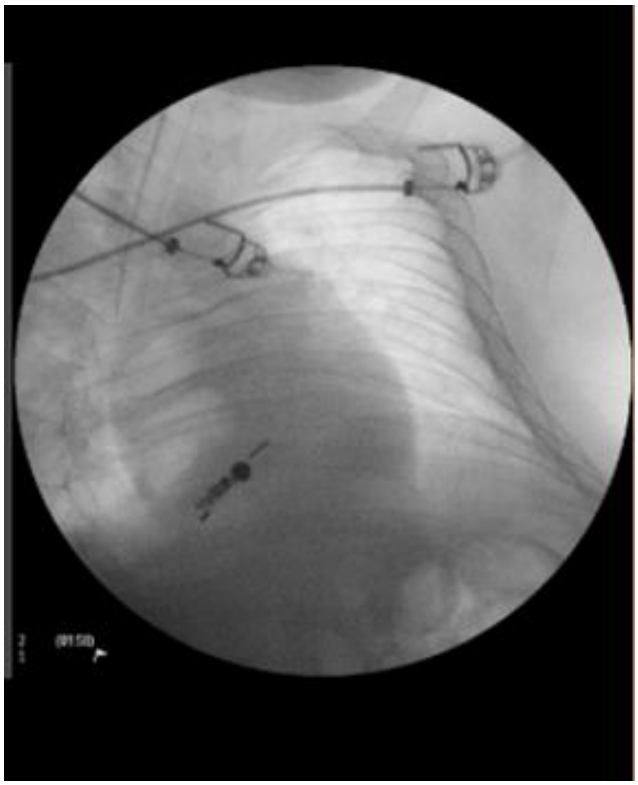
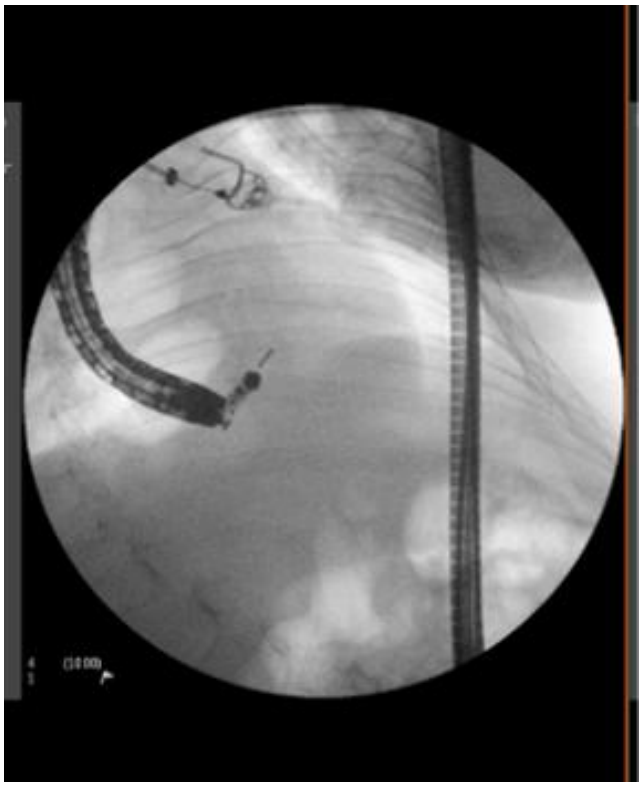
Figure 1d) Bottom left – Fluoroscopy imaging revealing retained Bravo capsule; Figure 1e) Bottom right – Retrieval of retained capsule under fluoroscopic guidance.





References

Sabreen Aulakh, Sharon Ashley, Kelly Haas, and Trinh Truong. Esophageal pH Capsule Retention. ACG Case Reports Journal.

Yasir Alshareefy, Ali Alshareefy. Oesophageal pH capsule retention: case report and proposed endoscopic management. Int J Surg Case Rep. 2023 Oct 3;111:108917. doi:10.1016/j.ijscr.2023.108917

Jose Cabrera, Miriam Davis, Debbie Horn et al. Esophageal pH Monitoring with the Bravo Capsule. Experience in a Single Tertiary Medical Center. JPGN Oct 2011; https://doi.org/10.1097/MPG.0b013e3182203caa

LBA2

Intestinal failure service provision – a national survey

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A multidisciplinary team (MDT) approach is a key factor associated with improved survival, higher parenteral nutrition (PN) weaning rates, and reduced complications in intestinal failure (IF). However, team organization varies widely among centres worldwide[1] and no studies have explored the impact of MDT structure/team composition and staff/patient ratios on patient outcomes.
The survey aimed to examine team structures across UK centres as an initial step toward developing a benchmark for the IF services.

Survey collecting UK data between September-October 2025, initially trough the National Paediatric PN Nurses and National Paediatric PN Dieticians channels; IF consultants were contacted at centres that did not respond or where discrepancies in responses were identified. The survey included number of home PN (HPN) patients/centre and team composition – number of consultants and whole time equivalent (WTE) for nurses, dieticians, pharmacists, psychologists and social workers.

Answers from 22/22 (100%) UK centres were collated. Another centre was excluded as recently closed the IF service due to lack of PN pharmacy support.
13 answers were received from the PN nurses' group and 10 from the dieticians (6 repeated) - 17/22 answers from allied health professionals and 5/22 from consultants.
459 patients were identified, median/centre 18 [IQR 12-26.5].
Consultant cover: one centre had allocated Programmed activities (PA's)/week for IF (8 hours/week for 15 HPN patients and inpatient work). Most centres had one to two consultants overseeing the IF service, without dedicated time allocated. 3 centres had the HPN patients divided between all consultants in the department (5-6), although one noted an intention to limit the number of consultants involved in HPN care. The number of consultants/patients ranged between 0.04 and 0.5.
Nurse provision: 100% services had allocated nurses for the IF service with substantial variability between centres, nurse WTE/10 patients ranging between 0.07 and 2; median 0.6 [IQR 0.4 – 1].
Dietician support: 21/22 centres (95.5%) had dietician support with wide variation - WTE dietician/10 patients ranging between 0.07 and 1.7; median 0.4 [IQR 0.3 – 0.6].
Pharmacy support: 21/22 centres (95.5%) had pharmacy support; WTE pharmacist/10 patients ranging between 0.1 to 1.7; median 0.4 [IQR 0.2 – 0.7].
Fifteen/22 (68%) centres had psychology support but not specific for IF. Four/22 (18%) had access to a gastroenterology social worker.
Two teams had an IF coordinator and one has access to a data manager.

Nutrition support team provision varies widely across UK centres. Only 27% (6/22) centres meet the recommended nurse staffing levels[2] and recommendations for other professional roles are lacking. One possible explanation is the lack of proportional growth in the workforce relative to patient numbers (18% increment since 2019)[3]. Future development should focus on collaboration with professional societies and commissioners to equalise resources across the country and promote equitable care.

References

1. Neelis E, de Koning B, van Winckel M, Tabbers M, Hill S, Hulst J. Wide variation in organisation and clinical practice of paediatric intestinal failure teams: an international survey. Clin Nutr. 2018 Dec;37(6 Pt A):2271-2279. doi: 10.1016/j.clnu.2017.11.008. Epub 2017 Nov 22. PMID: 29203343.
2. The paediatric gastroenterology, hepatology and nutrition UK national census 2021. PGHAN national quality standards audit. Published December 2021
3. Wiskin AE, Russell R, Barclay AR, Thomas J, Batra A; BANS committee of BAPEN. Prevalence of home parenteral nutrition in children. Clin Nutr ESPEN. 2021 Apr;42:138-141. doi: 10.1016/j.clnesp.2020.12.029. Epub 2021 Feb 11. PMID: 33745567.

LBA3

Is there a connection between having Coeliac Disease and developing Avoidant Restrictive Food Intake Disorder?

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Is there a connection between having Coeliac Disease and developing ARFID?

