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ABSTRACT BOOKLET

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

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OC1

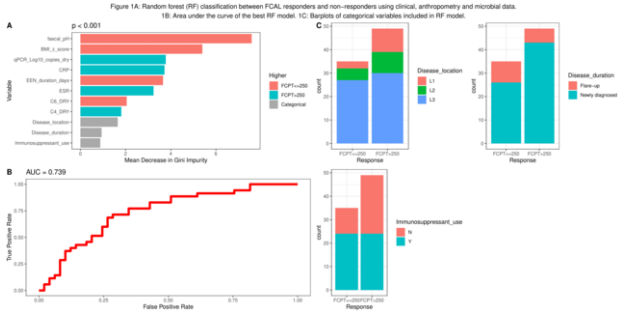
High faecal pH and low total microbial load associate with normalisation of faecal calprotectin in children with Crohn's disease treated with exclusive enteral nutrition; results from iPENS, a multicentre, prospective study by Konstantinos Gkikas[1], Maria Lima[1], Shona McKirdy[1], Lisa Gervais[2], Caroline Kerbiriou[1], Ben Nichols[1], Gillian Smith[1], Lawrence Armstrong[3], Thomas Jordan[4], Iain Chalmers[5,6], Hannah Barlow[7], Ghassan Al Hourani[8], Rafeeq Muhammed[9], David Wands[2], Priya Narula[10], Minal Patel[11], Umer Z. Ijaz[12], Simon Milling[13], Marco Gasparetto[14], Paul Henderson[15], David C. Wilson[15], Richard Hansen[16,2], Richard K. Russell[15], Konstantinos Gerasimidis[1], *[1]University of Glasgow, School of Medicine- Dentistry and Nursing, Glasgow, UK. [2]Royal Hospital for Children, Department of Paediatric Gastroenterology - Hepatology and Nutrition, Glasgow, UK. [3]University Crosshouse Hospital, Department of Paediatrics, Crosshouse, UK. [4]University Hospital Wishaw, Department of Paediatrics, Wishaw, UK. [5]Aberdeen Children's Hospital, Department of Paediatric Gastroenterology, Aberdeen, UK. [6]Tayside Children's Hospital, Department of Paediatric Gastroenterology, Dundee, UK. [7]Royal Manchester Children's Hospital, Department of Paediatrics, Manchester, UK. [8]Forth Valley Royal Hospital, Department of Paediatrics, Larbert, UK. [9]Birmingham Women's and Children's Hospital, Department of Paediatric Gastroenterology, Birmingham, UK. [10]Sheffield Children's Hospital, Department of Paediatric Gastroenterology, Sheffield, UK. [11]Royal London Children's Hospital, Department of Paediatric Gastroenterology, London, UK. [12]University of Glasgow, James Watt School of Engineering, Glasgow, UK. [13]University of Glasgow, School of Infection and Immunity, Glasgow, UK. [14]Norfolk and Norwich University Hospitals, Department of Paediatric Gastroenterology, Norwich, UK. [15]Royal Hospital for Children and Young People, Department of Paediatric Gastroenterology- Hepatology and Nutrition, Edinburgh, UK. [16]University of Dundee, Department of Child health-Division of Clinical and Molecular Medicine- School of Medicine, Dundee, UK.*

Background: Exclusive enteral nutrition (EEN) is a main therapy for active Crohn's disease (CD) in children, but normalisation of faecal calprotectin (FCAL) varies among patients, even in those who enter clinical remission. To better understand disease characteristics related to EEN efficacy and its mechanism of action, we compared clinical and microbial parameters between patients whose FCAL normalised against those who did not at EEN completion.

Methods: Children with CD, clinically responding to EEN, were recruited from 11 UK hospitals (January 2020- May 2023, NCT04225689) and provided a single faecal sample before EEN completion. Patients were divided in two groups according to levels of FCAL at EEN completion (FCAL<250 and FCAL>250 mg/kg). Levels of faecal short chain fatty acids (SCFA), faecal sample characteristics (pH, water content (%), bristol stool score) and total microbial load (qPCR) were compared between the two groups. Anthropometric and clinical parameters (blood inflammatory markers, use of immunosuppressants, disease duration, disease location) were also compared. Machine learning using feature elimination with data imputation for missing data was performed to identify associations between clinical, anthropometry, microbial parameters and FCAL normalisation.

Results: At EEN completion, 84 children (female, 35%) were recruited [age, median (IQR): 13.2 (11.8, 14.9 years)] with a median (Q1, Q3) FCAL of 643 (146, 2033) mg/kg. Out of 84 patients, 35 (42%) had an FCAL<250 mg/kg. Total microbial load and SCFA were measured in a subset of patients (n=44). Patients with FCAL<250mg/kg had a higher faecal pH and lower microbial load compared to those with FCAL>250mg/kg [faecal pH; FCAL<250 mg/kg: 8.3 (8.1, 8.6) vs FCAL>250 mg/kg; 7.95 (7.6, 8.3), p=0.001; microbial load (log10 16S rRNA gene copies/g): FCAL<250mg/kg: 10.7 (10.4, 10.9) vs FCAL>250mg/kg: 11.0 (10.5, 11.2), p=0.02]. Median BMI z-score was also non-significantly (p=0.052) higher in patients with FCAL<250mg/kg. The use of immunosuppressants at EEN completion, disease duration, disease location and other faecal parameters were not different between the two groups. A multicomponent random forest model (clinical, blood inflammatory markers, anthropometry, faecal parameters) predicted normalisation of FCAL with 71% accuracy (sensitivity: 69%, specificity: 71%, p=<0.001, Figure 1). Higher faecal pH, BMI z-scores and lower total microbial load were the most influential parameters relating to FCAL<250mg/kg.

Conclusions: We showed that the efficacy of EEN in reducing gut inflammation might be, at least in part, mediated via reducing gut bacterial biomass and modulating luminal pH and the downstream effects this may have on inflammatory members of the microbial community.



OC2

Cereal intake and diet-related microbial metabolites in faeces associate with recurrence of gut inflammation during food reintroduction in children with Crohn's disease treated with exclusive enteral nutrition; iPENS a multicentre, prospective study

by Konstantinos Gkikas[1], Maria Lima[1], Shona McKirdy[1], Lisa Gervais[2], Caroline Kerbiriou[1], Ben Nichols[1], Lawrence Armstrong[3], Thomas Jordan[4], Gillian Smith[4], Iain Chalmers[5,6], Hannah Barlow[7], Ghassan Al Hourani[8], Rafeeq Muhammed[9], David Wands[2], Priya Narula[10], Minal Patel[11], Umer Z. Ijaz[12], Simon Milling[13], Marco Gasparetto[14], Paul Henderson[15], David C. Wilson[15], Richard Hansen[16], Richard K. Russell[15], Konstantinos Gerasimidis[1], *[1]University of Glasgow, School of Medicine- Dentistry and Nursing, Glasgow, UK. [2]Royal Hospital for Children, Department of Paediatric Gastroenterology - Hepatology and Nutrition, Glasgow, UK. [3]University Crosshouse Hospital, Department of Paediatrics, Crosshouse, UK. [4]University Hospital Wishaw, Department of Paediatrics, Wishaw, UK. [5]Aberdeen Children's Hospital, Department of Paediatric Gastroenterology, Aberdeen, UK. [6]Tayside Children's Hospital, Department of Paediatric Gastroenterology, Dundee, UK. [7]Royal Manchester Children's Hospital, Department of Paediatrics, Manchester, UK. [8]Forth Valley Royal Hospital, Department of Paediatrics, Larbert, UK. [9]Birmingham Women's and Children's Hospital, Department of Paediatric Gastroenterology, Birmingham, UK. [10]Sheffield Children's Hospital, Department of Paediatric Gastroenterology, Sheffield, UK. [11]Royal London Children's Hospital, Department of Paediatric Gastroenterology, London, UK. [12]University of Glasgow, James Watt School of Engineering, Glasgow, UK. [13]University of Glasgow, School of Infection and Immunity, Glasgow, UK. [14]Norfolk and Norwich University Hospitals, Department of Paediatric Gastroenterology, Norwich, UK. [15]Royal Hospital for Children and Young People, Department of Paediatric Gastroenterology- Hepatology and Nutrition, Edinburgh, UK. [16]University of Dundee, Department of Child health- Division of Clinical and Molecular Medicine- School of Medicine, Dundee, UK.*

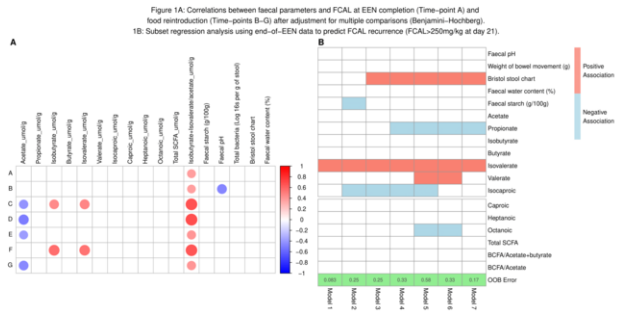
Background: Faecal calprotectin (FCAL) rises rapidly in children with Crohn's disease (CD) following treatment with exclusive enteral nutrition (EEN). We aimed to identify clinical, dietary and diet-related microbial metabolites which associate with the recurrence of FCAL above 250 mg/kg after 21 days of food reintroduction.

Methods: Children with CD (age 6-17 years), clinically responding to EEN, were recruited, prospectively, from 11 UK hospitals (January 2020-May 2023, NCT04225689). They provided a single faecal sample before EEN completion (timepoint A) and 6 serial samples (timepoints B-G; 3, 6, 9, 12, 15, 21 days) in the first 21 days of food reintroduction. Faecal short (SCFA) and branched (BCFA) chain fatty acids were measured as proxies of fibre and protein bacterial fermentation, respectively. In faeces, pH, water content (%), Bristol stool score, total microbial load (qPCR) and starch output were measured. Clinical parameters, medications, CRP, ESR, albumin and anthropometry were recorded at EEN completion. Nutrient and food group intake was analysed with Nutritics®. Relationships with FCAL levels were explored.

Results: Thirty children provided 209/210 (99%) of expected faecal samples. FCAL (median [Q1, Q3], mg/kg) increased within 12 days of food reintroduction (EEN completion: 328 [154, 2370] vs 12 days post-EEN: 1123 (451, 2073), $p<0.01$) and remained high throughout follow-up. Negative correlations were observed between FCAL with acetate, whereas positive correlations were noted with BCFA (isovalerate and isobutyrate) and their ratio over acetate; the latter remained significant at all 7 timepoints (Figure 1A). Use of immunosuppressants, blood inflammatory markers, clinical and anthropometry at EEN completion were not predictive of FCAL increase post-EEN.

In a subset of patients with FCAL<250 mg/kg at EEN completion, (n=13/30), subset regression using 'end of EEN' diet-related microbial data, generated a model with 91% accuracy to predict FCAL increase over 250 mg/kg at 21 days of food reintroduction, with isovalerate being the sole predictor of FCAL recurrence (Figure 1B). Average intake of cereal products (median [Q1, Q3], g/day) over 21 days was lower in patients who experienced an FCAL recurrence (FCAL<250mg/kg: 313 (223, 370) vs FCAL>250mg/kg: 186 (167, 217), p=0.013). Positive correlations were observed between the 21-day average intake of cereal products and concentration of SCFA at 21 days post-EEN; acetate (rho=0.38, p=0.041), butyrate (rho=0.46, p=0.0.01) and total SCFA (rho=0.41, p=0.026).

Conclusions: This study suggests that early FCAL rebound, following treatment with EEN, is related to an increased ratio of dietary protein to fibre bacterial fermentation and a lower intake of cereal products



OC3

PINPOINT: The prospective epidemiology of paediatric-onset inflammatory bowel disease in the UK – a prospective, national, cohort study by Paul Henderson[1,2], Liz Dobson[3], IBD Registry[4], PINPOINT Collaborators[2] ,[1]*Department of Paediatric Gastroenterology and Nutrition, Royal Hospital for Children and Young People, Edinburgh.* [2]*Child Life and Health, University of Edinburgh, Edinburgh.* [3]*Senior Management, IBD Registry, London.* [4]*IBD Registry, IBD Registry Ltd, London.*

Paediatric inflammatory bowel disease (PIBD) incidence and prevalence is increasing worldwide. Robust epidemiology can inform new aetiological hypothesis, inform healthcare provision and improve patient outcomes. The last prospective United Kingdom (UK) PIBD incidence study was performed in 1999 (5.2/100,000/yr); we aimed to update this incidence data and to provide a robust prevalence figure for PIBD prospectively across the UK.

Robust site selection identified all units in the UK providing endoscopy services for paediatric patients. Patients were included if they were diagnosed with Crohn's disease (CD), ulcerative colitis (UC) or IBD-unclassified (IBD-U) less than 16yrs of age while a permanent UK resident. A custom-built spreadsheet was used to record basic demographics prospectively from June 2021 – December 2022 (18 months). A point prevalence study on 28th February 2023 was also performed capturing all patients under 16yrs of age living in the UK. A subset of patients was approached to provide consent for future clinical note review, data linkage and future contact (the PINPOINT cohort). Multiple data points were triangulated to avoid duplicate records. Data was securely collated electronically by the IBD Registry (www.ibdregistry.org.uk) and basic descriptive statistics performed in R v4.1.3. Publicly available population data was used to calculate rates.

All 34 selected sites prospectively recorded cases; all were diagnosed by ileocolonoscopy. During the study 2,243 new diagnoses were recorded (1,050 patients [47%] also consented to join the PINPOINT cohort). UK PIBD incidence was 12.1/100,000/yr (England/Wales 11.7/100,000/yr, Northern Ireland 12.7/100,000/yr, Scotland 17.2/1000,000/yr). CD (56%) was more prevalent than UC (33%) and IBDU (11%). Median age at diagnosis was 12.9yrs (IQR 10.6-14.5). There was a male preponderance (62%) with CD, IBDU and UC having male to female ratios of 1.8, 1.7 and 1.4 respectively. With regard to ethnicity 72% of patients identified as white; those of other ethnicities were diagnosed younger (12.1yrs vs 13.0yrs; $p<0.001$) and had a higher incidence of UC (38.5% vs 30.3%; $p=0.003$). Regarding prevalence, 6,116 patients aged less than 16 years were identified as living with IBD on 28th February 2023 giving a UK prevalence of 49.6/100,000 (England/Wales 48.7/100,000, Northern Ireland 53.3/100,000, Scotland 58.6/1000,000).

There has been over a two-fold rise in PIBD incidence across all regions of the UK since 1999 with the first accurate prevalence figure mirroring this rise. Further detailed analysis of epidemiological trends using these data and the PINPOINT cohort are merited to drive improved care for this growing group of patients with high healthcare needs.

OC4

Understanding anti-TNF treatment failure in Crohn's disease: mechanisms and management of loss of response to anti-TNF therapy, three-year data from the PANTS study by Neil Chanchlani[1], Simeng Lin[1], Claire Bewshea[2], Benjamin Hamilton[1], Amanda Thomas[1], Rebecca Smith[1], Christopher Roberts[1], Maria Bishara[1], Rachel Nice[3], Charlie Lees[4], Shaji Sebastian[5], Peter Irving[6], Richard Russell[7], Timothy McDonald[3], James Goodhand[1], Tariq Ahmad[1], Nicholas Kennedy[1], *[1]Department of Gastroenterology, Royal Devon and Exeter Hospital NHS Foundation Trust, Exeter. [2]Exeter IBD Pharmacogenetics Research Group, University of Exeter. [3]Department of Blood Science, Royal Devon and Exeter Hospital NHS Foundation Trust, Exeter. [4]Edinburgh IBD Unit, Western General Hospital, NHS Lothian, Edinburgh. [5]Gastroenterology and Hepatology, Hull and East Yorkshire Hospitals NHS Trust, Hull. [6]Department of Gastroenterology, Guy's and St Thomas' NHS Foundation Trust, London. [7]Department of Paediatric Gastroenterology, Hepatology and Nutrition, Royal Hospital for Children & Young People, Edinburgh, UK.*

Background: We sought to report the effectiveness of infliximab and adalimumab over the first three years of treatment and to define the factors that predict anti-TNF treatment failure and the strategies that prevent and/or mitigate loss of response (LOR).

Methods: Personalised Anti-TNF Therapy in Crohn's disease (PANTS) is a UK-wide, multicentre, prospective observational cohort study reporting the rates of effectiveness of infliximab and adalimumab in Crohn's disease in patients aged 6 years and over. At the end of the first-year, sites were invited to enrol participants still receiving drug in to the two year PANTS-extension study between March 19th 2014 and September 21st 2017. We estimate rates of remission across the whole cohort at the end of years one, two and three using a modified survival technique with permutation testing. Multivariable regression and survival analyses were used to identify factors associated with LOR in patients who had initially responded to anti-TNF therapy.

Results: 387/955 infliximab-treated patients and 207/655 adalimumab-treated patients, 44% (96/219) paediatric patients aged 10 - 17 years, were recruited to the PANTS study entered the PANTS-extension The estimated proportion of patients in remission at the end of years one, two, and three were, for infliximab: 40.1% (95%CI 36.7 – 43.7), 34.4% (95%CI 29.9 – 39.0), and 34.7% (95%CI 29.8 – 39.5) and for adalimumab: 36.0% (95%CI 31.4 – 50.6), 32.9% (95%CI 26.8 – 39.2), and 28.9% (95%CI 21.9 – 36.3), respectively. Optimal drug concentrations at week 14 to predict remission at any later timepoints were 6.1 - 10 mg/L for infliximab and 10 - 12 mg/L for adalimumab.
LOR events for infliximab and adalimumab-treated patients were predicted by low anti-TNF concentrations at week 14 (infliximab: hazard ratio [HR] 0.43 [95%CI 0.29 – 0.63] for each 10-fold increase in drug concentration, adalimumab: HR 0.33 [95%CI 0.19 – 0.56]). For infliximab-treated patients, LOR was also associated with female sex (HR 1.47 [95%CI 1.12 - 1.92] and obesity (HR 1.88 [95%CI 1.25 – 2.82]).

Anti-drug antibodies associated with undetectable drug concentrations were detected in 44.0% (95%CI 38.1 – 49.4) and 20.3% (95%CI 13.8 – 26.2) of infliximab and adalimumab-treated patients by the end of year three, respectively. Treatment with an immunomodulator prior to, or at the time of, starting infliximab, but not adalimumab, was associated with increased survival without immunogenicity. The optimal thiopurine dose when used with infliximab was at least 2.2 mg/kg azathioprine and 1.1 mg/kg mercaptopurine. Amongst infliximab-treated patients whose dose was intensified at the point of LOR, those who experienced immune-mediated pharmacokinetic failure had the lowest rates of drug persistence.

Conclusion: Only about one-third of patients with active luminal Crohn's disease treated with an anti-TNF drug are in remission at the end of three years of treatment. LOR was predicted by low drug level. The emergence of anti-drug antibodies associated with undetectable drug concentrations can be mitigated by an immunomodulator started prior to, or on the day of, the first infliximab infusion.

References

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OC5

Effectiveness and safety of switching to subcutaneous infliximab in paediatric inflammatory bowel disease patients on established intravenous biosimilar infliximab maintenance therapy: real world data from a regional cohort by Laura Gianolio[1], Katherine Armstrong[1], Ewan Swann[2], Rhona Shepherd[1], Paul Henderson[1,3], David C. Wilson[1,3], Richard K. Russell[1,3], *[1]Department of Paediatric Gastroenterology, Hepatology and Nutrition, Royal Hospital for Children and Young People, Edinburgh, UK. [2]Paediatric Pharmacology, Royal Hospital for Children and Young People, Edinburgh, UK. [3]Child Life and Health, Centre for Inflammation Research, University of Edinburgh, Edinburgh, UK.*

Real-world data regarding subcutaneous infliximab (SC-IFX) in paediatric IBD (PIBD) patients is scarce. Our aim was to assess the feasibility of a switching program from intravenous infliximab (IV-IFX) to SC-IFX as maintenance in selected PIBD patients.