Coeliac Disease in an autoimmune disease with 1 in 100 members of the population being affected. [1]It is characterised by the immune system attacking the body's tissues when gluten is ingested. 1This causes a range of symptoms including those affecting the gastrointestinal tract, tiredness, skin rash, subfertility, and neurological problems. 1Having Coeliac Disease myself, I have noted that adapting to a lifelong gluten free diet causes restrictions to eating habits, leading me to query if this could contribute to the development of an eating disorder, particularly Avoidance Restrictive Food Intake Disorder (ARFID). ARFID involves restricting the amount of food eaten or avoiding certain foods. [2]To conduct my research, I used a range of secondary data, such as journals, studies, and the Coeliac UK charity.

A study conducted on 137 Coeliac patients found that 57% had a suspected ARFID, shown by a survey measuring food and social burden on impact of a gluten free diet. [3]The survey showed the main reason for restrictive eating was fear of gastrointestinal (GI) discomfort including IBS with 48% reporting this. 3As a main symptom of Coeliac Disease is GI discomfort this suggests that the fear of this causes patients to abnormally change eating habits, which can be characterised at ARFID. It is also important to consider the social factors Coeliac's face which can cause restricted eating. A Quality of life (QOL) survey carried out on 538 Coeliac's found that the social domain of life is negatively impacted, in particular dining out, with 81% of individuals noting they no longer do this. [4]

These results suggest that the gluten free diet can cause an ARFID, and as a result further support needs to be offered to patients, particularly at the beginning of their diagnosis. By pursuing strict dietary control Coeliac's are at risk of developing unhealthy habits, such as avoiding eating outside the home, or eating less to avoid associated symptoms. Therefore, gastroenterologists should consider offering psychological support to Coeliac's in their annual appointments, and consider not only physical health, but mental health also.

References

[1] National Health Service. Coeliac Disease. [Internet]. 2023 [cited 2023 Nov 1]; [1]. Available from: https://www.nhs.uk/conditions/coeliac-disease/

[2]Beat Eating Disorders. ARFID. [Internet]. 2019 [cited 2023 Nov 6]; [1]. Available from: https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/types/arfid/

[3]Bennett A, Bery A, Espsito P. Avoidant/Restrictive Food Intake Disorder Characteristics and Prevalence in Adult Celiac Disease Patients. Gastro Help Advances [Internet.] 2022 [cited 2023 Nov 6]; 1(3): 321-327. Available from: https://www.sciencedirect.com/science/article/pii/S2772572322000036

[4]Lee AR, Lebwohl B, Lebovits J. Factors associated with maladaptive eating behaviours, social anxiety, and quality of life in adults with celiac disease. Nutrients. [Internet]. 2021 [cited 2023 Nov 6]; 13(12): 4494. Available from: https://www.mdpi.com/2072-6643/13/12/4494#B22-nutrients-13-04494

LBA4

Aprepitant as a Novel Prokinetic in Paediatric Gastrointestinal Dystonia and Presumed Intestinal Failure: Three Case Reports

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Gastrointestinal dystonia (GID) is a rare but a challenging motility disorder in children with neurodisabilities, frequently resulting in profound feeding intolerance and, in some cases, presumed intestinal failure (IF). Conventional prokinetic therapies don't always provide full resolution of symptoms. Emerging evidence suggests that Neurokinin-1 (NK1) receptor antagonists, such as aprepitant, may exert prokinetic effects, but clinical data, particularly in paediatric IF, remain limited. This late-breaking abstract presents three paediatric cases in which aprepitant facilitated successful restoration of enteral feeding after failure of standard therapies.

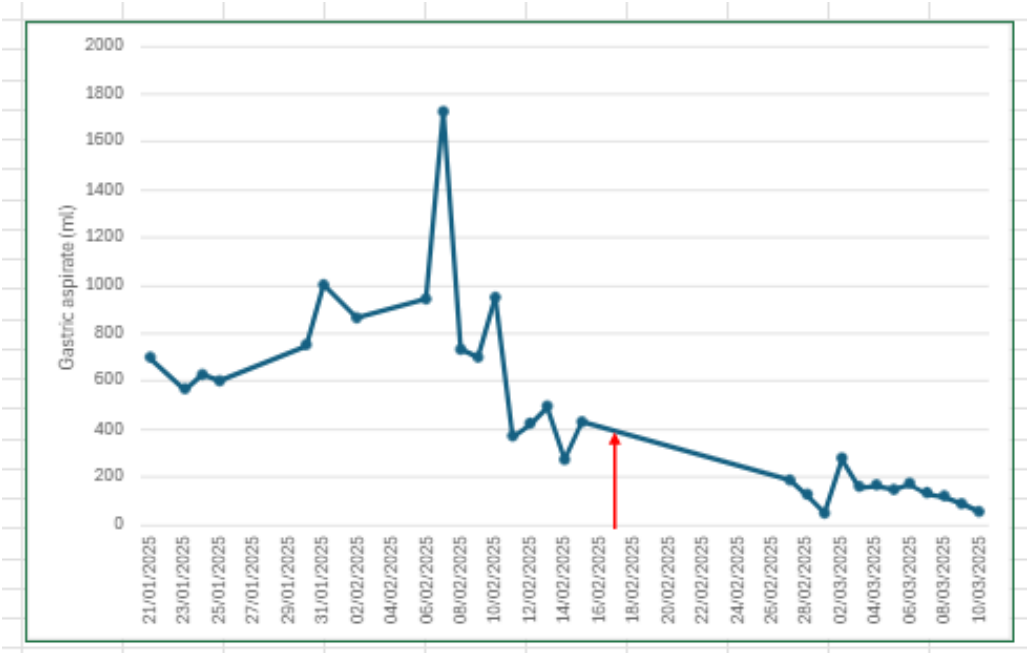
We retrospectively reviewed three children (aged 8, 12, and 16 years) with GID and severe feed intolerance or presumed IF. Clinical notes were examined to assess gastric output, feed tolerance, prokinetic regimens, and parenteral nutrition (PN) dependence before and after aprepitant introduction.

Case A: An 8-year-old with neurodysability due to Cerebral palsy presented with severe *Clostridium difficile* enterocolitis. The patient developed high gastric output and inability to tolerate enteric feed despite infection resolution. Multiple prokinetics including azithromycin, domperidone, and alimemazine were ineffective, with ongoing gastric losses of 10–30 mL/kg/day that would increase if feed was increased, hence inability to progress enteral feeds and PN dependence.Following aprepitant initiation, gastric output decreased by 25–30%,enabling gradual advancement to full enteral feeds and eventual discontinuation of PN.

Case B: A 12-year-old, neurodysability due to Wang syndrome, dependent on gastrojejunal (G-J) tube feeding, was admitted with suspected autonomic dysfunction. They required cessation of all prokinetics with arrhythmogenic risk. Furthermore, the patient's G-J tube kept recoiling in the stomach, with subsequent PN dependence. After aprepitant initiation, gastric output fell from 200–350 ml/day to near zero. Notably, the patient tolerated full gastric feeding for the first time in years.

Case C: A 16-year-old with Myotonic dystrophy, admitted with recurrent episodes of chronic intestinal pseudo-obstruction failed trials of conventional prokinetics and required repeated PN-dependent admissions. Introduction of aprepitant restored bowel motility, allowing tolerance of full gastrostomy tube feeds at 100 mL/hr.An inadvertent interruption of aprepitant therapy resulted in rapid clinical deterioration, reversed promptly upon re-initiation; further supporting its direct therapeutic effect. Across all three cases, aprepitant demonstrated a consistent and clinically meaningful impact on gut motility, gastric output reduction, and re-establishment of enteral nutrition, despite failure of multiple standard promotility therapies. None of the three patient developed any concerning side effects. This emerging pattern, particularly given the diverse underlying pathologies and ages, suggests aprepitant may address an unmet therapeutic need in children with GID and presumed IF. The rapid recurrence of symptoms after unintentional withdrawal in one case strengthens the causal relevance of NK1 receptor blockade.

These late-breaking findings highlight aprepitant as a promising, under-recognised prokinetic therapy in paediatric GID and presumed IF. While limited by the small case series, the consistent clinical improvements support the need for prospective, controlled studies to evaluate efficacy, dosing, safety, and long-term outcomes. Aprepitant may represent a significant therapeutic advancement for children with complex motility disorders unresponsive to standard treatments. The Graph shows the pattern of gastric output in case2(red arrow-Aprepitant)



References

Barclay, A.R., Meade, S., Richards, C., Warlow, T., Lumsden, D.E., Fairhurst, C., Paxton, C., Forrest, K., Mordekar, S.R., Campbell, D. and Thomas, J., 2025. Definition, investigation and management of gastrointestinal dystonia in children and young people with neurodisability. *Archives of Disease in Childhood*.

LBA5

Development of a successful multi-disciplinary gastroenterology clinic in a busy district general hospital

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Hospital A's paediatric gastroenterology service has evolved considerably over the last 10 years. In 2015, the first paediatric consultant with gastro special interest was appointed. The service was run single-handed until the secondment of a community nurse, during the Covid pandemic, who up-skilled to become a Gastro Specialist Nurse, becoming permanent in 2021. In 2023 a second consultant was appointed. Dietetic contributions to the service have historically been ad hoc and delivered separately to the gastro clinic. However, we have been fortunate to have a trial allocation of an experienced Band 7 dietitian to work within our gastro clinic, concurrently with submission of a business case. This has enabled us to run weekly MDT-style clinics followed by a cases meeting. We believe this is a significant advancement of the quality of care provided, allowing us to assess and treat each child holistically with their own tailored management plan. These clinics have been in place for approximately 8 months, and the authors were seeking to evaluate service users' perception of the clinic experience.

A Microsoft form survey was sent by text message to patients with IBD and other chronic gastro conditions. Despite a low response rate (30 returns), most of the cohort were IBD patients (93%), for whom we had a particular interest. Around a third of returns were by young people.

The ratings were generally very positive. Our average scores for each question were all between 4 and 5, except for ease of accessing help during a flare with an average score of 3.96.

In general, patients and their families feel we are approachable and feel listened to. Most feel that we explain clearly about symptoms and diagnosis and give a clear management plan. All but two felt they had the opportunity to ask questions when they had contact with the service. Children and Young People were treated with dignity and sensitivity.

17 of 20 who saw the dietitian in the clinic found this helpful. Free-text comments support this.
Patients and families are extremely positive about the support provided by the gastro specialist nurse. The majority of those with symptom flare, who were unable to access advice direct from our team, attended the emergency department which ideally should be avoided.

There was one comment about time taken to decide plans with the tertiary centre. Delays can be related to several issues, including patient provision of calprotectin samples. We have an extremely close working relationship with our tertiary centre. We have full access to tertiary centre records; we share information appropriately, seek advice where needed and attend the fortnightly virtual tertiary MDT meetings. We have always had very positive feedback from the tertiary team and are perceived as capable in dealing with challenging IBD locally.

Overall, in conclusion the survey demonstrates that the paediatric gastro service is generally well viewed by patients and families. There are, of course, always improvements to be made, particularly around ease of access for symptom flares. The recommendations are being instituted.

References

IBD UK Standards 2019

LBA6

The Shape of Paediatric Gastroenterology and Hepatology Training

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The national training programme in Paediatric Gasteroenterology, Hepatology and Nutrition (PGHAN), provides UK trainees with a structured route to become specialist consultants. It is essential that this programme generates well-rounded gastroenterologists and hepatologists equipped with the necessary skillset to meet the needs of the population they serve.

We conducted a national training survey to gain contemporary insight into trainee experience with the aim of highlighting areas of excellence and identify opportunities to generate positive change.

Methods:
Subspecialty trainees in a training post between March and September 2025 were invited to complete an anonymised electronic survey.

Results:
24 of 27 (89%) trainees completed the survey, representing all eighteen PGHAN UK training regions and training grades. 75% of trainees were LTFT. Common reasons for LTFT included caring responsibilities and reducing paediatric on-call burden. 87.5% were considering an OOP. 70.8% were considering applying for a post-CCT fellowship.

Endoscopy:
52.6% of gastroenterology trainees had achieved OGD JAG certification, 11.8% for colonoscopy. 50% of trainees had logged 0-20 colonoscopies. Common barriers to colonoscopy training were on-call burden, limited allocated lists and competition (e.g. consultant). All hepatology trainees were working towards OGD certification. 41.7% of trainees attended >2 endoscopy lists per month. 45.8% reported coming in monthly on an ‘off’ day for endoscopy experience.

Readiness for consultancy:
Of the 11 trainees in their final 12-months of training, all indicated being between 5-8 (54.5% at ‘7’) when rating their readiness for consultancy. 57.1% of gastroenterology trainees felt they would be confident in diagnostic colonoscopy by completion of training.

General paediatric training:
75% of trainees worked on a general paediatric on-call rota, with 47.4% reporting (the required subspecialty time is 70% so ideally would include above 30% away as 25% is well within reasonable and appropriate) 25-50% time away from subspecialty. Only 16.7% and 15.8% reported ‘never’ experiencing loss of endoscopy or clinic time respectively due to on-call burden. 37.% trainees were allocated 1 clinic per week, with variation in clinic exposure for the remaining cohort. 66.7% were able to attend specialty clinics including PN and transition.

Education and research:
66.7% of trainees were allocated SPA days. 45.8% were able to attend BSPGHAN educational sessions. 75% of trainees attended the annual BSPGHAN trainee meeting. Study leave budget allowance varied across training centres. 33.3% of trainees experienced barriers to accessing funding for mandatory courses. 83.3% had access to research and academic opportunities.

Conclusion:
The survey returned a high response rate with comprehensive trainee representation. Positive areas of practice included accommodation of an increased trend in LTFT working, educational and research opportunities, and inclusion of SPA days. There were high rates of trainees opting for LTFT, OOP and consideration of post-CCT fellowship. It remains vital that PGHAN trainees demonstrate competence in general paediatric skills, however there is a need for balance with impact on specialist training opportunities. We suggest future programme development should focus on this, along with minimising endoscopy training barriers by increasing list availability, and increasing specialist clinic exposure to avoid a shortfall in consultant skill level.

LBA7

INEFFECTIVE OESOPHAGEAL MOTILITY IS NOT A SIGNIFICANT DETERMINANT IN THE PATHOPHYSIOLOGY OF PAEDIATRIC GASTROESOPHAGEAL REFLUX DISEASE (GORD)

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OBJECTIVES AND STUDY

Ineffective oesophageal motility (IEM) is the commonest oesophageal motility disorder identified on high-resolution manometry (HRM) in children. The causal relationship between IEM and gastro-oesophageal reflux disease (GORD) remains unclear. The aim of this study was to correlate oesophageal body contractility with MII-pH parameters and endoscopic findings.