We analysed a prospectively-identified, single regional centre, cohort of PIBD patients who were in clinical remission on established biosimilar IV-IFX maintenance and were switched to SC-IFX (120mg every other week). Disease activity was monitored using PUCAI/wPCDAI scores, faecal calprotectin (FC), C-reactive protein (CRP) and erythrocyte sedimentation rate (ESR). Infliximab trough levels/antibodies were collected pre- and post-switch; levels reported as >14.0ug/ml were approximated to 14.0ug/ml. ANOVA with Bonferroni correction was used to analyse longitudinal trends.

Overall, 18 patients (50% male; median age at the switch: 17.1 years, IQR:16.2-17.7), 9 with Crohn's disease, were switched to SC-IFX as maintenance treatment. Patient details are summarised in Table 1. At baseline 11/18 (61%) were on co-immunosuppression on a median IV-IFX maintenance of 10 mg/Kg 6 weekly; 13/18 (72%) were in luminal remission. Cannulation issues (7/18, 39%) and geographical location (9/18, 50%) were the main reasons for switch. High treatment persistence (16/18, 89%) was observed with median SC-IFX length of 6 months (IQR:2-18). Concerning the 2 patients who discontinued SC-IFX, one stopped the treatment after 1.5 months due to high IFX-antibodies, already present before switching, and the second discontinued it after 17 months during a disease flare (wPCDAI 20, FC >1250ug/g) with decreased infliximab trough levels (pre switch: 14.0ug/ml; post switch: 6.1ug/ml). There was no difference in median infliximab trough levels at baseline (14.0ug/ml, IQR:12.1-14.0), 6 weeks post-switch (14.0ug/ml, IQR:12.7-14.0), 40 weeks (14.0ug/ml, IQR:13.3-14.0) and 70 weeks (14.0ug/ml, 12.0-14.0) (all p:>0.05). No newly-developed IFX-antibodies, adverse reactions or need for steroid rescue therapies were observed on SC-IFX. All patients were satisfied with the switch. Comparable direct costs were estimated for 6 weekly management (IV-IFX £410 vs. SC-IFX £482) but halved indirect costs (-£616, 54% saved yearly per patient) and reduced travel times (-4.2 hours saved yearly per patient) favour use of SC-IFX.

Our real-world data among selected PIBD patients switched to SC-IFX as maintenance reveal high treatment persistence with no new safety signals. No significant changes in clinical and biochemical disease activity or infliximab levels were noted with potential advantages in terms of patients' quality of life and healthcare burden. Further replication studies are required.

Table 1. Population characteristics pre and post-switch to SC-IFX.

Population Characteristics	**Population** (N = 18 patients)
Diagnosis Crohn's disease N (%) Ulcerative colitis N (%) IBD-Unclassified N (%)	 9/18 (50%) 8/18 (44%) 1/18 (6%)
Age at SC-IFX switch (years) Median (IQR)	17.1 (16.2-17.7)
Weight at SC-IFX switch (Kg)	63.0 (56.9-78.3)

Median (IQR)	
IV-IFX regimen at switch (10mg/kg) 8 weekly N (%) 6 weekly N (%) 5 weekly N (%) 4 weekly N (%)	 3/18 (17%) 7/18 (39%) 1/18 (6%) 6/18 (33%)
IV-IFX length (months) Median (IQR)	21.5 (13.8-49.0)
SC-IFX length (months) Median (IQR)	6 (2.0-14.8)
Faecal calprotectin pre-switch (ug/g) Median (IQR)	30 (25-117)
Faecal calprotectin post-switch (ug/g) Median (IQR)	70 (25-143)
Treatment discontinuation N (%)	2/18 (11%)

OC6

Sustained increase in paediatric inflammatory bowel disease incidence across the South-West of the United Kingdom over the last 10 years by Zachary Green[1,2], James J Ashton[1,3], Astor Rodrigues[4], Christine Spray[5], Lucy Howarth[4], Akshatha Mallikarjuna[5], Neil Chanchlani[6], James Hart[6], Christopher Bakewell[1], Kwang Yang Lee[5], Amar Wahid[2], R Mark Beattie[1], *[1]Department of Paediatric Gastroenterology, Southampton Children's Hospital. [2]Department of Paediatric Gastroenterology, Noah's Ark Children's Hospital for Wales. [3]Department of Human Genetics and Genomic Medicine, University of Southampton. [4]Department of Paediatric Gastroenterology, Oxford University Hospitals. [5]Department of Paediatric Gastroenterology, Bristol Children's Hospital. [6]Department of Paediatrics, Royal Devon University Healthcare NHS Foundation Trust.*

Paediatric inflammatory bowel disease (pIBD) incidence has increased over the last 25-years [1]. Datasets demonstrating this change in the United Kingdom have come from single centres or regions [2,3]. Heterogeneity is described in national and international cohorts; particularly in age group and disease subtype [1,4].

This work collected data over a greater population and multiple centres, in order to capture better resolution of incidence. We aimed to establish developing trends in incidence and highlight the demand for changes in service provision.

Data were provided from five centres covering the South-West of the United Kingdom, with a total area at-risk population (<18-years) of 2,947,534 [5]. Cases were retrieved for 2013-2022. Incident rates were calculated based on referral area populations, with temporal trends analysed through correlation. Subgroup analysis was undertaken for age groups - Very-Early Onset Inflammatory Bowel Disease (VEOIBD) (0-6 years); Early Onset Inflammatory Bowel Disease (EOIBD) (7-11 years); Paediatric-onset Inflammatory Bowel Disease (PIBD) (12-17 years) - gender and disease subtype. Choropleth maps were created for local districts (Figure 1).

In total 2,497 cases were diagnosed between 2013-2022, mean age 12.6 years (38.7% female). Diagnosis numbers increased from 187 to 376, with corresponding incidence rates of 6.0/100,000/year (2013) and 12.4/100,000/year (2022) ($b=0.918$, $p<0.01$) (Table 1).

Female IBD rose from 5.1/100,000/year (2013) to 11.0/100,000/year (2022) ($b=0.865$, $p=0.01$). Male rates increased from 5.7/100,000/year to 14.4/100,000/year ($b=0.832$, $p=0.03$).

Crohn's disease incidence increased from 3.1/100,000/year to 6.3/100,000/year ($b=0.897$, $p<0.01$). Ulcerative Colitis increased from 2.3/100,000/year to 4.3/100,000/year ($b = 0.813$, $p=0.04$). IBD-Unclassified (IBDU) rates also increased, 0.6/100,000/year to 1.8/100,000/year ($b= 0.851$, $p=0.02$).

Statistically significant increases were seen in PIBD 11.2/100,000/year to 24.6/100,000/year ($b=0.912$, $p<0.01$), and EOIBD, with incidence rising from 4.4/100,000/year to 7.6/100,000/year ($b=0.878$, $p=0.01$). There was no statistically significant increase in VEOIBD ($b=0.417$, $p=0.231$).

We demonstrate significant growth in pIBD incidence across a large geographical area and over multiple sites. We report continued increases, particularly in older children, across gender and disease subtype. We note stable incidence in VEOIBD. Rising incidence has significant implications for service provision for healthcare providers managing IBD. Further socioeconomic analysis of this cohort may provide greater insight into the causation of pIBD.

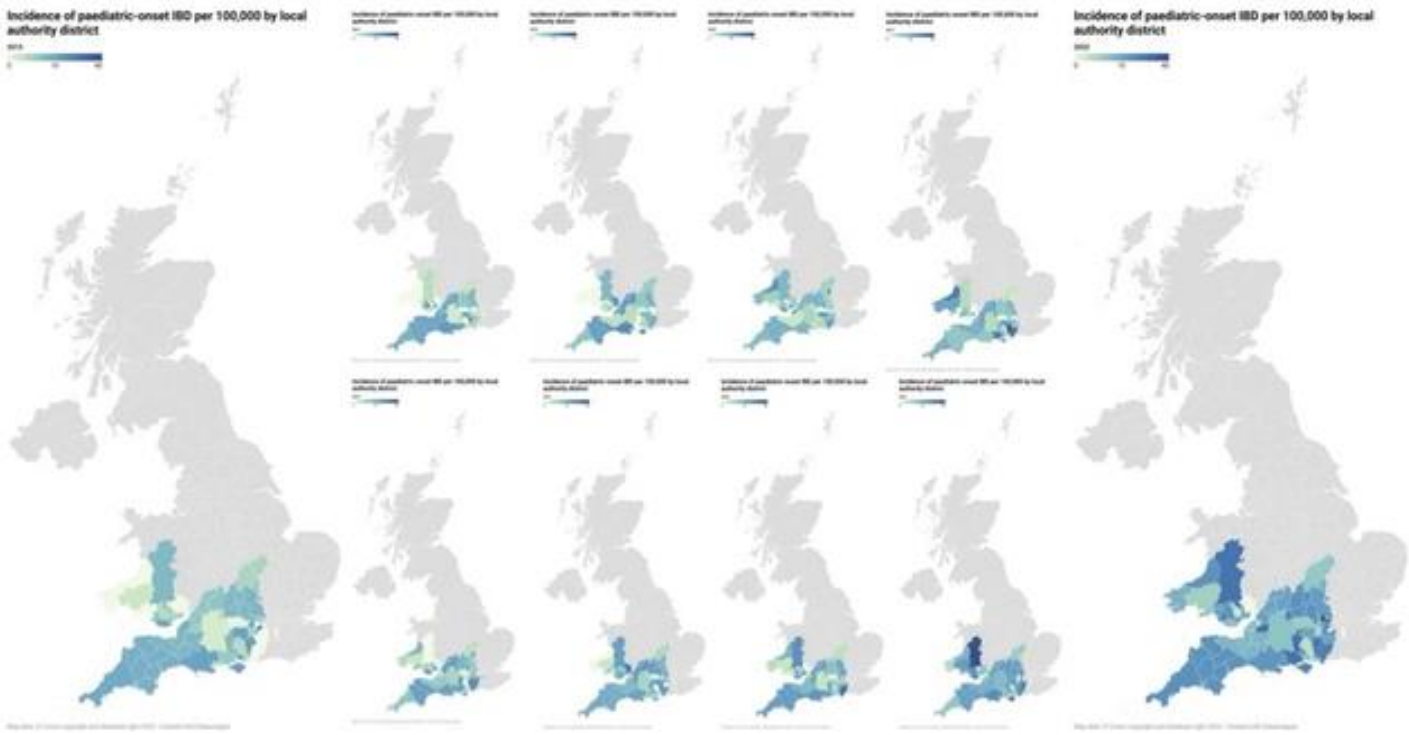

Figure 1 - Choropleth maps demonstrating incidence per 100,000 at-risk population for unitary and local authority districts 2013-2022

Table 1 - Total pIBD incidence per 100,000 at-risk population by year and disease subtype – b = Pearson's correlation coefficient.

	Incidence per 100,000 at risk population by year											
Disease Subtype	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	b=	p= (2 tailed)
Total Crohn's	3.1	3.3	4.2	3.5	4.1	4.0	4.7	4.9	6.1	6.3	0.897	<0.001
Total Ulcerative Colitis	2.3	2.7	1.8	2.8	2.8	2.9	3.5	2.6	3.4	4.3	0.813	0.004
Total IBDU	0.6	0.5	0.6	0.8	0.8	1.1	0.6	0.7	1.4	1.8	0.851	0.002
Total VEOIBD	1.1	1.1	1.1	1.5	0.6	2.0	1.4	0.6	1.4	2.2	0.417	0.231
Total EOIBD	4.4	4.3	5.4	4.6	4.5	6.5	6.5	5.7	8.0	7.6	0.878	0.001
Total PIBD	11.2	12.5	12.3	13.5	15.9	14.4	16.9	16.6	21.1	24.6	0.912	<0.001
Total	6.0	6.5	6.6	7.1	7.7	8.1	8.8	8.2	10.8	12.4	0.918	<0.001

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OC7

Liver fibrosis and correlations with genes related to muscle and adipose tissue metabolism in children with end-stage chronic liver disease by Eirini Kyrana[1,2], Cheng Zhang[3], Ragai Mitry[1], Siamak Salehi[1], Jonathan CK Wells[4], Maesha Deheragoda[4], Anil Dhawan[4,2] *Institute of Liver Studies, King's College London, London, UK. [2]Paediatric Liver, GI and Nutrition Centre, MowatLabs, King's College Hospital, London, UK. [3]SciLifeLab & KTH-Royal Institute of Technology, Stockholm, Sweden. [4]Institute of Child Health, UCL, London, UK.*

End-stage chronic liver disease (ESCLD) is associated with aberrations of systemic metabolism like sarcopenia and low respiratory quotient (RQ) linked to gluconeogenesis and fatty acid oxidation. We wanted to investigate correlations between genes expressed in the liver with genes expressed in muscle and adipose tissue in the context of childhood ESCLD aiming to discover genes or related molecular pathways that could inform future studies of how liver disease influences muscle and adipose tissue metabolism.

Liver tissue, muscle from the abdominis rectus and subcutaneous adipose tissue was collected at the time of liver transplant and samples were processed for gene expression by microarray analysis. Patients also had indirect calorimetry (RQ and resting energy expenditure per kilogram weight REE/Wt), basic anthropometry and standard labs including biochemistry recorded prior to liver transplant. Network analysis identified gene clusters in the liver, muscle, and adipose tissue and subsequently correlations were sought amongst gene clusters and clinical data.

13 patients had samples collected (6M:7F). Age range 7 months to 17 years. Median RQ 0.79 (mean 0.78), REE/Wt 53.7 Kcal/kg (mean 55.5), weight z-score -0.7 (mean -0.5), height z-score -1 (mean -0.7) and BMI z-score -0.3 (mean -0.3).

Liver gene cluster-1 which included genes related to liver fibrosis (e.g., ANXA5, DSG2, TES, BCL2L11, EPS8, HEG1, KIF3A, ITGB1, SUCO, ADGRL4, VCAN) correlated strongly with liver fibrosis biopsy index r=0.87** (both metavir and modified Ishak) and had a strong negative correlation with respiratory quotient (RQ) r= -0.77*, albumin r=-0.75* and urea r=-0.94**. It also had a strong significant negative correlation with muscle gene clusters-32 (r=-0.69*) and 35 (r=-0.78*). These included genes linked to inflammation, metabolism and proliferation of skeletal muscle like RelA (subunit of NfkB that sensitizes the cell to glycolytic enzymes and increases proliferation), IRF4 (metabolism of branch-chain amino acids and energy expenditure), FOXM1 (cell proliferation), TCF19 (regulates response to inflammation and DNA damage response), FHL2 (role in autophagy and myopathies), USF2 (role in mitophagy), FOXD3 (muscle development), FOXA2 (glucose sensing and fat metabolism), PREB (expression of glucokinase), RUVBL1 (ATP hydrolysis). These 2 muscle gene clusters also correlated independently with liver fibrosis index r=-0.84** and -0.85** respectively.

Liver gene cluster-1 had a strong negative correlation with muscle gene cluster-5 which had genes very well known for their association with muscle atrophy like TRIM-63 and FBX032, but muscle-5 didn't have any correlation with measures of indirect calorimetry.

Liver gene cluster-1 had a strong positive association with multiple genes regulated by RelA in adipose tissue gene cluster-1 (r=0.82*) and a strong negative correlation with multiple genes regulated by RXRA (when up-regulated increases import of fatty acids) and ZBTB16 (determines substrate utilisation in brown adipocytes and an increase in adiposity) in adipose tissue clusters-18 (r=-0.69*) and 35 (r=-0.7*) respectively.

Respiratory quotient had a negative relationship with liver tissue fibrosis and markers of liver function like urea and albumin. Genes related to fibrosis in the liver had a strong negative correlation with genes related to muscle metabolism and proliferation.

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OC8

Preservation of graft function with low rejection rates and good safety profile in paediatric liver transplant recipients on sirolimus by Sandra Fernandes Lucas, Penny North-Lewis, Marumbo Mtegha, Kavitha Jayaprakash, Palaniswamy Karthikeyan, Sanjay Rajwal, Suzan Warner, *Leeds Teaching Hospitals NHS Trust.*

Tacrolimus, a calcineurin inhibitor, is the maintenance immunosuppression of choice in paediatric liver transplant (LT) recipients (1-3). However, in selective cases, when this therapy requires discontinuation, sirolimus, a mTOR inhibitor is used as an alternative immunosuppressant (4, 5). We aimed to review our centre's experience using sirolimus immunosuppression as an alternative to tacrolimus in paediatric LT recipients. A single centre retrospective review was performed on paediatric LT recipients who were started on sirolimus as an alternative immunosuppressive therapy to tacrolimus. Children who were on sirolimus between 2017 and 2023 were included in the study.

A total of 16 children who underwent orthotopic liver transplantation (OLT) were started on sirolimus (median follow up time of 2.9 years (range 0.7-9.4)). There was equal gender distribution, the median age at time of OLT was 21.5 months (IQR 8.5,45) with sirolimus started at a median of 20 months (IQR 7.5,34) post OLT. The most common liver aetiology leading to transplant was Biliary Atresia (31.2%) followed by Progressive Familial Intrahepatic Cholestasis (25%). Post-Transplant Lymphoproliferative Disorder (PTLD) was the most common reason for tacrolimus discontinuation and conversion to sirolimus (n=11), followed by tacrolimus related adverse effects (n=4) and disease recurrence (n=1) (Table 1). There were no cases of PTLD recurrence or biopsy confirmed rejection whilst on sirolimus. The most common side effect observed on sirolimus was proteinuria followed by hyperlipidaemia. Fifteen patients remain on sirolimus to date, and none required discontinuation due to side effects. Interestingly, in patients with PTLD, 3 episodes of rejection occurred between the period that tacrolimus was discontinued and sirolimus was started (median time off 82 days), with one child regrafted due to ensuing chronic rejection. All children remained on prednisolone maintenance immunosuppression during this wash-out period while PTLD resolved.

In conclusion, the experience from our centre demonstrates sirolimus to be a safe and effective alternative to tacrolimus in a selected population of paediatric LT recipients. Further research with larger sample size is required to confirm these findings and evaluate the long-term safety of sirolimus in this population.

Summary of findings of Liver Transplant Recipients on Sirolimus		
Variable		Value, n (%)
Number of Paediatric Liver Transplant Recipients on Sirolimus		16
Indications for Liver Transplantation	Biliary Atresia	5 (31.2)
	Progressive Familial Intrahepatic Cholestasis	4 (25)
	Others	7 (43.8)
Indications for treatment change (tacrolimus* to sirolimus**)	Post-Transplant Lymphoproliferative Disorder	11 (68.8)
	Tacrolimus adverse effect	4 (25)
	Disease recurrence	1 (6.2)
Number of patients with confirmed rejection while transitioning from tacrolimus to sirolimus		3 (18.8)
Number of rejection episodes on sirolimus		0
Number of PTLD recurrences while on sirolimus		0
Number of patients who required re-grafting while on sirolimus		2 (12.5)

Most common side effect of sirolimus- proteinuria	12 (75)
Patient deaths whilst on sirolimus	0
Number of patients who remain on sirolimus	15 (93.8)

Table 1- Summary of patients' characteristics and variables exploring transition to sirolimus.
*Combination of tacrolimus and prednisolone (12/16) OR tacrolimus, prednisolone and MMF (4/16).
**Combination of sirolimus and prednisolone (14/16) OR sirolimus, prednisolone and MMF (2/16).