MATERIAL AND METHODS

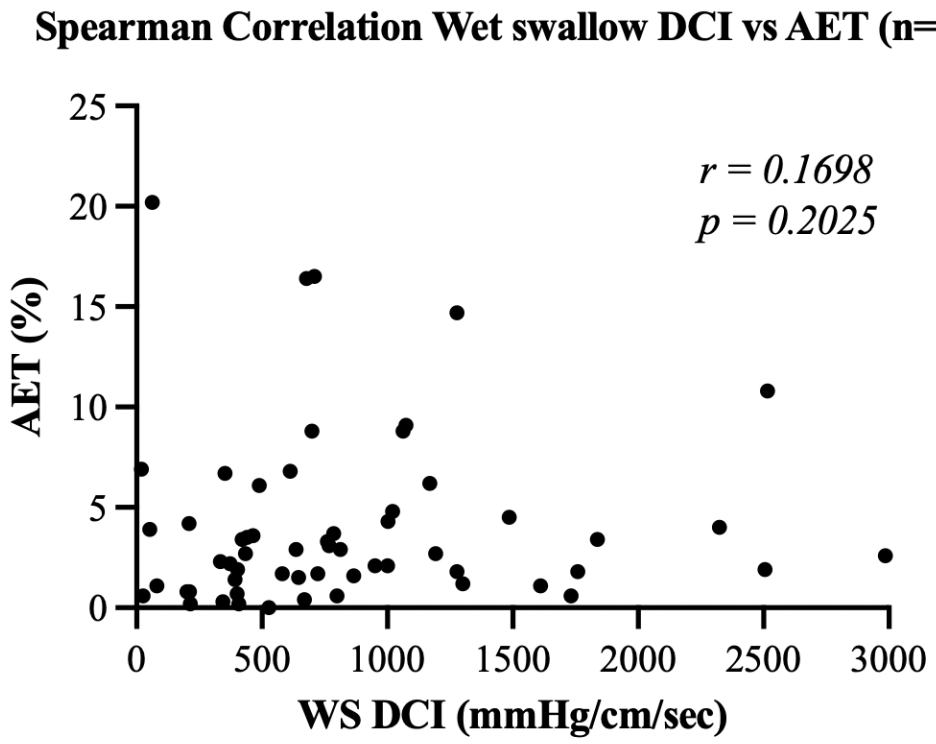
HRM and MII-pH data from children presenting with heartburn and/or vomiting symptoms between 2021 and 2025 were collected, excluding patients with previous oesophageal surgery, use of medications affecting oesophageal motility, or neurological disorders. Demographic, clinical, and endoscopic data were also recorded. IEM diagnosis was according to the CCv4.0 criteria. Mean wet swallow (WS) DCI was calculated as the average of the first ten wet swallows. Post-multiple rapid swallow (MRS) DCI was measured after a sequence of five 2-ml water swallows, and solid swallow (SS) DCI was calculated as the average of the first ten solid swallows.

RESULT

We identified 17 patients with IEM (mean age 11.9 years; 59% female) and 41 controls (mean age 14.2 years; 56% female). Mean WS DCI and SS DCI were significantly higher in controls (1084 mmHg/cm/sec and 1356 mmHg/cm/sec respectively) than in IEM patients (249.3 mmHg/cm/sec and 424.3 mmHg/cm/sec respectively) ($p<0.0001$), whereas no significant difference found for post-MRS DCI between groups ($p=0.143$). No significant group differences were noted in AET (total and supine), number of reflux episodes, mean nocturnal baseline impedance (MNBI), bolus clearance time (BCT) or oesophagitis (macroscopic or microscopic). Considering the whole children cohort (n=58), no significant correlations were observed between DCI versus AET, MNBI and BCT.

CONCLUSION

Oesophageal body contractility and MII-pH parameters are not directly correlated, suggesting that IEM is not a significant determinant of GORD pathophysiology.



LBA8

Improving access to paediatric dietetic-led coeliac clinic appointments

LBA9

Plugging in the mix: PN meets Epic

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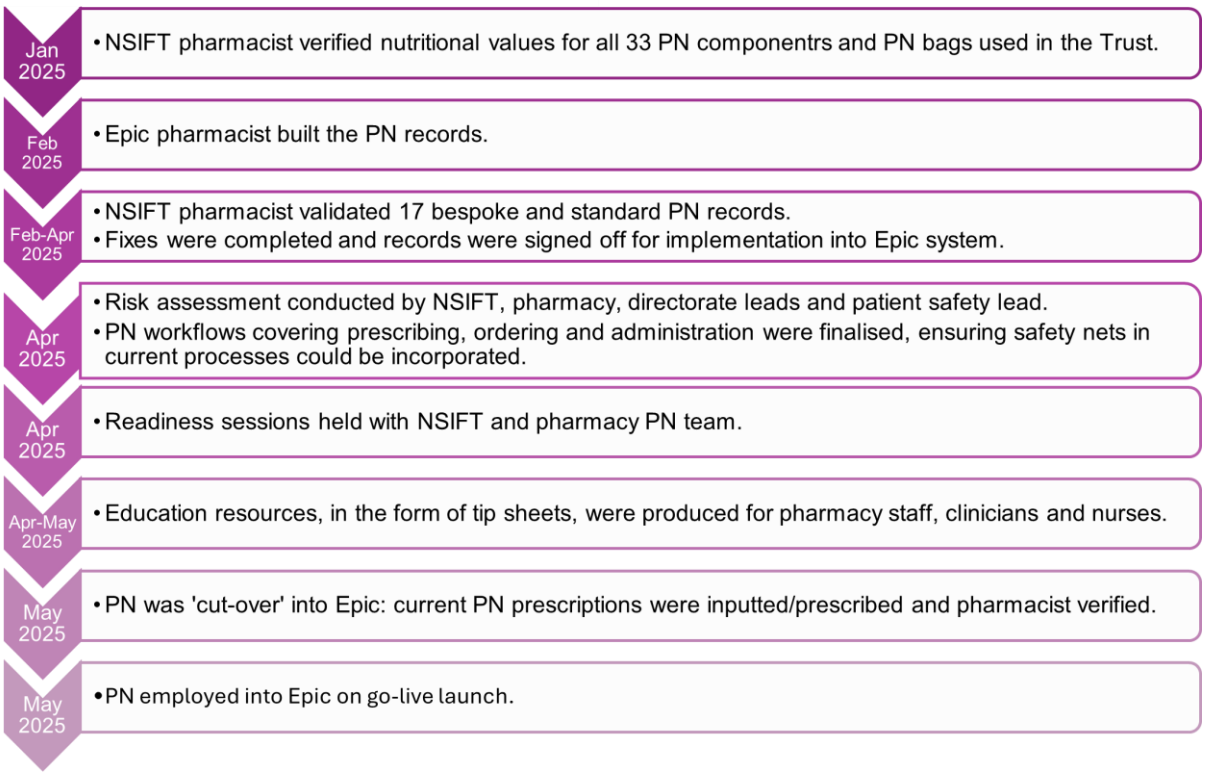
At a specialist paediatric centre, with 378 beds and a 31-bed paediatric intensive care unit, an expert Nutrition Support and Intestinal Failure Team (NSIFT) oversees parenteral nutrition (PN) provision, reviewing approximately 450 patients/year. NSIFT supports parent medical and surgical teams to prescribe PN for their patients as a consultative service. The hospital does not have an aseptic manufacturing unit, therefore all PN (bespoke and standard) is procured from external suppliers.
In May 2025, the Trust implemented Epic electronic patient records (EPR), with the system going live on all sites/systems at once after an 18-month roadmap. The intention was to fully embed all PN workflows and processes into Epic, which had not been done in the UK.

The PN module was developed and custom built by the Epic team in January 2025. Image 1 outlines the actions in the approach to go-live.

Image 1. Roadmap for PN go-live in Epic



Following go-live on 15/5/25, NSIFT absorbed PN prescribing activity for all patients, except intensive care (prescribed by independent pharmacist prescribers) and gastroenterology. Specific PN training was unable to be provided to staff as PN processes were finalised after Trust training was completed. Due to the complexity of Epic PN prescribing compared to paper prescriptions, and given the strict external manufacturing deadlines, it was necessary for NSIFT to manage this.

There were 102 tickets submitted for incidents in Epic that had 'PN' specifically referred to over a 29-week period from 16/5/25 to 3/12/25. NSIFT liaised with Epic analysts daily for the first four weeks to troubleshoot and add fixes where needed, then ad hoc thereafter.

In October 2025 two rapid risk assessments were conducted. The first was a patient safety risk assessment to review the patient safety incidents, review PN workflows in Epic and identify changes required to mitigate risks. The second risk assessment was to appraise if NSIFT were to continue prescribing PN, and assess the resource requirements for this. After fixes and updates were implemented in November 2025, PN was removed from the patient safety log managed by the Trust's EPR council. NSIFT continue to prescribe PN, with the intention to review the business case for the team and optimise resources to support ongoing prescribing activity.

Overall, a custom built PN module was successfully implemented into a complex EPR system. Patient safety concerns were addressed and updates made appropriately. PN in Epic has moved into a stabilisation phase and will gradually move towards optimisation for long term development.