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OC9

Maralixibat improves xanthomas and hypercholesterolemia in children with Alagille syndrome: an integrated analysis from two clinical trials by Brett Hoskins[1], Douglas Mogul[2], Francois Smuts[2], Raul Aguilar[2], Wikrom Karnsakul[3], *[1]Pediatric Gastroenterology, Hepatology, and Nutrition, Indiana University School of Medicine, Riley Hospital for Children at IU Health, Indianapolis, Indiana. [2]Mirum Pharmaceuticals Inc., Foster City, CA USA. [3]Division of Pediatric Gastroenterology, Hepatology, and Nutrition, Department of Pediatrics, The Johns Hopkins Hospital School of Medicine, Baltimore, MD, USA.*

Unlike other causes of cholestasis, a unique manifestation of Alagille syndrome (ALGS) is xanthomas in one-quarter of patients and no approved medical therapies for xanthomas exist. As xanthomas have not been well-characterized, we evaluated their baseline characteristics, impact of maralixibat, an ileal bile acid transporter inhibitor approved for the treatment of cholestatic pruritus in patients with ALGS ≥2 months of age in the EU and ≥3 months of age in the US, on xanthomas, and correlates of xanthoma reduction following treatment.

Data were obtained from the maralixibat ALGS clinical trial program. Xanthomas were assessed using the Clinician Xanthoma Scale (CXS) with response defined as ≥1-point reduction in CXS (xanthomas at Baseline present) versus non-response as unchanged/worsened CXS.

27 of 63 (43%) individuals had xanthomas at Baseline. At Baseline, higher CXS was associated with lower age ($p=0.0284$), higher total/direct bilirubin ($p<0.0001$; $p<0.0001$), higher sBA ($p=0.0004$), higher total cholesterol and LDL ($p<0.0001$; $p=0.0556$), lower HDL ($p=0.0005$), lower PedsQL social functioning (SF; $p=0.0193$), and lower PedsQL physical functioning (PF, $p=0.0367$). With maralixibat, the proportion with no xanthomas (CXS 0) increased over 96 weeks, from 60% to 86%, while the proportion with moderate xanthomas (CXS 1-2) decreased from 33% to 9%, and the proportion with severe xanthomas (CXS 3-4) decreased from 9% to 6% ($p=0.0039$). Follow-up data to Week 96 were available for 35 individuals of which 14 (40%) had xanthomas at Baseline. From Baseline to Week 96, there was a decrease in total cholesterol (-57 mg/dL, $p=0.0009$) and LDL (-22 mg/dL, $p=0.0041$) and increase in HDL (14 mg/dL, $p<0.0001$). Of those with week 96 data, 10/14 (71%) were xanthoma-responders. Responders with QoL assessments (n=9) had improved PedsQL-SF (20) and PedsQL-PF (15.5), whereas non-responders had little change in PedsQL-SF (1.2) and PedsQL-PF (3.1). At Week 48, xanthoma-responders vs non-responders had decreased total cholesterol (-189 mg/dL vs -11 mg/dL; $p=0.0045$).

At Baseline, increased xanthomas was associated with biomarkers of disease and QoL. Xanthomas improved following treatment with maralixibat over 96 weeks. Xanthoma reduction was associated with improved QoL and total cholesterol.

OC10

Baseline survey on the management of paediatric eosinophilic oesophagitis in the UK and Ireland from the BSPGHAN EoE working group by Constantinos Regas[1], Georgia May[1], Joseph Chan[2,3], Amanda Cordell[4,3], Jenny Epstein[5,3], Diana Flynn[6,3], Mark Furman[7,3], Edward Gaynor[8,3], Lucy Jackman[8,3], Hema Kenappan[9,3], Vinod Kolimarala[10,3], Kerryn Moolenschoot[11,3], Raj Parmar[12,3], Chris Spray[13,3], Julie Thompson[14,3], Efrem Eren[15], Michel Erlewyn-Lajeunesse[15], Marcus KH Auth[12,3], Nadeem A Afzal[15,3], *[1]University Hospital Southampton. [2]Cardiff Children's Hospital. [3]BSPGHAN Eosinophilic Oesophagitis Working Group. [4]EOS Network. [5]Chelsea and Westminster Hospital. [6]Glasgow Children's Hospital. [7]Royal Free Hospital. [8]Great Ormond Street Hospital. [9]University Hospitals Coventry & Warwickshire. [10]Maidstone and Tunbridge Wells NHS Trust. [11]St George's Hospital, London. [12]Alder Hey Children's Hospital. [13]Bristol Children's Hospital. [14]GutsUK. [15]Southampton Children's Hospital.*

The BSPGHAN eosinophilic oesophagitis working group (EoE-WG) was established in 2020, and identified heterogeneity in the management of paediatric EoE. BSG/BSPGHAN consensus guidelines for EoE in children and adults were published in 2022(1). This baseline survey was conducted between March 2021 and December 2022 by the EoE-WG, with 45 respondents from 33 paediatric centres in the UK and Ireland. The survey explored clinical presentation, diagnostic approaches, treatment modalities, monitoring and service setups used by clinicians managing this condition.

Dysphagia and bolus impaction emerged as prominent symptoms, with around a third of respondents highlighting increased liquid intake during meals and slow eating/prolonged chewing as important behaviours. In children with limited language, distress during feeding, food aversion, vomiting/regurgitation, and weight loss/failure to thrive were prevalent. The majority of patients were diagnosed within a year of symptom onset, although children at some centres took up to five years. The median age at diagnosis was 10 years. Common comorbidities include asthma, eczema, and allergies, aligning with expectations. Surprisingly, whereas three-quarters of patients had asthma as a comorbidity, only a quarter of clinicians identified it as a risk factor for EoE. Tracheo-oesophageal fistula exhibited a relatively high co-existence, prompting consideration for further prevalence data collection.

Oesophagogastroduodenoscopy (OGD) was performed by 93% of responding clinicians. While duodenal biopsies were universally taken, the approach to oesophageal biopsies differed among clinicians, with most taking six biopsies from three oesophageal levels. The number of biopsies varied based on disease probability and practical considerations. Some centres found that two biopsies at each level showed good agreement on EoE features.

A majority of clinicians use histology for description of disease activity (71%), with endoscopic appearance being equally used to grade EoE severity (73%). Contrast swallows were commonly requested in cases of dysphagia or suspected mechanical obstruction, while impedance measurement was used in reflux-related symptoms. Few clinicians opted for additional tests.

Disease severity, protocols, and patient preference were the primary factors influencing the selection of first-line treatment. PPIs were the preferred medical therapy across all age groups (91%). Topical steroids were used as second most common treatment (69%, increasing to 82% as second-line treatment). Exclusion diets were more used by 62% of clinicians (more commonly in younger children). Approximately 36% of clinicians had not encountered stricturing disease. Dilatation (often in consultation with surgeons or radiologists) was favoured as first-line treatment for strictures, followed by topical steroids. PPIs and exclusion diets were less commonly chosen.

Most clinicians reviewed treatment at three months, relying on clinician-initiated symptom reviews and histology. Most clinicians (93%) did not use EoE quality of life scoring systems. The majority of clinicians expressed a preference for re-scoping (73% with, versus 87% without clinical improvement, although they also highlighted limited endoscopy capacity.

This survey provides valuable insights into the current practices in the management of EoE, highlighting variations in diagnostic and treatment approaches. The findings underscore the need for education, training, funded research and standardisation in the management of this chronic condition.

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2. Contributors to this detailed survey will be listed as collaborators.

OC11

Health professionals survey of transition service in eosinophilic oesophagitis in UK – a BSPGHAN EoE Working group initiative by Raj Singh Parmar[1], Kerryn Moolenschot[2], Amanda Cordell[3], Ed Gaynor[4], Lucy Jackman[4], Hema Kannappan[5], Jenny Epstein[6], Joseph Chan[7], Diana Flynn[8], Mark Furman[9], Julie Thompson[10], Marcus KH Auth[1], *[1]Alder Hey Children's Hospital, Liverpool UK. [2]St Georges Hospital, London. [3]EOS Network. [4]Great Ormond Street Hospital London. [5]University Hospital Coventry and Warwickshire. [6]Chelsea and Westminster Hospital NHS Foundation Trust. [7]Noah's Ark Children's Hospital. [8]Royal Hospital for Children, Glasgow. [9]Royal Free London NHS Foundation Trust. [10]Guts UK Charity.*

Eosinophilic esophagitis (EoE) is a chronic, immune/antigen-mediated oesophageal disease requiring surveillance and treatment for most patients[1] and an increasing prevalence of around 1 in 3000 in the UK[2,3]. It has significant impact on physical and mental health and quality of life. Formal transition of care from paediatric to adult services may improve symptom control, concordance with therapy and reduce emergency presentations[4]. Therefore the BSPGHAN EOE Working group evaluated current arrangements for transition of patients with EoE.

The BSPGHAN EoE WG held number of professional consultations and developed an EoE Transition survey questionnaire for professionals, patients and parents. The transition survey was circulated electronically via BSPGHAN newsletter, EOS network, GutsUK Charity website and WhatsApp to BSPGHAN/PeGHAN members.

The survey period ranged from October to Nov 2023 and received 29 health professionals response.

Majority response were received from Paediatric Gastroenterologists (15/29) followed by Paediatricians with special interest in Gastroenterology/allergy (11/29) and working in tertiary care (18/29) followed by secondary care (11/29) from all across the UK.

We identified variation between units in terms of professionals/teams looking after children with EOE (Figure 1).

Most of the professionals transfer care by referral to adult gastroenterologists (60%) followed by GPs (16%) and most of referrals were paper referrals (73%) followed by face 2 face in MDT setting or paediatric to adult referral pathway (12% each)

It seems typically transition / discharge of patient to adult services occur at 16yrs (17/29) followed by 17yrs (8/29), and 18 yrs (4/29).

A formal transition process is reported in only 27% (8/29) of units with no such process in 73% (21/29) units.

Among 8 units with established transition clinics, 5 units reports >50% attendance, and 3 units report <25% attendance.

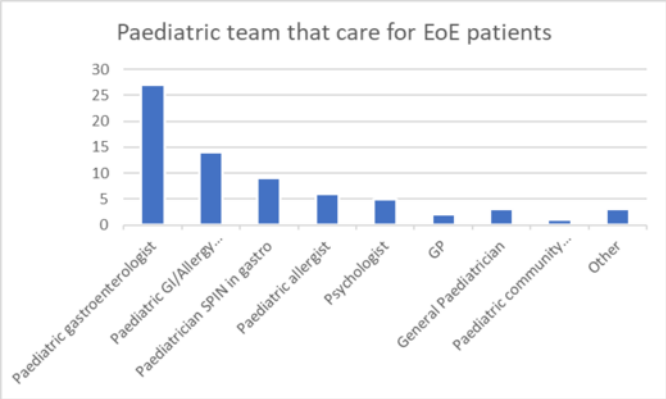
Out of 21 units with no formal transition process, 14 units consider the need.

Overall professionals identified following barriers for successful implementation of a transition process: Lack of guidance/guidelines on transition (27%), lack of resources (23%), lack of a transition clinic (20%), lack of adult gastroenterology service with EoE interest (20%), lack of adult dietitian (10%).

This transition survey captures view from all across the UK which represents the first nationwide EoE transition survey in the UK. The majority of EOE patients are discharged to adult gastroenterologist by means of traditional paper referral letter. Most of the units transition at the age of 16 years to 17 years. However national recommendation is for the transition process to start around 13-14 years of age[5]. There is lack of a formal transition process in 70 % of the units. In places where transition services are available there is good engagement as evidenced by high attendance. Main barriers for establishment of transition process is a lack of guidance/guidelines. The EoE working group is in the process of collecting responses from carers and patients and will develop evidence based guidance to patients and professionals.

Figure 1.

Paediatric team that cares for EoE patients in the region



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OC12

Umbrella review of effectiveness of digital technologies for the management of inflammatory bowel disease by Marco Gasparetto[1,2], Priya Narula[3], Charlotte Wong[4,5], James Ashton[6,7], Jochen Kammermeier[8], Marieke Pierik[9,10], Uri Kopylov[11], Naila Arebi[4,5], *[1]Norfolk and Norwich University Hospitals, Jenny Lind Children's Hospital, Norwich, Norfolk, UK. [2]University of East Anglia (UEA), Norwich Medical School, Faculty of Medicine and Health Science, Norwich, Norfolk, UK. [3]Department of Paediatric Gastroenterology, Sheffield Children's NHS Foundation Trust, Sheffield, South Yorkshire, UK. [4]Department of Inflammatory Bowel Disease, St Mark's National Bowel Hospital, London, UK. [5]Department of Metabolism, Digestion and Reproduction, Imperial College London, UK.. [6]Department of Paediatric Gastroenterology, Southampton Children's Hospital, Southampton, UK. [7]Human Genetics and Genomic Medicine, Faculty of Medicine, University of Southampton, Southampton, UK. [8]Department of Paediatric Gastroenterology, Evelina London Children's Hospital, London, UK. [9]Department of Gastroenterology-Hepatology, Maastricht University Medical Center, Maastricht, The Netherlands. [10]School of Nutrition and Translational Research in Metabolism, Maastricht University, Maastricht, The Netherlands. [11]IBD service, Department of Gastroenterology, Sheba Medical Center, Tel Hashomer, Israel.*

The use of digital technology is increasing significantly worldwide, with 67% of the global population (5.1 billion people) having subscribed to mobile internet services in 2018 [1]. Clinical trials assessing commercially available health tools are sparse, with limited evidence-based outcome data. Systematic reviews of the randomized clinical trials (RCTs) on digital health technology in inflammatory bowel disease (IBD) performed so far, provide mixed results from highly heterogeneous studies. This umbrella review aims to investigate the effectiveness of digital health technology for the care of patients with IBD, to identify research gaps and highlight areas where future work should focus on.

The following databases were searched for systematic reviews published from 2012 to August 2022: PubMed and Medline via OVID, Embase via Ovid, Cochrane Library and Prospero database of systematic reviews, CINAHL via EBSCO, PsycINFO via Ovid, AMED (Allied and Complementary Medicine database) via Ovid. Electronic search results were downloaded into the "Covidence" software and screened by two reviewers independently by titles and abstracts according to the inclusion and exclusion criteria. Standardised extraction forms were established in Microsoft EXCEL. The methodological quality assessment of the included reviews was performed using AMSTAR 2.0. [2]

The literature search identified 65 studies that were uploaded on the "Covidence" software for title and abstract screening. Three duplicates were removed. Of the 62 papers remaining, 32 were excluded based on title and abstract screening. The full text of the remaining 30 was analysed, with a resulting selection of 8 systematic reviews (four including meta-analyses) deemed relevant to this umbrella review. The RCTs on digital health technology in IBD conducted so far have identified aspects of IBD care that appear to benefit from the use of digital technology, including the patients' satisfaction, their quality of life and quality of care, their adherence to medications and a reduced number of hospital attendances. Existing trials have not, however, been able to prove a direct benefit of using technology to achieve or maintain clinical remission (Table 1).

Telemedicine should be regarded as an important adjuvant to routine clinical practice. Future larger trials with longer follow-up and defined interventions and outcomes have the potential to address unanswered questions in this area and to identify the patients with IBD who would most benefit from telemedicine so that these approaches can be tailored to specific groups.

Table 1. Colour-coded outcome summary table

Outcome	Author/year
IBD-related quality of life	Pang L, et al. 2022
	Gordon M, et al. 2022
	Huang VW, et al. 2014
	Rohde JA, et al. 2021
Disease activity	Pang L, et al. 2022
	Gordon M, et al. 2022
	Huang VW, et al. 2014 (Number of relapses)

Clinic/hospital visits	Pang L, et al. 2022 (Visits per patient)
	Gordon M, et al. 2022
	Huang VW, et al. 2014 (Visits per patient)
	Rohde JA, et al. 2021 (Hospital visits)
Medication adherence	Pang L, et al. 2022 (Compliance score)
	Gordon M, et al. 2022
	Rohde JA, et al. 2021

Table 1 legend: Primary outcomes in bold; “green”: positive effect; “amber”: no difference.

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OC13

Efficacy and safety of Upadacitinib in moderate to severe paediatric Crohn's disease and ulcerative colitis in a tertiary Paediatric IBD (PIBD) centre – A case series by Eleni Kontaki, Ayesha Merchant, Edward Gaynor, Fevronia Kiparissi, Great Ormond Street Hospital for Children, London, UK.

Upadacitinib is a selective Janus kinase 1 inhibitor approved for the treatment of patients 18 years and older with the diagnosis of Crohn's disease and ulcerative colitis. Although there is promising data for its use in adult inflammatory bowel disease (IBD), limited data are currently available on its use in paediatric IBD. We present our experience in this case series of patients ≤ 18 years on Upadacitinib.

We identified patients under the age of ≤ 18 years, started on Upadacitinib for the indication of IBD. Data on demographics, disease subtype, duration on Upadacitinib, number of biologic failures, tofacitinib use, concomitant biologic use, adverse events and clinical remission were gathered.

12 patients with paediatric IBD (median age at Upadacitinib start 15.5 years, range 13.9 to 17.8 years, 8 (67%) males, were identified. 7 patients had Crohn's disease, 3 patients had ulcerative colitis and 2 patients had IBD unclassified. 4 patients (33%) were diagnosed under the age of 6 years with early onset IBD (EOIBD), 1 was 3.5 years old, 1 was 4 years old and 2 were 5 years old. 11/12 (92%) patients had failed 3 or more biologics. Upadacitinib was used as monotherapy in all patients and previous biologic treatments were stopped. 1 patient with a partial response to tofacitinib was switched to Upadacitinib. All patients had active disease at commencement of Upadacitinib. All 12 (100%) patients were started on 45 mg of Upadacitinib. 8/12 (67%) patients have been followed up for at least 8 weeks. Out of the 8 patients, 5/8 (63%) patients were in clinical remission between 8-16 weeks of therapy, 2/8 (25%) had partial response and 1/8 (13%) has been refractory to treatment. Relapse of symptoms was noted in 1 patient after dose was dropped to 30 mg; this patient had achieved remission on 45 mg. No serious adverse events occurred; 2 patients noted to have increased triglycerides (max 5.75mmol/L; range 0.38-1.58mmol/L). 1 of them had previous exposure to tofacitinib and the triglycerides were already raised prior to starting Upadacitinib. 1 patient developed headaches, as a result, Upadacitinib dose was decreased. There were no incidences of shingles or other serious infections (Table 1).

Table 1. Patients characteristics

PATIENT	SEX	AGE AT DISEASE DIAGNOSIS (Y;MO)	AGE AT UPA START (Y;MO)	# OF BIOLOGIC FAILURES	TOFACITINIB EXPERIENCE	DURATION OF THERAPY (W)	MONOTHERAPY OR COMBINATION THERAPY	OUTCOME	AES
CD1	F	5y	15y 5mo	3	No	7	Mono	clinical response	
CD2	M	5y	13y 9mo	2	No	1	Mono	N/A	
CD3	M	7y 5mo	14y 8mo	3	No	22	Mono	partial response	
CD4	M	10y 5mo	16y 7mo	3	No	6	Mono	clinical response	
CD5	F	11y 5mo	15y 10mo	4	No	18	Mono	clinical response	Triglyceraemia
CD6	M	7y	15y 9mo	3	No	8	Mono	partial response	
CD7	M	4y	17y	4	No	26	Mono	clinical response; relapse on decreased dose	
UC1	F	3y 5mo	12y 1mo	4	No	7	Mono	clinical response	Headaches
UC2	M	11y	17y	4	Yes	13	Mono	clinical response	Triglyceraemia
UC3	M	15y	17y 8mo	3	No	11	Mono	clinical response	
IBD-U1	F	7y	17y 2mo	3	No	14	Mono	no response	
IBD-U2	M	14y 2mo	15y 2mo	3	No	24	Mono	clinical response	

Abbreviations: CD, Crohn's disease; UC, ulcerative colitis; IBD-U; inflammatory bowel disease unclassified; Upa, upadacitinib; AEs; adverse events

The patients in this case series, started on Upadacitinib, are a heterogeneous group with refractory disease. In these paediatric and adolescent patients Upadacitinib seemed safe and efficacious with a low side effect profile. Further national and international collaborative studies are needed to confirm our findings.

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OC14

The prevalence of Helicobacter pylori infection using monoclonal stool antigen test in apparently healthy Nigerian secondary school children in Surulere LGA Lagos state

by Elizabeth Ajayi[1], Oluwafunmilayo Adeniyi[2], James Renner[3], Chris Esezobor[4], *[1]Medway NHS Foundation Trust, Windmill Rd, Gillingham, Kent ME7 5NY. UK. [2]College of Medicine, University of Lagos. Lagos State, Nigeria. [3]Babcock University, Ilisan-Remo, Ogun State, Nigeria. [4]Lagos University Teaching Hospital, Ishaga RD, Idi-Araba 102215, Lagos, Nigeria.*

Helicobacter pylori (H. pylori) is known to cause chronic gastritis, peptic ulcer disease, gastric adenocarcinoma and mucous associated lymphoid tissue lymphoma and it is acquired in childhood.[1,2] There is limited knowledge about the prevalence and factors associated with H. pylori infection using a non-invasive method like the monoclonal stool antigen test with a high sensitivity, specificity and accuracy in Nigeria children. The current study aimed to determine the prevalence and the factors associated with H. pylori infection in apparently healthy Nigeria secondary school children in Surulere L.G.A of Lagos state.

A multistage sampling technique was used to recruit two hundred and fifty-nine apparently healthy children, aged 11 – 18 years (106 males, 153 females) in this descriptive observational study. A monoclonal stool antigen test was used to identify H. pylori while a pretested interviewer administered questionnaire was employed to obtain information on socio-demographic factors and their nutritional status was also determined to assess associated factors.

The majority (51.7%) were aged 11 – 13 years while about half were from the middle socio-economic class. The overall prevalence of H. pylori was 49.0% in 259 secondary school children as shown in Table 1.

Table 1: Prevalence of H. pylori infection using monoclonal stool antigen test

	Frequency	Percent
Stool Antigen Test	N = 259	% = 100.0
Positive	127	49.0
Negative	132	51.0

The age specific rates were 52.0% in children aged 11 – 13 years, 43.3% in children aged 14 – 16 years and 4.7% in the age group 17 – 18 years. H. pylori was associated with underweight malnutrition (p = 0.003) as shown in Table 2 but no association was found with age, gender, type of secondary school, Class category, maternal level of education and socioeconomic class.

Table 2: Relationship between nutritional status and prevalence of H. pylori infection

Variable	Positive H. pylori infection. n = 127	Negative H. pylori infection. n = 132	χ^2	p-value
Weight for Age Percentile				
< 3rd - Underweight	21 (16.5)	6 (4.5)	11.38	0.003**
3rd to 97th - Normal	104 (81.9)	120 (91.0)		
> 97th - Overweight	2 (1.6)	6 (4.5)		
Height for age z-score				
< -2 - Stunted	24 (18.9)	14 (10.6)	3.74	0.154**
-2 to +2 - Normal	99 (78.0)	112 (84.8)		

> +2 - Very Tall	4 (3.1)	6 (4.6)		
BMI for age z-score				
< -2 - Thin	8 (6.3)	5 (3.8)	1.03	0.794
-2 to +1 - Normal	103(81.1)	111(84.1)		
>+1 to +2 - Overweight	16 (12.6)	16 (12.1)		

(Figures in parenthesis are percentages of the total in column)

**Fisher's exact test applied

The prevalence of H. pylori infection is high among Nigerian secondary school children particularly in those who are underweight. Considering the long-term implication of H. pylori which includes gastric cancer[3,4] routine screening of underweight secondary school children for H. pylori is recommended.

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OC15

Location of histopathological changes in diagnostic biopsies for paediatric coeliac disease by Elizabeth Morrisroe, David Wood, Francesca Townsend, Andrew Fagbemi, Loveday Jago, Maureen Lawson, Adnaan Kala, Chai Lee, Virginia Chatzidaki, Sian Copley, *Royal Manchester Children's Hospital, UK.*

Coeliac disease (CD) is a gluten triggered autoimmune enteropathy with a global prevalence of around 1%.[1] Its clinical presentation varies from no symptoms to malabsorption and extra-intestinal manifestation.[2] This can lead to diagnostic challenges and delays in many patients. CD-specific antibodies (including anti-tissue transglutaminase (TTG) and endomysial antibodies (EMA)) are present, and enteropathy with villous atrophy, crypt hyperplasia and intraepithelial lymphocytes are found on duodenal biopsy.[1,3] The most recent (2020) European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) guidelines recommend endoscopic collection of at least 4 biopsies from the second part of duodenum (D2) and at least 1 biopsy from the first part (D1).[3]

Biopsies taken for CD in a single tertiary centre were evaluated to identify location of histological confirmation of CD. We aimed to evaluate location of histological changes (D1 versus D2), hypothesising that more disease would be identified in D1 based on local case discussion and increasing reports in literature of higher diagnostic yield in D1.[4,5]

73 children were identified retrospectively from the departmental CD database diagnosed on biopsy between 2015 – 2022 with complete histology records (29 male, 44 female). Patients diagnosed in other centres or without complete histology reports including specification of location of duodenal biopsy were excluded.

Data was collected from patient records on gender, age at diagnosis, co-morbidities, TTG and EMA results and diagnostic biopsy reports. This data was then analysed with particular focus on which area of the duodenum diagnostic histopathological changes were seen on.

Mean age at diagnosis was 9 years old (range 1 to 16 years). 72/73 patients had diagnostic changes in D1 (98%) and 47 (64%) in D2. 46/73 (63%) had changes in both D1 and D2. 26/73 (36%) had changes in D1 only and 1/73 (1%) had changes in D2 only. Mean TTG at diagnosis in those with solitary changes to D1 was 70 compared with a mean of 153 in those with changes to both D1 and D2.

The vast majority of patients in this study had diagnostic changes in the proximal duodenum, with over a third having changes only in D1 and not in the distal duodenum. Solitary changes in D1 were noted particularly with lower levels of TTG upon diagnosis. This data suggests that a change in practice, to routinely collect more samples from the proximal duodenum, may be indicated in order to increase likelihood of obtaining diagnostic samples during endoscopy.

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OC16

Regional nutrition support meetings are cost effective and reduce hospital admissions: a tertiary service evaluation

by Helen Penny, Gabrielle Petty, Kate Jones, Nicola Birdsey, Jessica Girvin, Joe Chan, Huda Atta, Amar Wahid, *Cardiff & Vale University Health Board, UK.*

The RCPCH PGHAN standards in 2017 envisioned the management of patients with complex nutritional needs through regional multidisciplinary networks (RCPCH, 2017). To provide equitable access to tertiary nutrition services in South Wales, a fortnightly nutrition support meeting was established in 2022 for regional network members to discuss cases with the specialist MDT.

The South Wales PGHAN network comprises five health boards, with local specialist interest consultants in each supported by varying provision of MDT members. The tertiary MDT includes gastroenterologists, specialist dietitians, nurses, SLT, psychologist & pharmacist. Regular virtual meetings provide an opportunity for local teams to discuss patients with nutritional challenges and supports clinical decision making, feeding plans and co-ordinates investigations.

Case notes were reviewed retrospectively for all patients discussed in the regional nutrition support meeting for the period September 2022 – September 2023. Outcomes were categorised to those requiring tertiary care, either escalation or ongoing, and those managed locally. These categories were further divided into those requiring inpatient or outpatient care.

It was assumed that all referrals would have required a tertiary outpatient referral or tertiary hospital admission in the absence of this meeting, and calculations are based on the average cost of a tertiary outpatient appointment with a consultant and 1 band 7 healthcare professional (£387), and a 7-night hospital stay at the tertiary centre for those requiring admission (£1210/night).

106 patients were reviewed in 28 regional nutrition meetings over 1 year. 58% (n=62) of patients were managed locally with advice, 26% (n=28) required escalation to tertiary care, and 15% (n=16) continued under the tertiary centre.

Table 1. Location of patient management

	Number	%
Managed locally	62	58
Escalated to tertiary care	28	26
Continue tertiary care	16	15
TOTAL	106	100

Of the patients escalated or continuing tertiary care, 59% (n= 26) required inpatient management, and 41% (n=18) were managed as outpatients.

Of the patients managed locally, 5% (n=3) were admitted to their local hospital with support and advice from the tertiary centre, thus preventing an admission to the tertiary centre. 95% (n=59) were managed as outpatients by the local team following advice from the nutrition support meeting, thus preventing an estimated 59 clinic appointments at the tertiary centre. Based on prevention of 3 tertiary hospital admissions and 59 clinic appointments, we estimate a saving of approximately £48,000.

Virtual fortnightly nutrition support meetings offer significant potential financial savings, and importantly, facilitate equitable care close to home. Regional tertiary services in the UK should consider adopting multidisciplinary nutrition support meetings to prevent unnecessary referrals and empower local teams to successfully manage patients with complex nutritional needs.

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OC17

A national survey on the feeding practices of United Kingdom children with paediatric intestinal pseudo-obstruction (PIPO) by Alessandra Mari, Keith James Lindley, Jutta Köglmeier, *Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK.*

Paediatric chronic intestinal pseudo-obstruction (PIPO) is the most severe disorder of gut motility in childhood, and it is associated with significant morbidity and poor quality of life (1). Despite advances in diagnostic work up, lack of a uniform therapeutic pathway contributes to difficulties in managing these children. Consensus on how and if patients should be fed (solid or bite and dissolve oral diet, gastric, jejunal or parenteral feeding) is lacking. Our aim was to investigate the current feeding practices amongst UK paediatric Gastroenterology centres caring for children (< 18 years) with PIPO to aid developing an evidence-based consensus guideline.

An electronic questionnaire was circulated via BSPGHAN. Data collected (October – November 2023) included patient demographics, disease phenotype, oral/enteral/parenteral feeding, and anthropometrics.

42 questionnaires were received from three large paediatric Gastroenterology centres across the UK: 2/42 did not meet PIPO criteria, 4/42 were duplicates as seen in 2 centres; 36/42 were hence included.

22/36 (61,1%) patients were female, 25/36 (69.4%) white British. 15/36 (41,6%) became symptomatic during the neonatal period and 23/36 (63.8%) within the first year of life.

29/36 (80,5%) patients had neuropathic and 4/36 (11,1%) neuromyopathic features on antroduodenal manometry, 3/36 (8,3%) had myopathic abnormalities on full thickness intestinal biopsies, 1 (2,8%) neuropathic and 1 neuromyopathic. 3/36 (8,3%) patients had mutations in the ACTG2 gene and 1 (2,8%) had a mitochondrial disease (POLG-associated). 8/36 (22,2%) had delayed gastric emptying, 4/36 (11,1%) delayed small bowel transit.

5/36 (13,9%) were fed with a normal solid diet: 2/36 (5,5%) of these never required artificial feeding, 2/36 (5,5%) reestablished a normal diet after short term parenteral nutrition (PN) in the first year of life, 1/36 (2,8%) reestablished oral eating after 10 years of total PN following small bowel transplant.

31/36 (86,1%) required permanent artificial feeding (enteral and/or parenteral) after an average time of symptoms of 14 months. 2/36 (5,5%) were exclusively on enteral nutrition (EN), 4/36 (11,1%) on total PN. 25/36 (69,4%) received a combination of PN and oral diet (normal, or bite and dissolve, or normal but minimal intake) and/or EN (table 1).

For the 29/36 (80,5%) on PN (9/36 (25%) partial, 20/36 (55,5%) total), average time between onset of symptoms and start of PN was 2 years. Average number of PN nights per week was 6,8.

The results show that feeding practices amongst UK centres caring for children with PIPO vary widely. Larger studies are needed to develop an evidence-based practice guideline.

Table 1: Mode of feeding of PIPO patients

	n	%
SINGLE TYPE of FEEDING		
Oral only	5	13,9%
EN only	2	5,5%
PN only	4	11,1%
COMBINATION OF TYPES OF FEEDING		
Partial PN + Normal oral	3	8,3%
Partial PN + EN	3	8,3%
Partial PN + aminoacidic formula + bite and dissolve	1	2,8%
Partial PN + Jejunal + bite and dissolve	1	2,8%

Partial PN + oral + jejunal	1	2,8%
Total PN + jejunal	2	5,5%
Total PN + gastric	1	2,8%
Total PN + normal diet	2	5,5%
Total PN + minimal oral intake	6	16,7%
Total PN + bite and dissolve	5	13,9%
TOTAL	36	

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OC18

A single-centre experience utilising tofacitinib in paediatric acute severe colitis: focus on colectomy-free survival and adverse events by Ben Rose, Zachary Green, Jessica Girvin, Emma Trow, Amar Wahid, *Department of paediatric gastroenterology, Noah's Ark Children's hospital for Wales, Cardiff, UK.*

Adult data have demonstrated promising benefits of tofacitinib, a small molecule Janus Kinase (JAK) inhibitor for preventing colectomy in inpatient steroid and anti-TNF unresponsive patients with acute severe colitis and for induction and maintenance of remission [1]. A concerning safety profile, including infection risk and venous thromboembolism have been documented, and tofacitinib remains unlicensed in the paediatric population [1,2]. We aim to report our experience of using this medication within a specialist paediatric gastroenterology cohort. The primary outcome was colectomy-free survival at 90 days. Secondary outcomes were total colectomy rate, steroid-free remission rates and tofacitinib-related adverse events.

Data from the paediatric gastroenterology specialist referral centre prospective pIBD database were retrieved for 2019-2023, the period over which tofacitinib had been utilised. Patients were included if they had a Porto criteria diagnosis of ulcerative colitis (UC), were under 18 years of age at diagnosis and had received tofacitinib. Records were reviewed for demographics and medical and surgical treatment history, including steroid use, prior biologics, pre- and post-tofacitinib inflammatory markers and adverse events. Baseline characteristics and outcomes were described by counts and percentages.

A total of 5 children (1 male and 4 females; 5 UC with pancolitis) were analysed. All patients received tofacitinib induction and maintenance treatment, continued for duration of follow-up. The mean age at diagnosis was 11.2 years and mean age at initiation of tofacitinib therapy induction was 12.8 years. Four out of five patients (80%) failed to achieve remission with at least 2 biologics including at least 1 anti-TNF therapy over a mean duration of 1.5 years. Further demographic information is included in table 1.

All patients remained colectomy-free at 90 days. Four of five patients were colectomy-free over the course of total follow-up, mean duration 9.8 months. Four of five patients included were steroid independent at 90 days, mean time to steroid discontinuation was 59 days. Three of five patients achieved steroid-free clinical remission at 90 days, maintained over maximal follow-up duration. One patient requiring colectomy was not steroid independent at time of procedure and had no post-operative complications. No patients had unplanned readmissions for worsening UC symptoms. No serious tofacitinib adverse events were observed over the follow-up period. One patient reported facial rash which was non-infective or pruritic and self-resolved.

Our cohort reflect reported high rates of short-term colectomy free survival in acute severe colitis. We did not observe reported incidence of adverse events; possibly due to small sample size. Multi-centre reporting of paediatric experience with emerging biologic therapies are required to further demonstrate utility, particularly over prolonged follow-up, as well as side effect rates. High-quality large-scale studies are required [3].

Table 1 – Demographic characteristics of tofacitinib cohort; years (y)

Total Chort	n=5
Sex (female), no. (%)	4 (80)
Age - initiation of tofacitinib, y (mean)	12.8
Mean disease duration (y)	1.49
Mean duration of follow-up (y)	0.82
Prior biologic expsoure, no. (%)	
Infliximab	5 (100)
Vedolizumab	4 (80)

Concomitant steroids, no. (%)	3 (60)

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OC19

Characteristics and treatment of children admitted to tertiary hospital with Functional vomiting/rumination disorder by Olivia Edgar, Nicole Ward, Sophie Velleman, Lauren McVeigh, Christine Spray, *Bristol Royal Hospital for Children, UK.*

Functional GI disorders (FGIDs) represent a variable combination of chronic or recurrent symptoms attributed to the GI tract that are not explained by structural causes (Longstreth et al) They are considered to be disorders of gut-brain interaction due to interactions between psycho-social factors, genes, environment, and physiological factors. FGID include functional vomiting and rumination syndrome and if severe, patients require hospital admission and can be challenging to manage. (Murray et al)

Our aim is to investigate presentation, investigation, management and outcomes of children admitted to a tertiary paediatric gastroenterology centre with FGID and assess the input from our multidisciplinary medical, psychology and dietetic team.

We used discharge codes to identify children admitted in the past 5 years with vomiting, children with organic disease and anorexia were excluded. We reviewed their medical records to assess their presenting symptoms, investigations, medical, dietetic and psychological management and frequency of inpatient and outpatient hospital contacts.

Nineteen patients were identified (12 female,7 male), 17 were White British, 1 was Black/British African and 1 patient's ethnicity was unknown. Age at presentation ranged between 7-16 y, although 73% were teenagers. Presenting symptoms included vomiting (89%), abdominal pain (78%), weight loss (83%), rumination (61%). Half of the included children had another functional diagnoses such as dissociative seizures, chronic fatigue and chronic pain. All children underwent extensive investigations including endoscopy, physiology studies, radiology, and blood tests, some requiring general anaesthetic, but no alternative pathology was identified.

We found 50% of patients required NG feeding and of those, half progressed to needing NJ feeding. Multiple medications were used with no noted improvement in symptoms. The average length of stay was 50.8 days.

Referrals to psychology occurred in 84% of cases, most at the point of admission. Inpatients averaged 8 hours psychology contact, whereas post-discharge outpatients averaged 7 hours. Thirty-two percent of patients had confirmed or suspected neurodiversity. Safeguarding was involved in 37% of cases and 68% had at least one adverse childhood experience (ACE). Over half of children and parents sought a medical explanation for symptoms and 37% expressed reluctance to engage with psychology input.

In summary, a diagnosis of FGID is often difficult for families and patients to accept leading to high morbidity, multiple investigations & multiple medications. We propose early adoption of a psychological model of care by the multidisciplinary team may improve outcomes for these children and reduce the impact on gastroenterology services.

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OC20

Improving the management of anaemia in children with inflammatory bowel disease by Emma Wilkinson, *Cambridge University Hospitals NHS Foundation Trust, UK.*

The management of anaemia in children with inflammatory bowel disease (IBD) remains controversial. Indications and thresholds for intervention and routes of administration are debated, with limited evidence available to guide clinical use[1,2].

In 2022 two patients at a tertiary hospital were administered intravenous (IV) iron (Ferinject®) and experienced cutaneous siderosis (iron staining). This uncommon and permanent side effect[3] prompted a review of the management of anaemia in children with IBD. Oral iron prescribing had fallen out of favour with an assumption it would be poorly tolerated and ineffective. Prescribing practice was not standardised.

The specialist pharmacist led development of a guideline describing the aetiology and management of anaemia in children with IBD. This project examines the impact of implementing the guideline on patient safety and the financial impact to the hospital.