References

N/A

LBA10

International trends in paediatric inflammatory bowel disease incidence before, during, and after the COVID-19 pandemic

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Preliminary data suggested a rise in paediatric inflammatory bowel disease (PIBD) during the COVID-19 pandemic. Building on this, the present study examined international PIBD incidence trends before, during, and after the pandemic using consistent methodology across all countries participating in a prospective PIBD-SET Quality Safety Study[1], enabling reliable comparisons of international data. The aim was to determine whether incidence rates changed significantly during the pandemic years (2020–2022) compared with pre- and post-pandemic years.

To achieve this, participating centres annually reported new PIBD cases alongside the geographical regions from which patients were referred. Denominator populations were derived from Eurostat NUTS3 data, allowing standardised incidence calculations. Centres using e-databases were analysed separately due to greater accuracy. Populations for the ten largest contributing countries ranged from 500,000 (Czech Republic) to 6.3 million (UK), totalling more than 19 million children. To assess whether PIBD incidence differed across years at the international level, Kruskal–Wallis tests and Dunn's post hoc comparisons were performed. Country-level trends were also examined using mixed-effects linear regression, whereby 'year' was the fixed effect and 'country' was the random effect to account for between-country heterogeneity.

The results showed that the international, annual incidence differed overall (Kruskal–Wallis $p \leq 0.009$), although no individual pairwise comparison remained significant after correction, implying a gradual temporal trend. When all countries were included, incidence increased from 2019 to 2021, decreased in 2022, and rose to its highest level in 2024. Patterns were similar for Crohn's disease and ulcerative colitis. The apparent 2022 decrease likely reflects differences in reporting and a greater reliance on e-datasets. Among the ten largest countries, the PIBD incidence generally increased from 2019 to 2024, and mixed-effects models confirmed that 'year' was not a significant predictor ($p \geq 0.54$). Individual country trends varied: four showed gradual increases, four fluctuated, and two experienced spikes in 2021-2022.

Overall, the PIBD incidence increased gradually from 2019 to 2024. Fluctuations are unlikely to reflect genuine epidemiological shifts, supporting an overall rise independent of COVID-related effects.

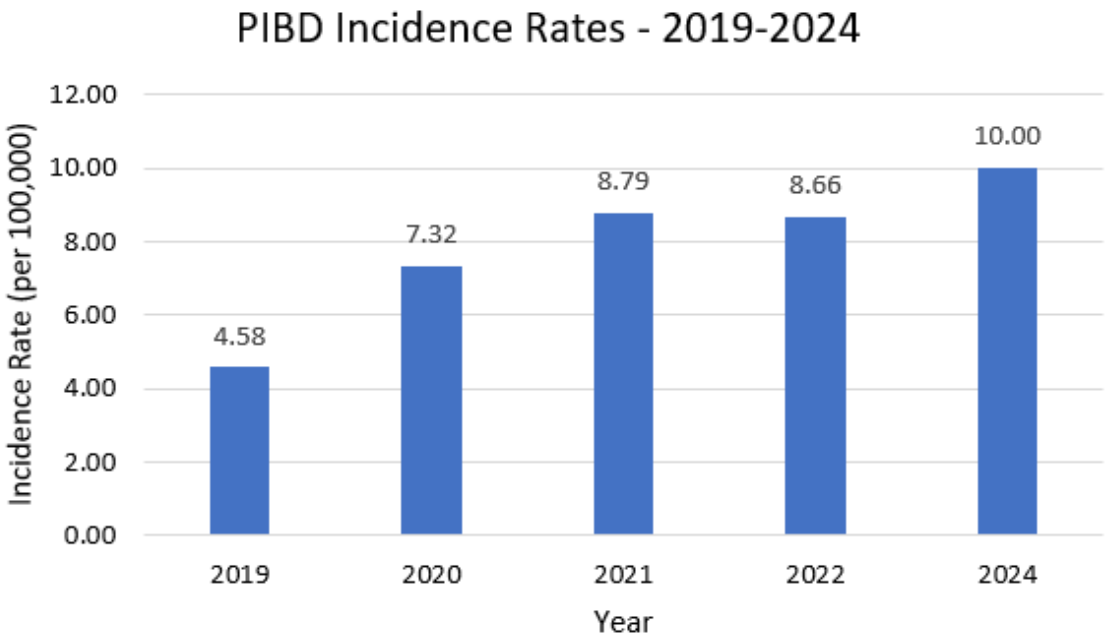

Figure 1. PIBD incidence rates (2019-2024) calculated using e-data.

References

1. Klomberg RCW, Hellendoorn AE, Kemos P et al. Rare and severe adverse events in children with inflammatory bowel disease: analysis of data from the PIBD-SETQuality Safety Registry. Lancet Child Adolesc Health. 2024;8(6):422-432. doi:10.1016/S2352-4642(24)00078-6.

LBA11

Diagnostic Concordance Between Small-Bowel Ultrasound and Magnetic Resonance Enterography in Paediatric Inflammatory Bowel Disease: A Retrospective Study at a tertiary Paediatric Gastroenterology unit in the United Kingdom.

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Small-bowel ultrasound (USS) is increasingly used in paediatric inflammatory bowel disease (IBD) owing to its safety, accessibility, and ability to provide real-time assessment. Magnetic resonance enterography (MRE) remains the reference standard for non-invasive evaluation of small-bowel inflammation because it enables assessment of transmural disease and detection of complications(1). However, comparative paediatric performance data remain limited, particularly regarding segment-specific accuracy and the identification of complications.

To evaluate the real-world diagnostic accuracy and concordance of small-bowel USS compared with MRE for detecting small-bowel inflammation, segmental disease distribution, and complications in a paediatric cohort at a tertiary gastroenterology centre.

A retrospective review was conducted of 66 children who underwent USS followed by MRE between 2020 and 2025. Demographic and clinical variables, including age, sex, and suspected and confirmed IBD phenotype, were collected. Imaging reports were coded as positive or negative for (1) terminal ileum (TI) involvement, (2) other small-bowel involvement, and (3) complications (stricture, fistula, abscess). MRE served as the reference standard. Diagnostic accuracy measures with 95% confidence intervals (CIs), concordance rates, and Cohen's κ were calculated.

Sixty-six children were included (25 female, 41 males; median age 13 years). Fifty were investigated for suspected new Crohn's disease, of these, 45 were subsequently confirmed to have Crohn's disease, 2 ulcerative colitis, 2 had non-IBD diagnoses and 1 IBD-unclassified. 13 children underwent imaging for reassessment of known Crohn's disease and 3 for known ulcerative colitis. The mean waiting times between USS and MRE for new diagnoses was 206 days.

USS demonstrated a sensitivity of 63.6% (95% CI 46.6–77.8) and specificity of 90.9% (95% CI 76.4–96.9) for detecting small-bowel inflammation, with a positive predictive value of 87.5% and a negative predictive value of 71.4%. Overall concordance with MRE was 77% (51/66), and Cohen's κ was 0.55, indicating moderate agreement.

Discordance occurred in 15/66 (23%) cases, predominantly due to USS-negative/MRE-positive findings (12/15). Most USS under-detection was attributable to limited acoustic windows. Agreement was higher for Terminal ileal disease than for proximal or deep small-bowel involvement. USS detected few complications compared with MRE, consistent with the latter's superior ability to assess transmural and extraintestinal disease.

In this paediatric cohort, USS showed high specificity and moderate sensitivity relative to MRE, with moderate overall concordance. Most discordant findings reflected technical rather than biological factors, with paediatric body habitus influencing acoustic windows and the sensitivity of ultrasound for small bowel disease detection. USS was less effective than MRE in delineating L4(proximal small bowel) and B2(structuring) disease. The long waiting times for MRE supports the use of USS as a pragmatic first-line cross-sectional imaging modality in paediatric IBD pathways, while emphasising the continued need for MRE when clinical suspicion of small-bowel disease persists despite a negative ultrasound.

References

1. van Rheenen PF, Aloi M, Assa A, et al. The medical management of paediatric Crohn's disease: an ECCO–ESPGHAN guideline update. J Crohns Colitis. 2021;15(2):171–194.
2. Bruining DH, Zimmermann EM, Loftus EV Jr, Sandborn WJ, Sauer CG, Strong SA, et al. Consensus recommendations for evaluation, interpretation, and utilisation of diagnostic imaging in paediatric Crohn's disease. J Pediatr Gastroenterol Nutr. 2018;66(3):403–17.
3. Kucharzik T, Koulaouzidis A, Mallant M, Armbruster M, Karstensen JG, Maconi G, et al. Use of intestinal ultrasound for monitoring paediatric inflammatory bowel disease: an international expert survey. J Crohns Colitis. 2021;15(7):1134–42.
4. Aloi M, Pacifico L, Passariello R, Tromba V, Di Nardo G, Catalano C, et al. Magnetic resonance enterography, bowel ultrasound and capsule endoscopy in children with suspected Crohn's disease. Aliment Pharmacol Ther. 2015;41(10):1054–62.
5. Rimola J, Ordás I, Rodriguez S, García-Bosch O, Aceituno M, Llach J, et al. Magnetic resonance enterography identifies transmural inflammation and complications in Crohn's disease. Gut. 2009;58(8):1113–20.
6. Puylaert CAJ, Tielbeek JAW, Bipat S, Stoker J. Ultrasound of the bowel in paediatric inflammatory bowel disease: systematic review and meta-regression. Eur Radiol. 2017;27(9):3969–82.
7. Di Nardo G, Aloi M, Oliva S, Ferrari F, Mallardo S, Casciani E, et al. Ultrasonography in paediatric Crohn's disease: diagnostic accuracy and prediction of disease course. Clin Gastroenterol Hepatol. 2010;8(2):146–52.

LBA12

Chemosensory dysfunction in inflammatory bowel disease: a systematic review of olfactory and gustatory impairment.

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Chemosensory disturbances are increasingly recognised as relevant yet understudied features of inflammatory bowel disease (IBD). This systematic review synthesised psychophysical, semi-objective, and subjective evidence to characterise olfactory and gustatory function in individuals with IBD.

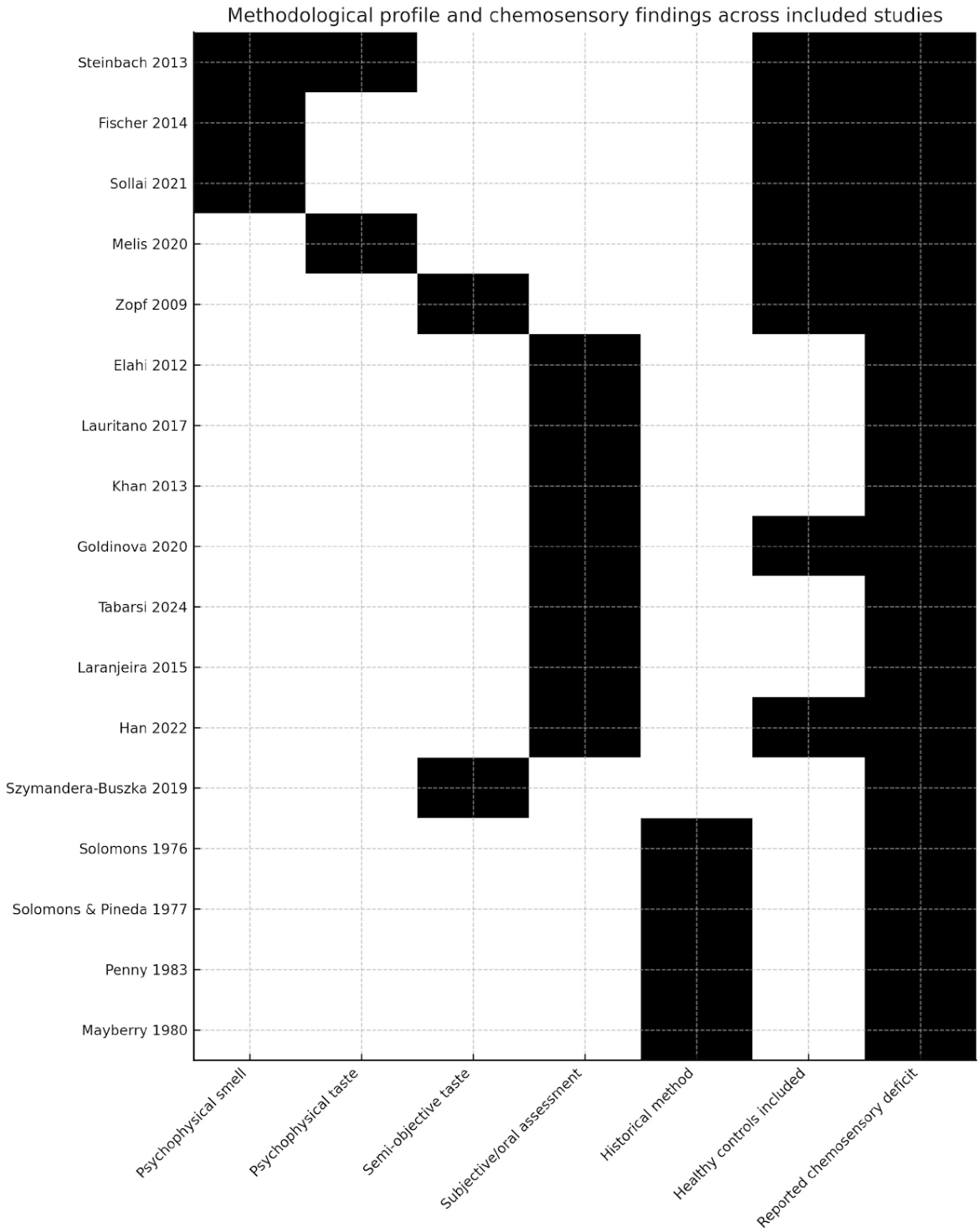
A systematic search of PubMed, Scopus, Cochrane, Web of Science, and ClinicalTrials.gov was conducted following the PRISMA 2020 guidelines. Eligible studies assessed smell or taste function in Crohn's disease, Ulcerative colitis, or IBD-unclassified using validated psychophysical tools, semi-objective gustatory methods, or clearly defined subjective measures. Data extraction captured study design, chemosensory domains, assessment methods, and availability of numerical outcomes. The feasibility of conducting a meta-analysis was evaluated according to PRISMA-SWiM guidance.

Seventeen studies published between 1976 and 2024 met the inclusion criteria. Psychophysical investigations consistently demonstrated reduced olfactory or gustatory performance in IBD compared with healthy controls. In the only study reporting complete extractable psychophysical taste data, IBD patients showed significantly lower Taste Strips scores (10.6±3.7; n=59) than controls (12.9±1.8; n=23). Additional psychophysical and semi-objective studies reported deficits across multiple taste qualities, most commonly involving sweet and bitter perception, as well as impairments in olfactory threshold, discrimination, and identification.
Seven subjective or oral-medicine–based studies described high rates of taste alteration, often associated with active disease, mucosal inflammation, or xerostomia and reduced salivary flow. A semi-objective study demonstrated selective impairment in sour and bitter perception in Crohn's disease. Historical investigations similarly indicated altered taste physiology with potential nutritional implications. A meta-analysis could not be performed due to the widespread absence of extractable numerical data for global olfactory and gustatory scores.

Across diverse methodologies spanning nearly five decades, the evidence consistently indicates that IBD is associated with clinically meaningful impairment in smell and taste function, influenced by disease activity, oral and salivary conditions, and specific taste-quality vulnerabilities. Standardised psychophysical testing and improved quantitative reporting are needed to clarify the prevalence, mechanisms, and clinical impact of chemosensory dysfunction in IBD.

Figure 1. Methodological profile and chemosensory findings across the 17 studies included in the systematic review. The heatmap uses a binary greyscale coding scheme. Black cells indicate the *presence* of a methodological feature or chemosensory finding, whereas white cells indicate the absence of that feature in the corresponding study.

LBA12 – Continued



LBA13

Outcomes for Paediatric Inflammatory Bowel Disease patients with entero-enteric fistulating disease and intra-abdominal collection.