Drug and laboratory costs were calculated between May 2021 and May 2022 before the guideline was published and between May 2022 and May 2023 when the guideline was piloted. Costs did not include NHS day case bed rates or nursing/medical time required for the admissions. The hospital's electronic patient records were analysed to assess the rationale for prescribing IV iron during the guideline pilot.

Between May 2021 and May 2022, 88 patients (3-17yrs old) were administered IV iron. Between May 2022 and May 2023, 34 patients (3-17yrs old) were administered IV iron, representing a 61% reduction in IV iron prescribing, despite the continued diagnosis of between 88-95 children with IBD each year at the hospital. Including the costs of increased oral iron prescriptions, there was a total drug saving of £6851.41/year. In addition, by switching from iron overload studies (£8.64/test) to ferritin only (£2.03/test) total lab savings were calculated as £8632/year.

Total savings per year (drug + laboratory) = £15483.41

Of the 34 patients who were administered IV iron following the introduction of the guideline, 11 (32%) were acutely unwell and hence met the guideline's recommendation for IV iron, 12 (35%) had failed to respond to a trial of oral iron, whilst 5 (15%) had a documented intolerance to oral iron – incl. stomach pain. Three patients (9%) had IV iron recommended following specialist haematological review for more complex anaemia and 3 (9%) had unreliable oral absorption. There were no further reports of iron staining.

The guideline for the management of anaemia in children with IBD led to significant changes in practice. These have had several positive impacts for patients and on cost of medications and laboratory tests. Oral iron is well tolerated and effective at treating anaemia in most children with IBD, avoiding the costly and time-consuming admissions and the absence from school and work. The reduction in IV iron infusions reduces the small but significant risk of unsightly and irreversible iron staining. Our pilot study demonstrates the benefits of guideline review and implementation of a more conservative approach to the management of iron deficiency in children with IBD.

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OC21

Does the Referral Pathway for new paediatric inflammatory bowel disease (PIBD) patients in our institution comply with the Paediatric Gastroenteroloy, Hepatology and Nutrition (PGHAN) UK National Census 2021? By Shiamaa Eltantawy, Edward Gaynor, Fevronia Kiparissi, *Great Ormond Street Hospital, London, UK.*

Patients with suspected inflammatory bowel disease (IBD) referred from primary and secondary care often face diagnostic and treatment delays. The national PGHAN audit from 2021 suggested that the diagnosis of paediatric IBD should be facilitated with a recommendation that they are seen by a specialist paediatrician within 4 weeks of referral, and resources are provided to achieve this 1. Our aim for this study was to audit our referral pathway and time frames from referral to endoscopy following PGHAN recommendations. We retrospectively collected data from our electronic patient records (EPIC). Patients referred to our service from 04/2021 to 01/2023 were included. Data collected included: demographics, internal or external referral pathways, the presence of a referral letter on EPIC, time frames of letter sent by referrer to us receiving them, discussion in weekly referral's meeting, outpatient (OP) or inpatient (IP) reviews prior to scopes and time to endoscopy. Data on 82 children, 54 males, aged 2–18 years were captured. 71 (86.5%) were external and 11 (13.5%) internal referrals. 70 (85.4%) of referral letters were uploaded on EPIC, in 8 (9.7%) no referral documents were found and in 4 (4.8%) referral time was established from other documents. Time frames were as follows:

1-Letters sent from referrer to our receipt: within one week 67 (81.7%), within 20 days 6 (7.3%), over 20 days was 1 (1.2%) and 8 (9.7%) letters unclear. Overall 86.6% of letters have been received within 10 days since referral.

2-Letters discussed in referral's meeting from referral time: within 1 day: 21 (25.6%), within one week 30 (36.5%), within 1-2 weeks 8 (9.7%) and within 2 weeks to 2 months 3 (3.6%). Unclear data in 15 (18.3%) patients and in 5 (6%) phone call referrals of unwell patients received prior to discussion in referral's meeting. Overall 72% of the patients were discussed in our referral's meeting within 2 weeks and overall 85.4% of referral letters have been uploaded to our electronic system.

3-Referral meeting until endoscopy: within 1 week 23 (28% of patients), within 1-2 weeks 14 (17%), between 2 and 4 weeks 15 (18.3%), between 1-2 months 13 (15.8%), after 2 months 11 (13.4%) which is unclear on EPIC; 3 (3.6%) patients had endoscopy with verbal referral only (urgent patients) and 2 (2.4%) patients postponed for medical reasons, 1 (1.2%) patient refused endoscopy.

4-37 (45%) patients were seen in outpatients prior whilst 45 (55%) went directly to endoscopy after having either been transferred as urgent inpatient transfers or having been seen in our ambulatory unit first. In conclusion in our institution 70 % of patients referred for possible new IBD had endoscopies with 4 weeks, complying with the recommendation of the PGHAN audit. Our future aim is to further improve this referral pathway and provide a diagnosis of PIBD to more patients in this referral pathway.

References

The paediatric gastroenterology, hepatology and nutrition UK national census 2021; http://www.rcpch.ac.uk/pghan-census

OC22

Use of Faecal Calprotectin in children with gastro-intestinal symptoms in primary care settings: A retrospective audit by Asanka Rathnasiri, Subramanium Mahadevan-bava, *Paediatric Department, Russel Hall Hospital, Dudley, West Midlands, UK.*

Faecal Calprotectin(FC) is a reliable, cheap, convenient and sensitive test for GI inflammation(I,II). We noticed high number of FC referrals from the primary care.

We conducted a retrospective case note audit in our DGH from 01/01/2022 to 31/12/2022. We recruited all the children referred from primary care.

Objectives were to assess

the distribution of GI and Paediatric clinic referrals

the common symptoms of referrals

the diagnosis made in GI and Paed clinics and outcome

We analysed data of 354 case notes. {Average age 7.1 years, M: F (54:46)} Main variables were FC level (<249µg/g & >250µg/g) and the age (0-4 years, 5-10 years and >11 years).

Most common symptoms were abdominal pain, loose stools and bloody stools. The common diagnosis were CMPI, functional constipation and functional abdominal pain in all age groups. Diagnoses made in both paediatric and GI clinics showed similar distribution.

Referrals to clinics and the outcome of the referral is summarized in the tables I and II.

Table I – Distribution of the clinic referrals

	0–4 years of age (n=103)		5–10 years of age (n=162)		>11 years of age (n=89)	
	FC <249	FC >250	FC <249	FC >250	FC <249	FC >250
Referred to GI clinic	9(10%)	7(44%)	22(15%)	8(61%)	12(15%)	5(63%)
Referred to Paed clinic	7(8%)	1(6%)	15(10%)	2(15%)	4(5%)	0
Not referred	71(82%)	8(50%)	111(75%)	3(23%)	65(80%)	3(37%)

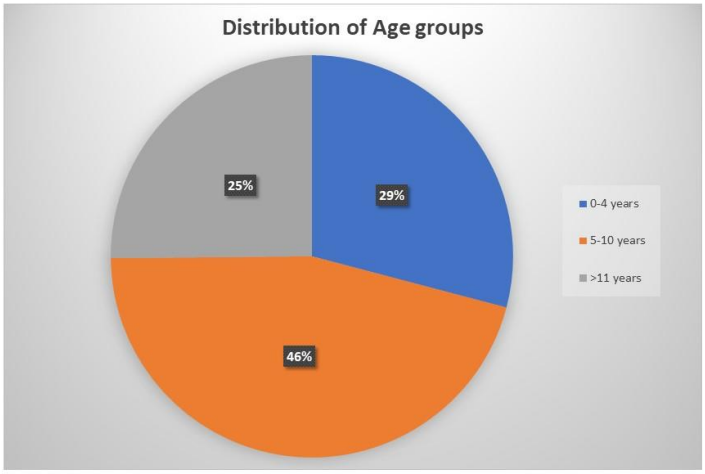
Table II – Outcome of the referral

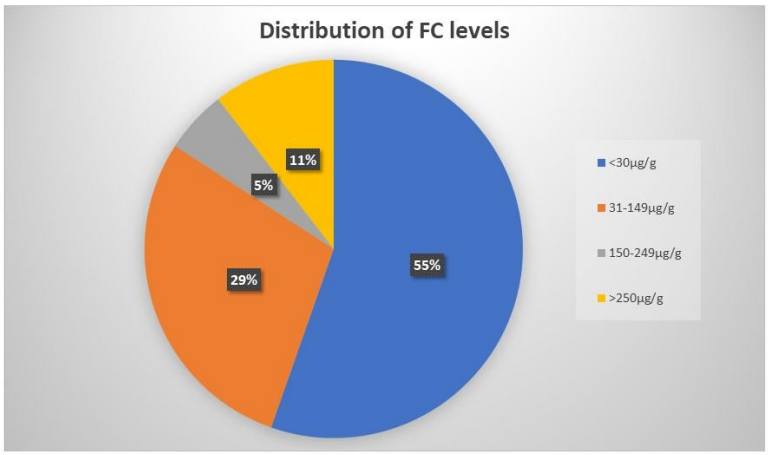
	0 – 4 age group				5 – 10 years age group				>11 years age group			
	Ref to GI		Ref to Paed		Ref to GI		Ref to Paed		Ref to GI		Ref to Paed	
	FC <249 (n=9)	FC >250 (n=7)	FC <249 (n=7)	FC >250 (n=1)	FC <249 (n=22)	FC >250 (n=8)	FC <249 (n=15)	FC >250 (n=2)	FC <249 (n=12)	FC >250 (n=5)	FC <249 (n=4)	FC >250 (n=0)
Discharged	6(67%)	7 (100%)	3(43%)	0	16(73%)	6(75%)	4(27%)	1(50%)	6(50%)	4(80%)	0	0
FU arranged	0	0	3(43%)	1 (100%)	1(5%)	1(13%)	7(47%)	1(50%)	2(17%)	0	3(75%)	0

High FC is shown in 10% of tests and only 1(0.003%) child being diagnosed with IBD may indicate the insufficiency of clinical screening in primary care. Combination of all 3 symptoms has shown 33% association with IBD.

All the children with low FC didn't had a significant condition which can be detected using FC(IBD). We believe FC >250µg/g can be considered as a safe cut-off. Approximately 30% of FC levels were performed on children of 0–4-year age group where routine FC measurement is not recommended[III].

Approximately a third of children with high FC were not referred to any clinic. In all groups discharge percentage from the Paediatric clinic was lower than the GI clinic. Lowest percentages were observed in children with high FC levels. This might indicate unnecessary follow up of the children with GI symptoms.





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OC23

How good are we in Azathioprine monitoring in District general hospital-Benchmarking by Jo Sims, Ayesha Tabassum, Jennifer Gould, *Bradford Royal Infirmary, UK.*

Azathioprine is one the commonest medications used to maintain clinical remission in inflammatory bowel disease. Several toxic side effects are known to be associated with this immunosuppressant medication, hence requiring close monitoring. We looked at our practice according to BSPGHAN Guidance and globally accepted ideal practice.

We looked at all patients (39 patients, 2 Excluded-Moved out of our area) who were on medication AZATHIOPRINE at our District general hospital. We reviewed their notes via electronic patient record and database retrospectively. Age range was found to be between 2-17years with mean age 15y.

The overall noticeable trends were noted as follows –All patients had appropriate pre-azathioprine screening of TPMT, Varicella and measles status (But less had EBV Screening and this was most recent). Written and verbal counselling was documented for majority of the patients. In earlier years of our monitoring between 2016-2020, there was less evidence of informing families about timing of blood tests in writing and less routine checking of thiopurine levels (Either not done or only done 1-2 years into treatments if symptoms persisted). However over the past 2 years this has become routine practice and there was evidence that patient had more than one thiopurine measurement. We probably are tolerant to the missed monitoring blood test due to COVID effect and Virtual appointments. Poor compliance was identified for those with low thiopurine levels and this improved after being addressed in clinic by our specialist nurse. Vaccination was indicated in about 30% of the patient out of which 42% did not received vaccines. The most common reason for this noted was being on prolonged low dose of steroids.

We aim to improve in our practice based on our benchmarking and relook at our practice next year. We are also looking to write a guideline for guidance.

Documented	Number of patients/39	Percentage%
Pre-screening bloods	38	100%
TPMT	38	100%
Written consent	36	92%
Letters to families	19	48%
Blood monitoring	34-first(Max) 28-second(Max)	87% 71%
Thiopurine blood levels	23	59%
Vaccines advised	12	30%
Vaccines received	7	58%
Reason for missed vaccine	5	42%

Side effects Tablet - 9 patients/39, 23%

Type of side effects	Action taken	Result
Rash	Stopped and restarted at low dose	2 out of 2 patients tolerated after
Nausea and headache	Split	Tolerate there after
Nausea	Dose spilt	Changed to 6mercaptopurine
Low WCC	Stopped and restarted at low dose	Tolerate there after
Increased Thiopurine levels	Stopped and restarted at low dose	Tolerate there after
Epigastric pain	Dose spilt initially & Stopped later	Escalated to Infliximab
Increased ALT	Stopped	Changed to Methotrexate
Pancreatitis	Stopped	Changed to Methotrexate

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OC24

Myelosuppression with pancytopenia and alopecia secondary to Azathioprine in two patients with NUDT15*3 allele with Inflammatory Bowel Disease (IBD) by Rayna Alamurova, Natalia Nedelkopoulou, Priya Narula, Prithviraj Rao, Arun Urs, Shishu Sharma, Dominique Schluckebier, Akshay Kapoor, Mike Thomson, Zuzana Londt, *Sheffield Children's Hospital, UK.*

We present two Slovak girls with IBD, both from Roma ethnic origin, who developed severe pancytopenia and alopecia secondary to Azathioprine. Both have normal thiopurine S-methyltransferase (TPMT) level. Due to the severity of their presentation, we have performed genetics for nucleoside diphosphate-linked moiety X-type motif 15 (NUDT15) and both patients were found to have a mutation.

The first patient was diagnosed with severe Ulcerative Colitis (UC) at 13-years of age. Induction of remission was achieved with intravenous steroids and Infliximab accelerated regime. Azathioprine 2mg/kg was given with the third dose of Infliximab, 11 days post diagnosis. Three weeks post starting Azathioprine the patient presented with alopecia, pancytopenia, febrile neutropenia, S. aureus bacteraemia, toxic megacolon and HSV 1 tonsillitis and stomatitis. She was acutely unwell, required 27 days hospital stay, a long course of intravenous antibiotics, 2 weeks of parenteral nutrition, 7 red blood cells transfusions, 1 platelets transfusion, 10 days of granulocyte colony-stimulating factor (G-CSF).

The second patient was diagnosed with IBD-U favouring UC at 5-years of age. Induction of remission was with intravenous steroids, maintenance treatment with 5-aminosalicylates. Azathioprine 2mg/kg was started 140 days post diagnosis and 3 weeks later the patient presented with alopecia, pancytopenia, febrile neutropenia, Influenza A and B. She had 19 days hospital stay, required intravenous antibiotics, 1 red blood cells transfusion, 3 platelets transfusions, 9 days of G-CSF.

Both patients recovered and alopecia resolved.

The first patient was heterozygous for the NUDT15*3 allele and the second patient was homozygous. This genetic abnormality predisposes patient to increased myelotoxicity following Azathioprine treatment.

We therefore recommend not only TPMT testing but also genetic testing for NUDT15*3 deficiency in certain ethnic group as it can have a significant impact on preventing development of severe side effects.

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OC25

Iatrogenic adrenal insufficiency on discontinuation of glucocorticoid treatment in children and adolescent patients with inflammatory bowel disease: to screen or not to screen? by Sibongile Chadokufa[1], Bonita Huggett[1], Rachael Buckingham[2], Catherine Lashley[1], Kelsey Jones[3], Fevronia Kiparissi[4], Edward Gaynor[1], *[1,2,3]Great Ormond Street Hospital, [4]GOSH, London, UK.*

Background: Glucocorticoids are a mainstay of inflammatory bowel disease (IBD) treatment to induce remission or limit flares. Iatrogenic adrenal insufficiency (AI), due to suppression of the hypothalamic-pituitary-adrenal (HPA) axis is an established side effect of exogenous glucocorticoids. The rate of AI in this population is unknown. There is no standard guidance or recommendations to suggest routine screening of paediatric IBD (pIBD) patients. This study aimed to better understand the rates of AI with a screening and management protocol developed for pIBD patients given glucocorticoid therapy.

Methods: All patients with IBD under 18 years of age treated with glucocorticoid therapy (prednisolone) for 3 weeks or longer from March 2022 to August 2023 were identified. Patients were excluded if on other exogenous steroids or long-term steroid use. All patients were screened for AI by testing serum early morning cortisol (Vitros Ortho Clinical Diagnostics immunoassay) and ACTH, and if indicated underwent standard short synacthen (SST) testing. Adrenal axis function was divided into normal adrenal axis allowing cessation of glucocorticoid therapy, or impaired response requiring hydrocortisone maintenance therapy. Evaluation of the adrenal-axis response was then assessed by a protocol piloted by this study – see figure 1.
A serum morning cortisol >250nmol/l indicates a normal adrenal axis; whereas dynamic adrenal axis testing was recommended for cortisol of 175-249 nmol/l. Those with cortisol <175nmol were diagnosed with adrenal insufficiency and started on maintenance hydrocortisone. Repeat adrenal axis testing with SST was performed 3 monthly to assess normalisation of the adrenal-axis. Patients with an abnormal SST at the 6-month mark were referred for formal endocrinology assessment.

Results: 14 of 16 patients were eligible for the study (8 male) , 7 were diagnosed with Ulcerative colitis, 4 with Crohn's disease, 1 with IBD-unclassified, 2 with early-onset IBD. Median age at diagnosis was 10 years (range 8 months -14 years). Duration of glucocorticoid therapy with prednisolone was for an average 3 months (range 6 - 16 weeks).
42%(n=6) initiated glucocorticoid therapy with IV methylprednisolone before switching to 2mg/kg oral prednisolone (maximum dose of 40mg) for 2 weeks, weaning 5mg every week.
On completion of glucocorticoid therapy 57% (n=8/14) had significant AI - 6 patients had a morning cortisol <175nmol and 2/5 requiring synacthen testing, demonstrated an impaired HPA axis on SST.
Longer-term AI remains in offered follow-up HPA axis testing: 100% at 3 months (5/5) and 75% at 6 months (4/4). 3 patients await their first follow-up SST.
No child suffered an adrenal crisis during the study period.

Conclusion: AI following glucocorticoid therapy is common in this small cohort. Screening for AI should be considered in pIBD patients receiving conventional doses of glucocorticoids longer than 3 weeks, with appropriate advice given. The incidence and risks of iatrogenic adrenal insufficiency (AI) requires further investigation

OC26

Educating Paediatric Inflammatory Bowel Disease Clinical Nurse Specialists: are we doing enough? by Gemma Lee[1], Pippa Taylor[2], Nancy Mew[3], Elena Gil-Zaragozano[2], *[1]Evelina London Children's Hospital. [2]Bristol Royal Hospital for Children. [3]Oxford University Hospital, UK.*

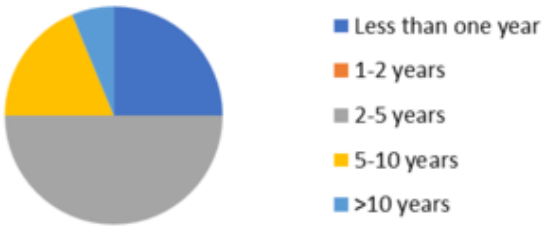
The Clinical Nurse Specialist (CNS) plays a pivotal role in the care of young people with Inflammatory Bowel Disease (IBD) and their families (1,2). It is recognised in the IBD UK Standards (statement 1.16) that all members of the IBD team should be educated to an appropriate level, and have access to professional support (3). Specialist IBD nurses within the UK report higher levels of stress and lower job satisfaction with a lack of training and development opportunities. This ultimately leads to nurses leaving both the speciality and profession (4,5). Specific educational opportunities for PIBD CNS' are limited and they gain most of their education from attending other discipline's educational events, or adult IBD nursing events. The authors are unaware of any formal training specifically for PIBD nurses. Recent discussions within the PIBD CNS Network, highlighted the requirement for paediatric specific education for members.

The aim of this study was to analyse the educational opportunities received to date by paediatric IBD (PIBD) CNS' and to identify what the perceived needs are.

A steering committee organised a dedicated PIBD nurse education day. Spaces were made available for 23 PIBD CNS'; the UK has approximately 70 in total. Invites were circulated via email.

An online registration and a post-event feedback questionnaire was sent to all delegates.

Figure 1. Number of years delegates in post



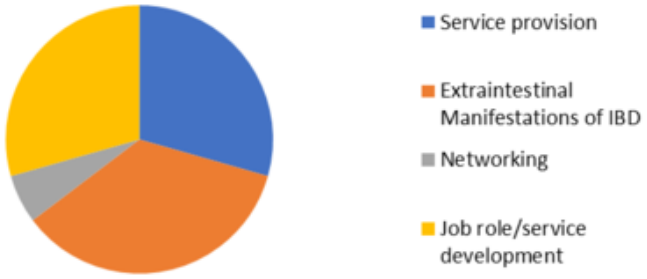
All places at the event were filled and there was a waiting list for applicants unable to secure a place. Of the 23 nurses who attended the event, 16 (70%) responded to the registration questionnaire; 12 (75%) of these nurses have been in post for 5 years or less, with 4 (25%) of those, less than a year (Figure 1).

Figure 2. Previous attendance at a dedicated educational event for PIBD

4 responders (25%) stated that they had been to previous paediatric specific education events in the past, of which 2 (50%) of these responders listed the PIBD CNS Network meetings as the prior events (Figure 2).

On analysis of delegate feedback, all speakers scored 75% and above in the excellent category. Verbal responses on the day were encouraging and requests were made for further events of a similar nature. The topics that nurses felt would be helpful at future events were varied (Figure 3).

Figure 3. Topics/skills requested by delegates for future events



This study highlights the interest in specific formal education for PIBD CNS'. It also demonstrates the relatively junior taskforce and therefore invaluable need for greater peer support and education at an appropriate level. Feedback from the day indicated appreciation for both education and networking;

'great opportunity to network' *'sharing ideas and practice has been invaluable'*

'loads to take away, feel inspired' *'topics discussed were relevant to my role'*

'networking with other PIBD nurses is invaluable'

With a clear lack of specific PIBD nurse events, the need for both education and networking for individuals in these roles has been established. The aim is to now continue these events, commencing with yearly education days.

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OC27

Investigating the role of family history in IBD presentation and course in children by Abdullah Riaz, Sue Underhill-smith, Catharine Searle, Eleanor Goodale, Sara Pullan, Iona Humphries-Cuff, Mary-Anne Morris, Marco Gasparetto, *Paediatric Gastroenterology, Jenny Lind Children's Hospital, Norfolk and Norwich University Hospitals, Norwich, UK.*

Background: While the incidence of inflammatory bowel disease (IBD) is rising globally [1], the role of family history in its phenotype and course is still debated. Over 240 loci associate with IBD diagnosis, however each predisposing locus only has a modest impact (odds ratios 1.1-1.5). Other factors like demographics, environment, clinical aspects, diet and lifestyle are also involved and researched into [2]. A positive family history increases the risk of IBD (up to 4-15 times if a first-degree relative is affected), however it's observed in just 10% of cases, leaving the role of inheritance not fully qualified [3].

Aim: To explore the IBD phenotype and disease progression in children with a first-degree relative affected by IBD.

Patients and Methods: This retrospective study was conducted at Norfolk and Norwich University Hospital (NNUH), the sole referral centre for paediatric gastroenterology in Norfolk. The region's demographic stability across age groups enabled access to medical data from both children and adult participants. Paediatric IBD patients with a family history of IBD (i.e. at least one first-degree relative affected) were identified through our internal database. Clinical information, including type of IBD diagnosis, age at diagnosis, disease location at diagnosis as per Paris classification, treatment, IBD related surgeries, and number of relapses & treatment escalations, was retrieved from paper and electronic patient records. Informed written consent was obtained, and additional data from the family members affected were collected through phone calls, where not available from the hospital records. All data were recorded anonymously in an Excel spreadsheet.

Results: We identified six paediatric IBD patients (4 females; age at diagnosis: mean 11.72 years; median 11.63 years; range: 9) with a positive family history. Three had CD, three had UC, and most were diagnosed in their second decade of life (Paris A1b). Additionally, six adult first-degree relatives (5 females) had IBD, with most diagnosed in their third decade (Paris A2) or second decade (Paris A1b). While partial concordance in IBD diagnosis and symptoms at disease onset (abdominal pain, increased bowel movements, loose stools, rectal bleeding) were observed between paediatric cases and their relatives, no other specific clinical correlations were identified (Table). One of the six paediatric patients had IBD-related surgery. Three relatives also underwent surgery, one shortly after diagnosis due to intestinal obstruction, and two after 16 and 20 years, respectively.
A trend related to age of diagnosis was observed, where the child diagnosed in their first decade of life was related to the youngest diagnosed adult relative.

Conclusion: This retrospective data is an initial step of a larger project exploring the role of family history in the IBD phenotype and clinical course. The next step will be to prospectively extend our cohort of paediatric cases with positive family history and conduct whole-genome sequencing to investigate the genetic factors involved and their correlation with the disease phenotype and its course.

Table. Summary of the clinical characteristics reflecting IBD diagnosis and course in six paediatric patients and their first-degree relatives, highlighting concordant (green) and discordant (red) variables.

Patient/First-degree relative	Gender	Diagnosis	Age at diagnosis (Paris classification)	Disease location (Paris classification)	CD behaviour (Paris classification)	Abdominal pain at dg	Increased BO at dg	Loose stool consistency at dg	Constipation
Patient 1 - Relative 1 (Brother)	M - M	CD - CD	A1b – A2	L3p – L1	B1p – B1	Y - Y	Y - N	Y - N	N - N
Patient 2 - Relative 2 (Mother)	M - F	CD - CD	A1b – A2	L3 – L3	G1B3p – B2B3p	Y - Y	Y – N	Y – N	N – N
Patient 3 - Relative 3 (Mother)	F - F	UC - CD	A1b – A2	E2 – L2	S1 – B2p	Y - Y	Y - Y	Y - Y	N - Y
Patient 4 - Relative 4 (Mother)	F - F	UC - CD	A1b – A2	E2 – L3	S0 – B2B3p	Y - Y	Y - Y	Y - Y	Y - Y
Patient 5 - Relative 5 (Mother)	F - F	CD - CD	A1a – A1b	L3 – L3	G1B1p – B2B3p	Y - Y	Y - Y	Y - Y	N - N
Patient 6 - Relative 6 (Mother)	F - F	UC - UC	A1b – A2	E3 – E4	S0 – S0	Y - Y	Y - Y	Y - Y	N- N

	Mucous in stools	PR bleeding	Wt loss	Nocturnal symptoms	Nausea - vomiting	Urgency - tenesmus	Lethargy	Iron deficiency anaemia	Mouth ulcers
Patient 1 - Relative 1 (Brother)	N - N	Y - N	N - Y	Y - Y	Y - N	Y - N	Y - Y	Y – N	Y - N
Patient 2 - Relative 2 (Mother)	N – N	N –N	Y – Y	N – N	Y – Y	Y – N	Y – Y	Y – Y	Y – N
Patient 3 - Relative 3 (Mother)	N – n.a.	Y - Y	N – n.a.	n.a. – n.a.	n.a. – n.a.	Y – n.a.	Y - Y	Y – n.a.	N – n.a.
Patient 4 - Relative 4 (Mother)	Y - Y	Y - Y	N - Y	Y - Y	N - Y	Y - Y	Y - Y	N – N	N - Y
Patient 5 - Relative 5 (Mother)	Y - Y	Y - Y	Y - Y	Y - Y	Y - N	Y - Y	Y - Y	Y - Y	Y - Y
Patient 6 - Relative 6 (Mother)	N - Y	Y - Y	Y – Y	Y - Y	N - Y	Y - Y	N - Y	N - N	N – N

	Reflux symptoms	Fever	Perianal disease	IBD associated liver disease	Joint pain	Extra-intestinal manifestations	Induction treatment	Maintenance treatment	IBD-related surgery
Patient 1 - Relative 1 (Brother)	N - N	N - N	Y - N	N - N	Y – Y	Y - N	EEN+CS+IFX - CS	AZA+IFX – AZA+ADL	N - N
Patient 2 - Relative 2 (Mother)	N – N	N – N	Y – Y	N – N	N – N	N – N	EEN+IFX – CS	AZA+IFX+ADL+USTE – AZA+5-ASA	Y- Y
Patient 3 - Relative 3 (Mother)	N – n.a.	Y – n.a.	N – Y	N – n.a.	N – n.a.	n.a. – n.a.	CS – 5-ASA+CS	5-ASA+AZA – None	N - N
Patient 4 - Relative 4 (Mother)	N - N	N - Y	N – Y	N - N	Y - N	Y – Y	CS+IFX - CS	6-MP – ADL	N- Y
Patient 5 - Relative 5 (Mother)	Y - N	Y - N	Y - Y	N - N	N - Y	Y – Y	EEN+CS – EEN+PN+CS+IFX	AZA+IFX – AZA+ADL	N - Y
Patient 6 - Relative 6 (Mother)	N - N	N - N	N – N	N – N	N - Y	N – Y	5-ASA - CS	5-ASA – 5-ASA	N - N

Table legend: 5-ASA: 5-amino-salicilates; 6-MP: 6-mercaptopurine; ADL: adalimumab; AZA: azathioprine; CD: Crohn's disease; CS: cortico-steroids; EEN: exclusive enteral nutrition; F: female; IBD: inflammatory bowel disease; IFX: infliximab; M: male; N: no; PR: per rectum; UC: ulcerative colitis; USTE: Ustekinumab; Wt: weight; Y: yes.

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OC28

My Heart Is In My Throat: A Delayed Presentation of Oesophageal Foreign Body (FB) by Muhammad Abu Bakar[1], Lucy Howarth[1], Oliver Brain[1], Merrill McHoney[1], Asad Nasim[2], [1]*Oxford University Hospital NHS Foundation Trust.* [2]*Wexham Park Hospital, Slough, UK.*

Introduction: Oesophageal Foreign body (OFB) ingestion, a common and serious problem in children, can present with a wide variety of symptoms. This paper describes and discusses the rare case of delayed presentation of an oesophageal foreign body, initially presenting as severe nose bleed after trauma.

Presentation of Case: A 7-year-old girl presented with a three-day history of intermittent severe upper gastrointestinal bleed following minor nose trauma. She had multiple episodes of haemetamesis and vasovagal syncope. She had a background history of oral feeding aversion leading to faltering growth from a very young age but no obvious cause was found. She was pale, tachycardic and her haemoglobin dropped from 80 g/l to 49 g/dl. She was transfused, and a CT head was reported as normal, with no fractures identified. Because of the nasal trauma, anterior rhinoscopy and flexible nasendosopy (FNE) was performed by ENT, with no source of bleeding identified. Oesophago-gastrodudenoscopy (OGD) showed an ulcer at 15cm from the incisors, and a 2cm wide plastic heart shaped foreign body embedded in the base of the ulcer. It was associated with post-infammatory polyps covering half the circumference of the oesophagus. The foreign body was removed successfully and there was no further bleeding noted after foreign body removal. Chest X ray performed following procedure demonstrated a pneumomediastinum which was later confirmed on CT chest. She was kept nil by mouth and had a insertion of gastrotomy for feeds. Repeat contrast studies were performed in the convalescent period to confirm healing of the presumed oesophageal leak. Four months post-surgery a contrast study demonstrated no leak and no further oesophageal abnormality noted. She was restarted on feeds, and tolerated this with no clinical concern, and is now asymptomatic and well.

Discussion: Ingestion of FB is a common problem in young children. The majority of OFBs pass harmlessly through the gastrointestinal tract; however, some OFBs can cause significant morbidities. The diagnosis may be delayed leading to several complications especially if the ingestion of the FB is unwitnessed and when the clinician does not think of FB ingestion as part of the differential diagnosis of oral food aversion.

Conclusion: It was a case of long standing oesophageal foreign body (EFB) which unusually presented with a life threatening upper gastrointestinal bleed. This case highlights the importance of considering FB ingestion in a child with background history of ongoing feeding difficulties

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OC29

Improving the diagnosis and management of bile salt malabsorption in Paediatrics by Shubhra Ahluwalia[1], Chloe Corlett[2], Esther Blanco[2], Astor Rodrigues[2], Lucy Howarth[2], *[1]Royal Berkshire Hospital. [2]John Radcliff Hospital, UK.*

Introduction: Chronic diarrhoea, malnutrition, and deficits in fat-soluble vitamins are signs of bile salt malabsorption (BSM), which is characterised by the inadequate reabsorption of bile acids from the ileum. This condition is well-recognised amongst adult patients and can be diagnosed in up to a third of patients presenting with features of irritable bowel syndrome. BSM is less commonly considered in children. The aetiology of BSM in children can be multifactorial. Secondary causes of BSM (such as ileal resection, ileal Crohn's disease, coeliac disease, and specific infections like giardiasis) are more prevalent in children, while primary BSM is frequently idiopathic.

Aims: This study aims to audit the outcome of 23-seleno-25-homotaurocholic acid, selenium homocholic acid taurine or tauroselcholic acid test (SeHCAT scan) requests to gain an understanding of how to improve the diagnosis and management of children with symptoms consistent with BSM.

Methods: This was a retrospective single-centre study of all children aged 5 to 17 years with chronic diarrhoea (defined as passing 3 or more loose stools for > 1 month) with no clear diagnosis found on initial/standard screening investigations who had SeHCAT scans completed at a tertiary centre between 2018 and 2023 (5 years).

Results: 20 out of the 43 (47%) children who had SeCHAT scans were diagnosed with BSM. Of these, 7 (35%) had mild BSM (retention values of SeHCAT between 10-15%), 4 (20%) had moderate BSM (retention values of SeHCAT between 5-10%), and 9 (45%) had severe BSM (retention values of SeHCAT <5%).

Of the 13 cases with moderate-severe BSM, secondary causes were found in 8. 3 children had an ileo-caecal resection for Crohn's disease, 2 children had radiotherapy for neuroblastoma, and there was 1 child each with coeliac disease, AIRE gene defect, and post-cholecystectomy. In the 5 remaining cases with moderate-severe BSM and all of the 7 cases with mild BSM no secondary causes were identified and were therefore considered as primary/idiopathic. All patients were given dietary advice. 18/20 (90%) patients were given a trial of bile salt sequesters, Cholestyramine or Colesevelam. 10/18 (55%) had significant symptom improvement with resolution of diarrhoea and of these, 7/10 (70%) experienced notable improvements in their growth trajectory.

Conclusion: This audit suggests the importance of considering a diagnosis of BSM in those with chronic diarrhoea especially if the initial/standard screening investigations are negative. It highlights the improvements in symptoms and growth that can result from timely diagnosis and effective management.

References

National Institute of health

OC30

The role of the gut microbiome in intestinal rehabilitation in children with short bowel syndrome: a meta-analysis

by Jemma Cleminson[1,2], Greg Young[1], Christopher Stewart[1], David Campbell[1,2], Janet Berrington[1,2], Andrew Gennery[1,2], *[1]Newcastle University. [2]Royal Victoria Infirmary, Newcastle upon Tyne, UK.*

Short bowel syndrome (SBS) is the most common cause of paediatric intestinal failure, with a prevalence of 15 per million, an increase of ten-fold over the past three decades. Although parenteral nutrition (PN) is lifesaving, it is associated with severe complications. Intestinal rehabilitation (IR) is a process that occurs when the remaining bowel undergoes structural and functional changes that increase its absorptive capacity and results in the child no longer requiring PN. The mechanisms underpinning this change are poorly understood. One potential mechanism is the role of the gut microbiome.

We aimed to review the literature and perform a meta-analysis on the available data on the gut microbiome before, during and after IR in children with SBS. We searched Ovid MEDLINE, EMBASE and The Cochrane Database of Systematic reviews for studies of the gut microbiome in children with SBS, that used next generation sequencing techniques. We identified sixteen studies, six of which included data on comparison of the gut microbiome of patients dependent on PN to those who had achieved IR. Studies that did not have the sequencing data available from a public repository, or following email communication with the study authors, were excluded.

We included six studies in the meta-analysis. We compared taxonomic richness, diversity and proportions of individual bacterial features quantifiable in patients with SBS, on PN and achieving IR.

The gut microbiome may be predictive of IR. Further research into its role as a biomarker for predicting IR and as a therapeutic target may lead to earlier intestinal rehabilitation.

OC31

'Living Alongside Symptoms': Facilitating and evaluating an online ACT-based therapeutic group for young people living with gastrointestinal disorders and their parents by Michael Cornish, Emma Harlow, Elizabeth Archer, Mohamed Mutalib, Jochen Kammermeier, Michalis Papadopoulos, Rakesh Vora, *Evelina London Children's Hospital, UK.*

Introduction: The Paediatric Gastroenterology Psychology Service receive referrals for patients with gastroenterological conditions which are contributing to poor quality of life. To address this, the Paediatric Gastroenterology, alongside the Paediatric Pain and Rheumatology Team, created and delivered the Living Alongside Symptoms Workshop, an Acceptance and Commitment Therapy (ACT)-based therapeutic group intervention.

Participants and Methods: Young people and their parents were invited to an online workshop which focused on equipping young people with the strategies needed to cope with their condition. This was achieved in the workshop by young people:

- Identifying what is important to them (their core values)
- Learning mindfulness and ACT based strategies to support new ways of coping
- Creating value driven SMART goals

Attendees were provided with a workbook to use alongside the session which contained additional information and written exercises to consolidate their learning.
All attendees were invited to complete brief pre and post questionnaires. Using a 1-5 Likert rating scale, they were asked about their happiness to carry out (or support their child to carry out) activities when experiencing their physical symptoms, and their confident in understanding mindfulness strategies to manage living alongside their/their child's symptoms.

Results: The team ran five workshops between March 2021 and August 2023. Overall 34 participants attended the workshops. The quantitative data was analysed using descriptive statistics (Mean; M, and Standard Deviation; SD), and free text qualitative date was collated and reviewed. Results are shown below.

Table 1. Pre and post questions mean scores

		How happy are you to carry on with activities when you are experiencing physical symptoms?	How confident are you in using mindfulness strategies to help live alongside your physical symptoms?
Young Person	Pre	M=2.0, SD=1.1	M=2.6, SD=0.7
	Post	M=2.6, SD=1.0	M=3.4 SD=0.8
	Change	+0.6	+0.8
Parent	Pre	M=3.9 SD=1.3	M=3.1, SD=0.8
	Post	M=4.2, SD=0.9	M=3.7, SD=0.6
	Change	+0.4	+0.6

Both young people and their parents reported, following the workshop, that they are planning to continue to use 'SMART goal' techniques and other strategies they learnt in the workshop, including mindfulness. Additionally, parents reported feeling more able to support their child to manage their symptoms, using the strategies from the workshop.

Summary and Conclusions: After attending the workshop, young people reported feeling happier to, and parents happier to support them to, carry on with activities when experiencing their symptoms. Young people and parents reported feeling more confident in using mindfulness strategies to help live alongside their symptoms. Overall, the results indicate the therapeutic group was perceived positively by young people with GI disorders and their parents and may increase confidence managing GI-associated pain.