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Intra-abdominal abscesses and entero-enteric fistulas are severe penetrating complications of paediatric Crohn's disease, associated with significant morbidity, prolonged hospitalisation, and complex multidisciplinary management.[1] Although guidance supports early biologic therapy and nutritional optimisation in penetrating disease, paediatric outcome data for internal fistulas and abdominal abscesses remain limited. [2]

This retrospective cohort study aimed to evaluate the clinical characteristics, management, and outcomes of penetrating paediatric Crohn's disease (intra-abdominal abscess, enteroenteric fistula (EEF), or both).

Patients with radiologically confirmed intra-abdominal abscess and/or EEF between 2022 – 2025 were identified from the Paediatric Inflammatory Bowel Disease (PIBD) database with data collected on age at diagnosis, age and disease duration at complication onset, inflammatory markers, nutritional support, imaging modality, management and outcomes. Outcomes included resolution, recurrence, need for surgery, biologic escalation, and length of stay (LOS). Median radiological follow-up duration was 8 weeks (range 2–26) for abdominal abscesses and 19 weeks (range 4–52) for EEF.

A total of 16 had penetrating (B3) disease characterised by EEF and/or intra-abdominal abscess. 4/16 (25%) had intra-abdominal abscess only, 6/16 (37.5%) had EEF only, and 6/16 (37.5%) had both. Median age at diagnosis was 13.5 years, and median age at complication was 14.5 years. Median disease duration at complication occurrence was 2.5 months. Exclusive Enteral Nutrition (EEN) was required in 12/16, parenteral nutrition in 4/16 (duration 3 – 112 days, median 28 days).

All 10 abscess patients received antibiotics (100%), 3/10 (30%) underwent percutaneous drainage, and 1/10 (10%) required a diverting stoma. At follow up, clinical resolution was 100%, and radiologic resolution 90%. Abscess recurred in 20%.

Of 12 children with EEF, 10/12 (83%) received antibiotics, 12/12 (100%) received nutritional support, and 1 (8.3%) required bowel resection. At follow up, radiologic fistula closure occurred in 6/12 (50%), with no recurrences.

Biologic therapy was initiated in 13/16 patients (81.3%) following complication onset, while the remaining 3/16 (18.7%), who were already receiving biologics, required switching of therapy.

Length of stay ranged from 12–80 days (median 46 days) in abscess only cases, 14–150 days (median 44.5 days) in patients with both abscess and EEF, and 4–17 days (median 14 days) in EEF-only cases. No mortality occurred.

This shows favourable short-term outcomes in penetrating PIBD with abscess resolution, fistula closure in half, and low recurrence. Nutritional support and early biologic use were central to management. The short interval between disease onset and complication supports the use of early biologics. Abscess related disease imposed the greatest hospital burden, reinforcing the importance of multimodal care.

References

1. Van Rheenen PF, Aloi M, Assa A et al. The medical management of paediatric Crohn's disease: an ECCO-ESPGHAN guideline update. J Crohns Colitis. 2014;8(10):1179–1207.
2. Turner D, Ruemmele FM, Orlanski-Meyer E et al. Management of paediatric Crohn's disease: an updated ESPGHAN guideline. J Pediatr Gastroenterol Nutr. 2021;72(2):320–335

LBA14

Single-centre experience with upadacitinib in children with anti-TNF failure inflammatory bowel disease

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Upadacitinib is a selective Janus kinase-1 inhibitor with proven efficacy in adults with moderate to severe ulcerative colitis and Crohn's disease. Paediatric use remains off-label, largely due to delays in paediatric approvals, and real-world data are needed to better understand its effectiveness and safety profile in children with inflammatory bowel disease.

A retrospective case series was undertaken, including children aged 6–16 years with inflammatory bowel disease who were treated with upadacitinib following failure of anti-tumour necrosis factor therapy. Post-induction steroid-free clinical remission, as determined by the treating clinicians, requirement for surgery, and adverse events were assessed up to the last follow-up.

Nineteen children were included (12 Crohn's disease, 3 ulcerative colitis, 4 inflammatory bowel disease-unclassified), of whom 52% were male, with a median age of 12 years. Sixty-three per cent had been exposed to two or more biologic therapies before treatment. All patients received upadacitinib as monotherapy for at least 12 weeks, with a median treatment duration of 35 weeks (interquartile range 14.8–55.3). Steroid-free clinical remission at week 12 was achieved in 68% (13/19) of patients, and all responders remained in remission at last follow-up. Five patients who did not respond required surgical intervention, including colectomy (n=3), right hemicolectomy (n=1), and ileocaecal resection (n=1). One patient was subsequently recommenced on upadacitinib following surgery. Adverse events were reported in two patients and included recurrent oral ulceration and shingles.

Upadacitinib appears to be a promising treatment option for children with refractory inflammatory bowel disease following biologic failure. Its oral administration offers a practical advantage by avoiding injections or hospital-based intravenous infusions, which may be particularly appealing in paediatric practice. Larger multicentre studies with longer follow-up are required to further evaluate efficacy and confirm the safety profile in this population.

References

1. Sandborn WJ, Feagan BG, D'Haens G. Upadacitinib as induction and maintenance therapy for ulcerative colitis. *N Engl J Med*. 2022;386:2373–84.
2. Vermeire S, Schreiber S, Petryka R. Clinical remission in Crohn's disease with upadacitinib. *Lancet*. 2020;395:2015–24.
3. Turner D, Ruemmele FM, Orlanski-Meyer E. Management of paediatric ulcerative colitis. *J Pediatr Gastroenterol Nutr*. 2018;67:257–91.
4. Levine A, Koletzko S, Turner D. ESPGHAN revised porto criteria for inflammatory bowel disease. *J Pediatr Gastroenterol Nutr*. 2014;58:795–806

LBA15

The Association Between Fibroscan and Liver Biopsy in Children

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The Association Between Fibroscan and Liver Biopsy in Children

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Objective:
Liver biopsy (LB) is considered the test of choice for diagnosing liver fibrosis in children. Although LB provides extensive information, it is an invasive procedure that requires anesthesia and needs to be interpreted by experts to provide reliable information. In recent years, non-invasive tests, including Fibroscan, have been developed to assess liver fibrosis, aiming to reduce the need for LB. This study aimed to evaluate the relationship between Fibroscan measurements and liver biopsy findings in children, and to assess its potential as a reliable alternative.

Methods:
A retrospective study included all children under 18 years old who underwent LB between August 2024 and November 2025 and had a Fibroscan test at King's College Hospital, with an interval of less than one year between the two assessments.

Results:
Eighty-nine children were included in the study, 50 were males (56.2%), and the median age was 11.5 years (IQR 5.66,14.91). The most common background disease was autoimmune diseases (36, 40.5%), followed by biliary diseases, including biliary atresia (12, 13.5%). Seven children did not have fibrosis in the LB (F0 according to the METAVIR score), 21 had F1, 26 had F2, 15 had F3, and 20 had F4. The median time between the LB and the Fibroscan was two days (IQR 0,108) and average of 56.3 days. There was a significant association between the liver stiffness measure (LSM) and the fibrosis score (6.5, 9.2, 9.2, 17.5, and 29.9 kPa, p-value<0.0002, respectively). There was no significant association between the fibrosis score and transaminases, Gamma-Glutamyl Transferase (GGT), or the AST-to-platelet ratio (APRI). A multivariable analysis showed a significant association between the METAVIR score and LSM, adjusted for the child's age, background disease, and the interval between the LB and Fibroscan (OR=1.1, 95%CI 1.055-1.147). A ROC analysis was performed, showing a threshold of 5.8 kPa with a sensitivity of 75.6%, a specificity of 71.4% and a positive predictive value of 97% for identifying children with fibrosis.

Table 1 : Comparison of Liver Stiffness and Biochemical Markers by Fibrosis Stage

	F0	F1	F2	F3	F4	Pvalue
Number	7	21	26	15	20	
LSM average	6.5	9.3	9.2	17.5	29.9	**<0.0002**
AST	309.6	206.3	232.9	344.9	231.4	0.4
ALT	210.1	161.6	194.4	360.2	507.2	0.74
Total Bili	7.14	45.1	40.8	31.1	41	0.002
Conjugated Bili	20	44.3	40.4	19.5	27.8	0.27
GGT	243.9	101.2	138	217	204	0.15
ALP	492.7	321.9	317.4	787	387	0.06
APRI	2.5	2.6	2.9	3.3	15	0.23
Heterogenous liver (%)	14.3	31.6	48	40	80	**0.0084**

Conclusion:
There is a significant association between LB and Fibroscan results, especially among patients with more advanced fibrosis (F2 or higher). A larger homogenous cohort study is required to establish a threshold with higher sensitivity and PPV.

LBA16

Clinical Spectrum of Paediatric MASLD: Fibrosis Burden, Steatosis Severity, and Extrahepatic Comorbidities in a Large Tertiary Cohort

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Objectives and study

The clinical spectrum of paediatric MASLD is poorly understood. We aimed to characterise a large tertiary paediatric MASLD cohort, with emphasis on transient elastography findings and extrahepatic comorbidities.

Methods

We retrospectively reviewed 288 children with MASLD managed at the Paediatric Hepatology Service at King's College Hospital over an 18-month period. Inclusion required imaging evidence of hepatic steatosis following exclusion of other aetiologies. Demographic, anthropometric, transient elastography, ultrasonographic and comorbidity data were collected. Fibrosis staging was based on liver stiffness measurement (LSM: F1 <8 kPa, F2 8–10.9 kPa, F3-4 ≥11 kPa), and steatosis grading by controlled attenuation parameter (CAP: S1 <248 dB/m, S2 248–279 dB/m, and S3 ≥280 dB/m). Differences across categories was assessed using Kruskal–Wallis test, and associations among markers using Spearman correlations.

Results

Median age was 15 years (IQR 4), with a male predominance (71.2%). Median CAP was 299 dB/m (IQR 73.8), with severe steatosis (S3) in 63.7% of patients. Median LSM was 7 kPa (IQR 2.8), with significant fibrosis (F2) in 28% and advanced fibrosis (F3-4) in 11%. Splenomegaly was detected in **32.6%**. ALT, AST, GGT, and CAP were significantly higher in fibrosis stages F2 and F3-4 compared to F1, although F2 and F3-4 did not differ. No biochemical marker independently predicted LSM in multivariable analysis. Correlations were seen between BMI z-score, LSM, CAP, spleen stiffness measurement, ALT, and uric acid (Table 1), while platelet count showed no correlation with fibrosis or steatosis. Extrahepatic comorbidities were frequent, including neurodevelopmental/behavioural disorders (13.8%), hypothyroidism (3.8%) and hypogonadal abnormalities (6.6%). Alpha-1-antitrypsin heterozygosity was seen in 10%, and isolated autoantibody positivity in 15.2%. Metabolic complications were common; including acanthosis (19%), elevated HbA1c (16.3%), treated diabetes (11.1%), hypertension (5.9%), sleep-related issues (17.7%), and menstrual irregularities in 60% of adolescent girls.

Conclusions

In this large tertiary paediatric MASLD cohort, severe steatosis and significant fibrosis were common, alongside a broad burden of metabolic and extrahepatic comorbidities. The findings emphasise the need for integrated multidisciplinary management.

Table 1: Spearman rank correlation coefficient between BMI z-score, fibroscan and biochemical parameters

Variable pair	BMI z-score	LSM	CAP
BMI z-score		r 0.24 p 0.001	r 0.36 p <0.001
LSM	r 0.24 p 0.001		r 0.40 p <0.001
CAP	r 0.36 p <0.001	r 0.40 p <0.001	
Platelet count	r 0.18 p 0.007	r 0.34 p 0.67	r 0.092 p 0.216
SSM	r 0.46 p 0.004	r 0.37 p 0.025	r 0.65 p <0.001
ALT	r 0.18 p 0.007	r 0.37 p <0.001	r 0.38 p <0.001
Uric acid	r 0.24 p 0.032	r 0.24 p 0.016	r 0.34 p 0.04

LBA17

Liver Involvement in Paediatric Turner Syndrome: A Single-Centre Cohort Study

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Background: Liver abnormalities are recognised in Turner syndrome (TS), but most data come from adult cohorts describing metabolic, cholangiopathic, vascular and autoimmune phenotypes. Paediatric data are scarce. We aimed to characterise liver involvement, imaging findings and metabolic associations in a paediatric TS cohort at a single tertiary centre.

Methods: A retrospective review of TS patients aged <18 years referred to the liver service between 2001 and 2025 was performed. Clinical, biochemical and imaging data were extracted from records, including age, karyotype, BMI z-scores, liver biochemistry, autoantibodies, ultrasound, CT/MRI, liver biopsy, growth hormone (GH) therapy, metformin use and hormone replacement therapy (HRT). Neonatal conjugated jaundice cases were classified within a cholangiopathic/early bile duct phenotype. Liver phenotypes were defined as metabolic (steatosis or elevated ALT/AST/GGT), autoimmune (ANA or SMA positivity), cholangiopathic (neonatal conjugated cholestasis or bile-duct abnormalities), and vascular/nodular (FNH/NRH/vascular lesions), allowing overlap.

Results: Nineteen children were included (median age 11.0 years; range 0.03–18.0; median BMI 24.3 kg/m²; range 14.8–39.2). Three had documented cardiac anomalies; 10/19 were receiving GH, 9/19 HRT and 3/19 metformin. Overall, 12/19 (63%) had abnormal liver function tests. Steatosis was present on ultrasound in 47% and persisted on follow-up imaging in half, clustering with higher BMI z-scores/hypertriglyceridaemia. Three children had low-titre ANA and/or SMA positivity with abnormal transaminases; in all, liver biopsy showed only mild, non-specific changes. Four children met cholangiopathic criteria- three with neonatal conjugated hyperbilirubinaemia (resolved), and one with bile duct–related imaging changes (MDR3 heterozygous). No focal nodular hyperplasia, nodular regenerative hyperplasia or vascular lesions were identified.

Conclusions: In this paediatric TS cohort, biochemical abnormalities and steatosis were frequent and predominantly metabolic, whereas vascular or nodular lesions were not seen, suggesting these may develop later. Low-titre autoantibodies appeared incidental. Longitudinal linkage of paediatric and adult cohorts is needed to define the natural history of TS-related liver disease and guide counselling and surveillance.

References

N/A

LBA18

The mortality burden of paediatric Intestinal Failure Associated Liver Disease (IFALD)- a single centre experience

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Background: Paediatric patients awaiting combined liver and intestinal transplant (LITx) face a high risk of deterioration. We aimed to evaluate whether perceived long wait times for these patients would increase waitlist mortality or necessitate life-saving isolated liver transplantation.

Methods: A retrospective case review of LITx candidates (n=50), evaluated waitlist mortality as the primary outcome. Subgroup analyses compared patients requiring urgent isolated liver transplantation due to deterioration with those receiving other grafts. Statistical analyses included survival analysis, correlation between wait times and mortality, and multivariate regression to identify predictors of waitlist death.

Results: Median transplant wait-time was 209 days (20–1248), longer than recent UK adult registry data of median 54 days. Waitlist mortality was 20%. Intestinal Failure Associated Liver Disease (IFALD) was the key risk-factor, with 27.6% mortality among IFALD patients compared to 0% in non-IFALD ($p=0.035$). In IFALD, extended wait-time ($r=0.663$, $p<0.001$) and higher referral bilirubin levels ($r=-0.424$, $p=0.024$) predicted poorer outcomes. Nine patients (24%) initially listed for small bowel and liver containing grafts, underwent isolated liver transplantation due to clinical deterioration. These patients had shorter median wait-times (379.5 vs 411.7 days) and higher serum bilirubin levels (179.3 vs 116.9µmol/L) than those receiving other transplants.

Conclusions: These findings highlight the need for timely transplantation, particularly for IFALD. Early consideration of isolated liver transplantation as a life-saving bridge for rapidly deteriorating patients is required. Further measures, such as increased use of living-related liver bowel transplant and machine perfusion, may be needed to reduce long wait times