OC32

Refractory upper gastrointestinal bleeding secondary to vasculitis: A case report by Vangelis J Giamouris[1,2], Huey Miin Lee[2], Bethany Tucker[1], Serena Kyrana[1], Tassos Grammatikopoulos[1], *[1]Paediatric Liver, King's College Hospital NHS Trust, London, UK. [2]Paediatric Gastroenterology, King's College Hospital NHS Trust, London, UK.*

Upper gastrointestinal bleeding is infrequent in children. Although the majority of cases are self-limiting, severe upper GI bleeding can potentially be life-threatening and challenging to manage. We present a case of refractory upper GI bleeding caused by vasculitis and successfully managed with steroids and cyclophosphamide, after failure of multiple endoscopic interventions to stop the bleeding.

A previously healthy 12.5-year-old boy presented to the emergency department (ED) of a non-specialised centre with vomiting, diarrhoea, syncope and hypovolaemic shock. At presentation, his haemoglobin was 76 g/L and INR was 1.5. His had a normal platelet count, low albumin 33g/L and otherwise normal liver markers. He subsequently had melena whilst in ED with haemoglobin drop to 57 g/L. He had fluid boluses, Vitamin K, blood transfusion, intravenous antibiotics, and omeprazole.

Patient was transferred to Specialised Centre A. An abdominal ultrasound scan showed a normal liver and spleen, a small volume pelvic free-fluid and mild generalised mesenteric inflammation. His upper and lower GI endoscopy was unremarkable. A diagnostic laparoscopy that followed showed abnormal appearance of the liver described as 'white plaques/capsular lesion'. His CT abdomen showed irregular appearance of the liver and enlargement of the left lobe suspicious for a primary hepatic malignancy or lymphoma. MRI liver and spleen showed features of chronic hepatopathy but no evident signs of portal hypertension and multiple indeterminate focal liver lesions which did not demonstrate any restricted diffusion.

Patient was transferred to Specialised Centre B for liver specialist input. CT Thorax and pelvis showed multiple liver nodules on a background of heterogeneous, nodular parenchyma, with small splenic and gastric varices and moderate ascites. There were multiple abnormal enlarged lymph nodes in the chest and upper abdomen. CT-guided liver biopsy showed non-specific findings including heterogeneous architecture, porto-portal and porto-central bridging fibrosis with partial nodule formation without significant interface activity.

Further endoscopy in Specialist Centre B showed diffuse gastropathy with white spots and friable mucosa. Removal of fundal clot revealed an ulcer oozing blood and a haemangioma-like lesion. Endoclips and haemosprayed were applied. Due to recurrent melena and haemetemesis, he had 2 further interventional endoscopies with endoclips, injection of adrenaline and haemospray, Sengstaken-Blakemore tube placement and embolization of the left gastric and branches of the left hepatic artery by interventional radiologists, where vasculopathy type changes were observed.

This finding, along with fever and persistently raised CRP indicated a possible systematic vasculopathy. His MRI brain showed tiny mature cerebellar infarcts and a small anterior communicating artery aneurysm measuring 1.5 mm along with some slightly bulbous appearances in the intracranial arterial circulation elsewhere.

Patent was referred to the Rheumatology team and treated as medium-vessel vasculitis. Corticosteroids was commenced and the gastrointestinal bleeding episodes stopped after 14 days of treatment. During the prednisolone tapering regimen, a biweekly IV cyclophosphamide regimen was administered for three months with no further bleeding episodes to date.

Vasculitis is a rare cause of gastrointestinal bleeding in children. This case demonstrates the importance of considering vasculitis as a differential diagnosis, particularly in refractory upper gastrointestinal bleeding.

OC33

Barrier creams – is it time for a child proof lid? by Zainab Husain, Oluwakemi Ogunmoye, Kathryn Allan, David Devadason, Sabarinathan Loganathan, *Queens Medical Centre, Nottingham, UK.*

Introduction: We present a case study of an eleven-month-old boy with an unusual cause of an acute upper gastrointestinal bleed.

Result: A previously well 11 month old presented at his local hospital with severe haematemesis. His haemoglobin at presentation was 65g/L. Following stabilisation, he was transferred to a tertiary paediatric gastroenterology centre where he required a unit of packed red cells. Xrays excluded foreign body. There was a history of acute viral gastroenteritis in the week preceding this episode and a past history of milk protein intolerance which was well controlled with dietary intervention. When the history was revisited, parents recalled that 3 days prior to the onset of symptoms, he had managed to consume almost the entire tube of Cavilon barrier cream. They called NHS 111 and were reassured at the time. He was started on IV omeprazole and taken to theatre for upper GI endoscopy within 24 hours of presentation. Upper GI endoscopy revealed three healing gastric ulcers near the pyloric opening. These ulcers were not actively bleeding and therefore no therapeutic intervention was carried out. Following 72 hours on IV omeprazole and with no ongoing GI bleeding, he was discharged on oral omeprazole. Upon interrogating the safety data sheet for Cavilon, it emerges that it contains a number of ingredients, that can potentially cause GI irritation. Reassessment endoscopy 3months later revealed ulcer healing.

Conclusion: Ingestion of skin barrier creams may result in GI irritation resulting in significant upper GI bleed in small children. This to our knowledge this has not been previously reported. Most barrier creams contain ingredients that have been implicated in irritation of the digestive tract in animal models when ingested. Parents and carers of children should be told of the dangers of accidental ingestion of barrier creams. Paediatricians should enquire about ingested substances when dealing with upper GI bleeds in all children but particularly so in non verbal infants and toddlers.

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OC34

Efficacy of Pranic Psychotherapy and Pranic Healing in the management of chronic pain, associated medical conditions and stress and anxiety by Les Flitcroft, Huey Miin Lee, Ben Hope, Anju Bhatia, *King's College Hospital NHS Foundation Trust, UK.*

Pranic Psychotherapy and Pranic Healing are non-touch energy treatments used to alleviate psychological and medical conditions. Pranic Psychotherapy and Pranic Healing are based on the principle that the overall structure of the human body is composed of two parts: The physical body and the energy system (Figure 1). Every medical condition has a unique energy pattern. Normalising the energy system aims to alleviate the psychological and clinical symptoms, disease activity and improve the rate of recovery of patients.

Our primary aim is to evaluate the efficacy of Pranic Psychotherapy and Pranic Healing (1-3) for paediatric and adolescent patients with chronic pain associated with their medical conditions. Secondary outcomes are the improvement of non–pain clinical symptoms (NPCS, e.g. vomiting and diarrhoea) and stress and anxiety.

This is a prospective, single group, qualitative and quantitative study. Patients were recruited in 5 consecutive phases. Inclusion criteria: Chronic pain, 5-21 years old. Patients underwent 8 weekly treatments. Pranic Psychotherapy and Pranic Healing protocols specific to each participant's psychological and medical diagnoses were applied in each session.

Table 1 demonstrates data collected.

Pain-Visual Analogue Scale (PVAS) scores were considered as ordinal and categorical data with No (PVAS score 0-2), Mild to Moderate (PVAS score 3-7) and Severe to Very Severe (PVAS score 8-10) pain respectively.

NPCS frequency (NPCSF) scores were considered as ordinal and categorical data.

Reduction in PVAS and NPCSF scores and improvement in low mood (LM), poor concentration (PC) and fatigue were analysed for week 0, week 8 and week 20.

100 participants underwent treatment from July 2022 to August 2023, with Phase 5 patients' Week 20 review in November 2023. M: F ratio was 37:63, median age 13.5 years (range 7–21 years). 79/100 and 9/100 participants' chronic pain was associated with DGBI and IBD respectively. 85/100 participants recruited had NPCS at Week 0.

Table 2 demonstrates the improvement of PVAS scores, NPCSF scores, LM, PC and fatigue.

93 participants had an evaluable PVAS score at Week 0 and Week 8. 60/93 (65%) reported No pain at week 8. PVAS was reduced by -2 as a median (range [-4, 0]) change in PVAS between week 0 and 8 ($p<1.0e-10$).

80 participants had an evaluable NPCSF score at Week 0 and Week 8. 52/80 (65%) reported no NPCS at Week 8. NPCSF was reduced by -3 as a median range (range [-4, 0]) change in NPCSF between week 0 and 8 ($p<1.0e-10$).

64 and 57 participants had an evaluable PVAS and NPCSF score respectively at Week 0 and Week 20. At Week 20, 54/64 (84%) reported no pain. 47/57 (82%) reported no NPCS.

Patients with data at Week 0 and Week 20: 87%, 86% and 92% reported resolution of LM, PC and fatigue, respectively.

In conclusion, Pranic Psychotherapy and Pranic Healing are safe and effective interventions which significantly improve chronic pain, NPCS and reduce symptoms of stress and anxiety. Further studies are needed to facilitate the integration of Pranic Psychotherapy and Pranic Healing into patients' standard of care.

Table1: Data Collected Week 0, 8 and 20		
Participant Number:	Date:	Session Number:
Age:	DOB:	Gender:

Medical Diagnosis	
Medication :	
Duration of symptoms Score 0-1 year = 0 1-2 years = 1 2-5 years = 2 5-10 years = 3 > 10 years = 4	
Pain Location	
Non-Pain Clinical Symptoms	
Psychological Symptoms	
Pranic Psychotherapy Protocols	
Pranic Healing Protocols	

Pain Visual Analogue Scale Score	✓
0-2 = 0	
3-4 = 1	
5-7 = 2	
8-9 = 3	
10 = 4	
Severity Score: 0 = None (0-2); 1= Mild (3-4); 2 = Mod (5-7); 3 = Severe (8-9); 4 = Very Severe (10) Did not attend (DNA)	

Non–Pain Clinical Symptoms Frequency Score	✓
Several times a month and no affect to routine = 0	
Several times a month and affect to routine = 1	
Several times a week, routine activities continue = 2	
Several times a week, routine activities disturbed = 3	
Several times a week, nocturnal disturbance and routine activities disturbed = 4	
Severity Score: 0 = None ;1= Mild; 2 = Mod; 3= Severe; 4 = Very Severe; DNA	

Stress and Anxiety Symptoms	**Y / N**
Low Mood	
Poor Concentration	
Fatigue	
Yes (Y); No (N); Did not attend (DNA)	

Patient Primary Concerns - Week 0
Clinical Summary
Patient's Response to treatment – Week 8
Clinical Summary
Patient's Response to treatment – Week 20
Clinical Summary
Testimonial 1 – week 8
Patient's and Parent's Written Summary
Testimonial 2- week 20
Patient's and Parent's Written Summary

Table 2: PVAS, NPCSF, LM, PC and Fatigue Results		
	Pain Visual Analogue Scale	**Non-Pain Clinical Symptoms Frequency**
Number of patients with symptoms at Week 0	**100**	**85**
Data available for N patients	**93**	**80**
Categorized at week 0, n (%)		
No	0 (0%)	0 (0%)
Mild to moderate	29 (31%)	14 (17.5%)
Severe to very severe	64 (69%)	66 (82.5%)
Categorized at week 8, n (%)		
No	60 (65%)	52 (65%)
Mild to moderate	28 (30%)	13 (16%)
Severe to very severe	5 (5.4%)	15 (19%)
Change from baseline to week 8[1]	-2.0 (-3.0, -2.0), (-4.0, 0.0)	-3.0 (-3.0, -1.0), (-4.0, 0.0)
p-value[2]	**p<1.0e-10**	**p<1.0e-10**
Data available for N patients	**64**	**57**
Categorized at week 0, n (%)		
No	0 (0%)	0 (0%)
Mild to moderate	22 (34%)	11 (19%)
Severe to very severe	42 (66%)	46 (81%)
Categorized at week 20, n (%)		
No	54 (84%)	47 (82%)
Mild to moderate	8 (12%)	6 (11%)
Severe to very severe	2 (3.1%)	4 (7%)
Change in from baseline to week 20[1]	-3.0 (-3.0, -2.0), (-4.0, 0.0)	-3.0 (-4.0, -2.0), (-4.0, 0.0)
p-value[2]	**p<1.0e-10**	**p<1.5e-10**

[1]Median (interquartile range), (Min, Max), [2]Wilcoxon Signed-Rank Test p-value

Low Mood:

Week 0: N=100; 98 (98%) with low mood, 2 (2%) had no issues with mood

	N*	**Resolution of low mood n (%) [95% CI]**
At Week 8	91	69 (76%) [66% to 84%]
At Week 20	63	55 (87%) [77% to 93%]

Poor Concentration:

Week 0: N=100; 98 (98%) with poor concentration, 2 (2%) were able to concentrate

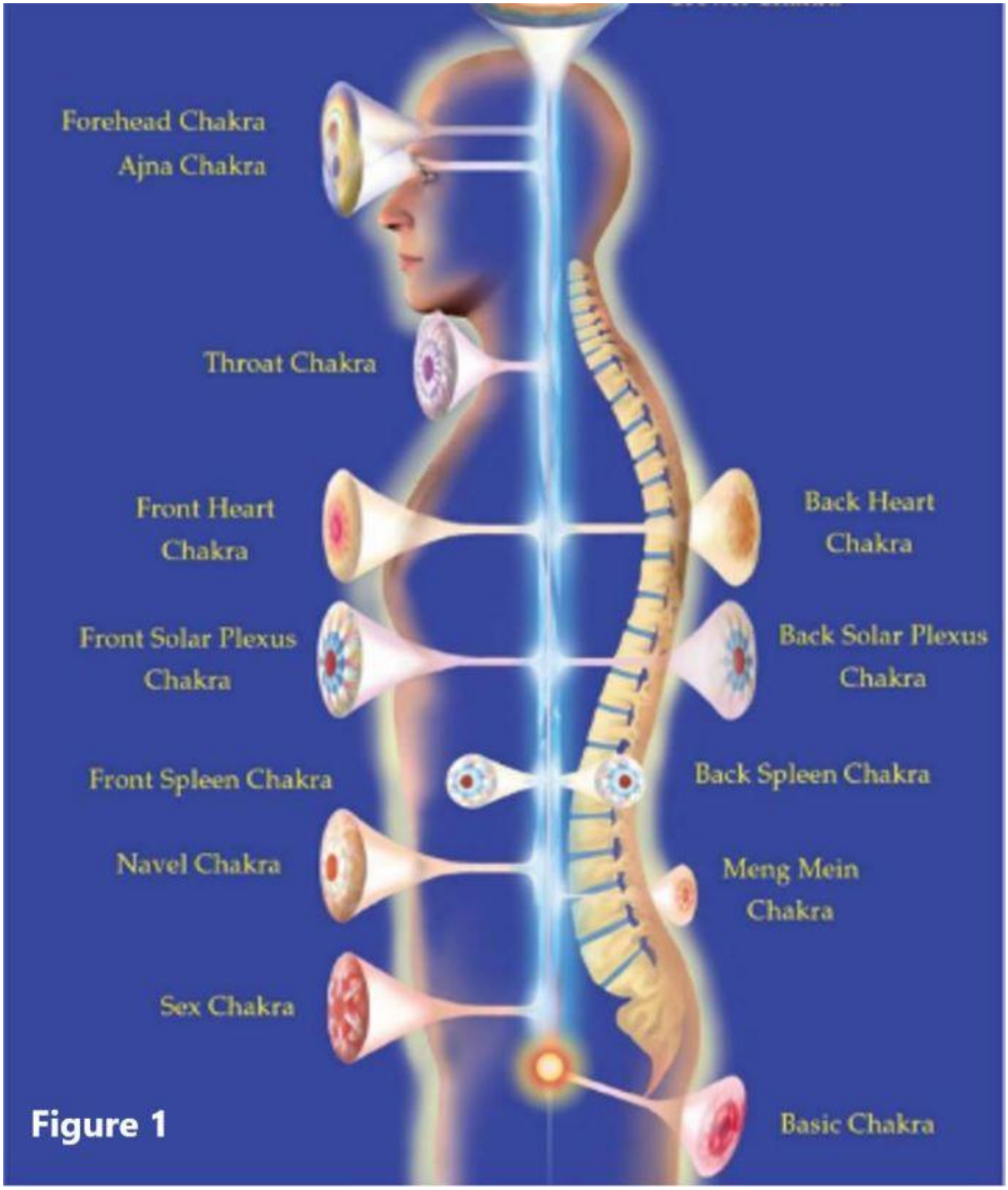
	N*	**Able to concentrate n (%) [95% CI]**
At Week 8	91	65 (71%) [61% to 80%]
At Week 20	62	53 (86%) [75% to 92%]

Fatigue:

Week 0: N=100; 79 (79%) with fatigue, 21 (21%) had no issues with fatigue

	N*	**No fatigue n (%) [95% CI]**
At Week 8	74	56 (76%) [65% to 84%]
At Week 20	50	46 (92%) [81% to 97%]

*Number of participants with presence of Low mood, poor concentration, and fatigue respectively at week 0 with available data at week 8 and week 20 respectively.



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OC35

Supporting medication training in non-english reading and illiterate parents/carers following intestinal transplantation by H Butler, K Martin, C Gilbert, L Hogg, G Gupte, *Birmingham Children's Hospital, UK.*

Introduction: The compliance with medications in solid organ transplantation is important in preventing complications related to over or underimmunosuppression i.e. rejection and infection. In children, compliance is dependent on parental training of medication administration. The specialist nurses use a self-medication chart to train families in administering medications, thus ensuring confidence in delivering medications at home. There are several stages of training for self-medications that have been developed to ensure early intervention, prevent delay in discharge and amend training if required. One barrier we face is teaching parents/carers who cannot read English, as this is the primary language used in our self-medication charts

Aim: Report experience of an intestinal transplant centre in which we overcome barriers in medications training when parents/carers cannot read English. Identify reasons for admissions, and how they differ in non-English reading/writing (NERW) and English reading/writing (ERW) patients and assess effectiveness of modified chart, compared to none modified chart.

Methods: Families that were unable to read English were identified from the intestinal transplant database, 9 control patients were Identified that had none modified medication training. Admissions for both NERW and ERW in their first-year post transplant were documented. The knowledge and recollection of our specialist team past and present to recall which families required modified medication charts and how we trained these families was recorded.

Results: 104 patients had 110 intestinal transplants in our Centre from 1993-2022.

7 transplant patients parents required modification to the self-medication charts, 2 of the transplant patient's parents were illiterate, they could speak English but were unable to read or write English. 5 families that did not understand English, they couldn't speak, read or write English. The self-medication chart was modified by colour coding the bottle of medicine against the chart, and time was spent with interpreters (NERW) to ensure that they understood what the medicines were for and why they were so important.

Average number of days resident in hospital on the transplant admission; 54.8 days in NERW 44.2 days in ERW. On further investigation the NERW discharge time for one patient had been delayed due to an issue not related with training/teaching. The number of admissions within the first year of transplant were 3.4 admissions in NERW and 5.4 admissions in ERW. I also separated admission in the first year into planned and unplanned; 39% planned in NERW, 33% planned in ERW, 61% unplanned in NERW, 67% unplanned in ERW.

Admissions reasons were separated into categories, only one admission had issues that could be related to the way we train parents in self-medications. This patient were ERW, so they did not have a modified chart.

Conclusion: Modification to the self-medication chart meant that those who were unable to read English, were not at a disadvantage when learning the medicines that their child required to keep their graft healthy. The modified chart helped ensure that there were no prolonged stays in hospital or no increase in readmissions in the first-year post-transplant due to misunderstandings regarding medication.

OC36

A review of phase 1 of the Joint United Kingdom Health Security Agency (UKHSA) and National Hepatitis C paediatric Multi-disciplinary operational delivery network (pMDT ODN) National Hepatitis C Paediatric tracking project by Rachel Cockayne[1], Monica Desai[2], Sema Mandal[2], Ruth Simmons[2], Paddy McMaster[3], Alastair Bamford[4], Sarah Tizzard[5], Maxine Brown[1], Stephen Corcoran[6], Carla Lloyd[1], Deirdre Kelly[1], William Irving[7], *[1]Birmingham Women's and Children's Hospital. [2]UK Health Security Agency. [3]North Manchester General Hospital. [4]Great Ormond Street Hospital. [5]St George's Hospital. [6]Speedwell Practice. [7]University of Nottingham, UK.*

Hepatitis C virus (HCV) infection is a major global health problem in adults and children and can cause serious, potentially life-threatening damage to the liver[1]. HCV Global Elimination by 2030 remains a target for the World Health Organisation (WHO) and NHS England (NHSE)

HCV is treated by Direct Acting Anti-viral therapies (DAAs) achieving cure rates of 99% in adults and adolescents. DAAs were licensed for children >3yrs of age in 2020

In 2021 a specialised National MultiDisciplinary Team Operational Delivery Network (MDT ODN) supported by NHSE hosted at Birmingham Women's and Childrens NHS FT, was established to receive referrals; assess, and approve treatment for HCV RNA+ children[2,3]

Laboratory results reported to Public Health England (now the UK Health Security Agency (UKHSA)) from 2019 identified 1086 children and young people nationally who had tested positive but no further follow up known.

In 2022 the pMDT ODN established a joint project sub-group with UKHSA to track these patients and determine their current HCV status.

Phase 1:

- March 2022: UKHSA rechecked 1086 laboratory records, those with a clear outcome or requiring further information were removed.
- July 2022: 481/1086 records, including GPs details shared with the sub-group. Letters sent to GPs requesting information on current HCV status. Details of these 481 patients are shown in Table 1.

Table 1. Outcome 481 patient records shared by UKHSA

Number	Current Status	Current Action:
50/481	>18yrs, referred to adult ODN	n/a
262/431	No further action required 1. 185 retested negative 2. 62 Treated 3. 51 through ODN11 in trials before 2021 4. 14 laboratory tests miscoded 5. 1 returned to home country 6. 1 spontaneously cleared virus	n/a
86/169	Follow up stopped; Laboratory reporting inconsistencies - no further action required; All GPs informed	n/a
83 patients' HCV status yet to be confirmed		
20/83	4 parent/guardian refused testing 9 no longer registered at GP practice 5 further case details required 2 no response from family	Awaiting advice required from UKHSA on next steps; new GP details
13/63	RNA+ve indicating active infection	Awaiting re-testing
18/50	HCV positive – Ab +ve	Awaiting re-testing
25/32	No response from GP.	Follow up letters and calls in progress.

7/7	Awaiting results/ GP follow up	Awaiting results

A GP champion has joined the project assisting with access to primary care records to support the tracking of patients; promoting awareness; understanding of the disease and tests available;

Communication and engagement with GPs is being strengthened to ensure GPs engage with requests for information; understanding of long term risks of the HCV infection, and need for testing.

Phase 1 of the project has been successful in determining the HCV status of 348/431 (80%) children, providing treatment for 51 children ensuring equity of treatment and care closer to home.

Phase 2: November 2023

605/1086 records

- 459/605 – no further action required
- 146/605 HCV RNA+/Ab+ to be followed up

Phase 2 will build on the successes of Phase 1 and continue to follow up the 229 outstanding patients whose HCV status is unknown.

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OC37

PEG: Embraced by families, a useful tool in the nutritional management of early childhood cholestasis by Elizabeth Griffiths, Kirsten Tremlett, Kavitha Jayaprakash, *Leeds General Infirmary, UK.*

Nutrition is a key part of the management of chronic liver disease and supplemental feeds are often required in young children with significant cholestasis. Whilst the insertion and use of gastrostomies in the management of children requiring long term Nasogastric (NG) feeds in other fields of paediatrics is well established, historically units been reluctant to utilise them in children with chronic liver disease due to insertion challenges and potential complications, concerns of development of varices at gastrostomy site and interference with transplant surgery.[1,2]

We show that percutaneous endoscopic gastrostomy (PEG) insertion can be a useful tool, in the right cohort, of children with cholestatic liver disease and can have a significant positive impact on the wellbeing of the child and family. Since 2013 15 children managed in our specialist liver unit with (non-biliary atresia) cholestatic chronic liver disease have required supplemental, non-oral feeds as part of their nutritional management in early childhood. See table 1 for breakdown of diagnosis. All required supplemental feeding before 6 years of age due to fat malabsorption, poor growth and parental difficulties in managing the child's dietary needs orally. 8 of these children received a PEG and one further child is awaiting PEG insertion. Of these 7 were established on NG feeds prior to PEG insertion, one child progressed straight to PEG insertion. 3 patients progressed rapidly to PEG insertion due to frequent loss of NG tube due to pruritis. 8 of 15 have received a liver transplant, of which 3 had a PEG in situ at the time of transplant, one of whom required resiting at the time of transplant. None had a portal hypertension at the time of PEG insertion, however 2 developed portal hypertension at a later date, prior to transplantation. Neither developed varices at the PEG site.

One child who underwent a PEG insertion shortly after commencing NG feeding was able to transition back to full oral feeding in the years following transplant.

One child died two years after PEG insertion from an unrelated condition.

There were no significant complications of PEG insertion in this cohort.

Although there was no significant change in nutritional or growth parameters in these children, pre and post PEG nor compared to those who did not undergo PEG insertion, families report a significant improvement in the quality of life of both themselves and their child, most strongly seen in those for whom frequent repassage of NG tubes were causing distress.

Those who have required long-term NG feeds display ongoing behavioural feeding difficulties even post transplantation.

As a result of these experiences, we are moving increasingly towards early PEG insertion in select patients.

In conclusion, gastrostomies have a key role in the nutritional management of early childhood cholestasis and early insertion should be considered in those requiring long term NG feeds, particularly when oral aversion has developed after NG insertion, or when frequent tube insertions are required.

Table 1.

Diagnosis	Number
Alagille	4
BSEP deficiency	5
MDR3	4
FIC type 1	2

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OC38

Total pancreatectomy and islet cell autotransplantation in a 13-year old with chronic pancreatitis: complexities and multidisciplinary approach

by Paul Henderson[1,2], Philip Hammond[3], John Casey[4], Sarah Thomasset[5], Catherine Paxton[1], Heather Grant[6], Su Ying Ong[7], Jillian McFadzean[7], John Morrice[8], Sarah Kiff[9], Daniela Elleri[9], Shareen Forbes[10], Mandy Hamilton[7], Blair Thomson[11], Lora Irvine[12], Sharon Zahra[12], Pauline Clemison[13], Rajan Ravindran[5],*[1]Department of Paediatric Gastroenterology and Nutrition, Royal Hospital for Children and Young People, Edinburgh. [2]Child Life and Health, University of Edinburgh, Edinburgh. [3]Department of Paediatric Surgery, Royal Hospital for Children and Young People, Edinburgh. [4]Edinburgh Transplant Centre, Royal Infirmary of Edinburgh, Edinburgh. [5]Department of General Surgery, Royal Infirmary of Edinburgh, Edinburgh. [6]Department of Dietetics, Royal Hospital for Children and Young People, Edinburgh. [7]Department of Anaesthetics and Pain Management, Royal Hospital for Children and Young People, Edinburgh. [8]Department of Paediatrics, Victoria Hospital, Kirkcaldy. [9]Department of Endocrinology and Diabetes, Royal Hospital for Children and Young People, Edinburgh. [10]Department of Endocrinology, Royal Infirmary of Edinburgh, Edinburgh. [11]Learning Disabilities Service, Astley Ainslie Hospital, Edinburgh. [12]Scottish National Blood Transfusion Service, The Jack Copland Centre, Edinburgh. [13]Children and Young People's Community Nursing Service, Lynebank Hospital, Dunfermline, UK.*

Recurrent acute and chronic pancreatitis remain rare in children and young people but can lead to significant morbidity with regard to significant pain, nutritional compromise, frequent hospital admissions, reduced quality of life. Total pancreatectomy (TP) can be performed to control pain and reduce complications, however insulin-dependent “brittle” diabetes is inevitable. One solution is TP with islet cell autotransplantation (TPIAT) to preserve endogenous islet function and insulin production – hopefully sufficient to wean from exogenous insulin and avoid hypoglycaemia unawareness post-operatively.

A 13-year old boy with previous episodes of recurrent pancreatitis (raised amylase/lipase with characteristic pain) and subsequent chronic pancreatitis (i.e. pancreatic atrophy on cross-sectional imaging, calcification and stone formation on endoscopic ultrasound, need for pancreatic enzyme supplementation) was worked up thoroughly for the cause of his disease. No anatomical abnormality, classical genetic mutation (e.g. PRSS1, SPINK) or other aetiology was determined, although he was heterozygous for a CFTR mutation and had a PiMZ alpha-1-antitrypsin phenotype. His course continues to be complicated by severe autism with significant learning and communication difficulties. Following local, regional and national MDT discussion the decision was made to perform TPIAT. Full written consent from the family was obtained to present the case and associated images.

Over an 18-month period the patient’s nutrition was optimised by gastrostomy insertion with fat-soluble vitamin and pancreatic enzyme supplementation. Pain limited his feed rate (18hr daily) and oral intake remained poorly tolerated. During work-up and discussions his quality of life deteriorated (e.g. house-bound, poor social interaction, significant analgesia requirements including daily opiates); prior to TPIAT HbA1c and blood glucose were normal. The family were counselled about the complications, especially diabetes, cross-sectional imaging updated, baseline bloods performed and multiple MDT discussions were required to plan nutrition pre- and post-operatively, practicalities of theatre, HRA requirements for islet cell infusion, PICU considerations and intra- and post-operative blood glucose and pain management as well as PICU and behavioural considerations. The procedure took 19hrs during which time the patient had a total pancreatectomy, splenectomy, cholecystectomy, hepatico-jejunostomy, gastro-jejunostomy and insertion of jejunal extension through his PEG. During the procedure the pancreas was transferred to the islet lab at the Scottish National Blood Transfusion Service where it was digested and islet cells isolated – this then allowed the infusion of 93,000 islet equivalents via a temporary Broviac line (with intraoperative etanercept) into the portal vein (with continuous portal pressure monitoring). He was commenced on an intravenous insulin infusion in theatre after the pancreas was removed, maintaining his glucose between 4-7mmol/l.

We present what we believe is the youngest child to have a TPIAT performed in the UK, his pre- and post-operative progress, his complex intra-operative management, the multidisciplinary aspects of his ongoing care and his outcome.

OC39

Diagnosis and monitoring treatment for inborn errors of bile acid synthesis: moving towards dried blood spot analyses by Youssef Khalil[1], Rohit Hirachan[1], Francesca Mazzacuva[1], Helen Prunty[2], Philippa Mills[1], Peter Clayton[1], *[1]UCL Great Ormond Street Institute of Child Health, London. [2]Great Ormond Street Hospital NHS Foundation Trust, London, UK.*

Inborn errors of bile acid synthesis (IEBAS) can cause cholestatic liver disease and fat-soluble vitamin malabsorption in infancy and neuropsychiatric disorders later in life. Early diagnosis can prevent some of these problems. Treatment with parenteral vitamin K can prevent catastrophic bleeds. For 3ß-hydroxy-D5-C_{27}-steroid dehydrogenase (HSDH) deficiency and D4-3-oxosteroid 5ß-reductase deficicency, treatment with cholic acid can prevent progression of liver disease to cirrhosis and liver failure. Chenodeoxycholic acid treatment has led to resolution of liver disease in oxysterol 7a-hydroxylase deficiency and can prevent or even reverse neuropsychiatric problems in cerebrotendinous xanthomatosis. In some countries, progress is being made towards neonatal screening for IEBAS by measurements of bile acids and bile alcohols. In England, 6 IEBAS are being included in the trial of newborn screening using DNA sequencing.

In the UK, most IEBAS have been diagnosed by looking at a spectrum of urinary bile acids and bile alcohols. This is satisfactory for cholestatic infants but may not detect the abnormal bile acids in a school-age child with a peroxisomal disorder and no overt cholestasis; for this group we have used quantitative assays of bile acids in plasma.

The use of dried blood spots (DBS) has obvious advantages in terms of the ease of getting a sample and sending it to the reference laboratory. We have developed a method for quantitative assay of normal and abnormal bile acids in DBS / plasma using UPLC – tandem mass spectrometry[1-3].

Recent validation experiments have shown that elution of bile acids from a DBS is improved by using 80% methanol rather than 100%. The additional information provided by the UPLC retention time can be very important in determining the identity of unusual bile acids. The stability of unsaturated bile acids in urine and DBS is being evaluated.

Data has previously been presented as a poster at an SSIEM meeting on the use of dried blood spots for diagnosis and monitoring cholic acid treatment in 3 children with HSDH deficiency[3]. The measurement of both the unsaturated bile acids generated by the disorder and the saturated bile acids that derive from the cholic acid treatment, shows that the levels of cholic acid conjugates can rise to potentially toxic levels at the start of treatment when the bile acid export pump is still inhibited by the unsaturated bile acids. Starting treatment at a lower dose combined with ursodeoxycholic acid appears to prevent this.

The UPLC-MS/MS assay successfully demonstrated the presence of markedly raised C27 bile acids in plasma in acyl-CoA oxidase 2 (ACOX2) deficiency in an 8-year old boy with transaminase elevation, liver fibrosis, ataxia, and cognitive impairment[2].

In 3 adults with a-methyl-acyl-CoA racemase (AMACR) deficiency presenting with a movement disorder, the UPLC-MS/MS assay on plasma showed that unconjugated dihydroxycholestanoic acid was the best diagnostic metabolite.

Further work is needed on stability of bile acid and bile alcohol metabolites in DBS but already results suggest that UPLC-MS/MS analysis on plasma or DBS is going to prove an improvement on semi-quantitative methods using urine for diagnosis and monitoring IEBAS.

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OC40

Impact of maralixibat on cholestatic pruritus in young adults aged 16 years and older with Alagille syndrome by Gideon Hirschfield[1], Douglas Mogul[2], Francois Smuts[2], Marshall Baek[2], Pamela Vig[2], Binita Kamath[3], *[1]University of Toronto, Toronto Centre for Liver Disease, University Health Network, Toronto, Ontario, Canada. [2]Mirum Pharmaceuticals, Inc., Foster City, California, United States. [3]The Hospital for Sick Children and the University of Toronto, Division of Gastroenterology, Hepatology and Nutrition, Toronto, Ontario, Canada.*

Data in ALGS has primarily focused on pediatric patients, however adults with ALGS who survive with their native liver may require treatment for cholestasis and pruritus. We report on the efficacy and safety of MRX, an IBAT inhibitor, in young adults aged ≥16 years with ALGS transitioning to adult care.

Participants received ≥1 dose of MRX ≥16 years of age within the MRX ALGS clinical development program. Pruritus [ItchRO(Obs)] and serum bile acids (sBA) were assessed at Baseline, before and after 16 years, and at study end.

14 individuals were included; 11 began treatment at <16 years of age and 3 patients began MRX ≥16 years. Baseline mean (SE) pruritus score was 2.5 (0.21), and significantly decreased to 0.8 prior to 16 years (delta = -1.7; p = 0.002); pruritus response was durable with no significant change before and after age 16 years (delta = -0.2; p = 0.2), or to end of therapy (delta = 0.2; p = 3) in individuals that started MRX <16 years old. Baseline mean sBA was 130 µmol/L, significantly decreased to 52 µmol/L (delta = -79; p = 0.03) prior to 16 years; no significant change before and after age 16 years (delta = -7; p = 0.3), or to end of therapy (delta = -3; p = 0.4) was observed. Three individuals that started MRX ≥16 years had improvements in pruritus from Baseline (delta = -2.8, -0.6, and -1.0). One patient had a large decrease in sBA (delta = -112 µmol/L) and two had small increases in sBA (delta = 8 and 11 µmol/L). MRX was generally well tolerated with the same safety profile previously reported.

MRX was effective, durable, and well tolerated in ALGS patients ≥16 years, providing critical data for patients who transition to adulthood while on therapy.

OC41

Use of Triple (Elexacaftor/Tezacaftor/Ivacaftor) Cystic Fibrosis Transmembrane Conductance Regulator modulator in children with cystic fibrosis associated liver disease by Joseph Valamparampil[1], Benjamin Davies[2], Maya Desai[2], Indra Van Mourik[1], *[1]Liver Unit (including small bowel transplantation), Birmingham Women's and Children's NHS Foundation Trust. [2]Birmingham Women's and Children's NHS Foundation Trust, UK.*

Cystic fibrosis transmembrane conductance regulator (CFTR) modulators directly target molecular defects in CFTR protein and has shown to improve lung function, respiratory symptoms, nutritional status and overall life expectancy in children with CF. Combination therapy with Elexacaftor/Tezacaftor/Ivacaftor is approved for children homozygous F508del or heterozygous F508del with any other mutation. Data on use of CFTR modulators in children with CF-associated liver disease (CFLD) is limited because patients with clinically significant cirrhosis with or without portal hypertension (advanced liver disease), elevated bilirubin or liver enzymes were excluded from trials assessing efficacy and safety.1

Aim of this retrospective audit was to analyze our experience in using triple therapy (Elexacaftor/Tezacaftor/ Ivacaftor) in children with CFLD. The diagnosis of CFLD was based on established criteria.2 Study participants were divided into two groups (mild and advanced) based on the severity of liver disease.2 We analyzed the lung function (FEV1, FVC), nutrition (weight & height z-scores), liver biochemical tests, non-invasive markers of liver fibrosis (APRI- AST to Platelet Ratio Index, Fib-4) at initiation and 1-y follow-up. Statistical analysis was done using SPSS with p-value <0.05 as significant.

28 children (males-17) with CFLD were started on triple CFTR modulator at median age 12 (IQR 11 -13.5) years. 14 had advanced-CFLD. 12 children were switched from dual therapy (lumacaftor/tezacaftor + ivacaftor). There was no statistically significant change in bilirubin, AST, ALT, GGT, albumin, platelet count, APRI or Fib-4 after 1-y. There was a statistically significant increase in weight but not height after 1-y. FEV1 & FVC did not show significant change. 5 children with mild-CFLD required temporary cessation due to raised transaminases but was reintroduced successfully. Only one patient with severe-CFLD had clinical progression of portal hypertension requiring trans jugular intrahepatic porto-systemic shunt insertion. The total duration of follow-up was 28.5 (IQR 20-35) months; all children had stable liver synthetic function and normal bilirubin at the last follow-up.

In summary, triple-CFTR modulator therapy was well tolerated in children with mild & advanced CFLD without significant worsening of liver disease.

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OC42

Bone mineralization in children with Wilson's disease by Shiamaa Eltantawy[1], Gihan Sobhy[2], Alif Allam[3], *[1]National Liver Institute, Menofia University, Egypt +Great Ormond Street Hospital, London, UK. [2]National Liver Institute, Menofia University, Egypt +Vaseen Abdelghafar Charity Center for hepatology. [3]National Liver Institute, Menofia University, Egypt.*

Wilson disease, or hepatolenticular degeneration, is an autosomal recessive disease that results in excess copper buildup in the body. It primarily affects the liver and basal ganglia of the brain, but it can affect other organ systems[1]. Musculoskeletal abnormalities, including premature osteoarthritis, skeletal deformity, and pathological bone fractures, can occasionally be found in WD patients with a hepatic or neurologic type[2].

The aim was to assess the prevalence of osteoporosis and osteopenia in Wilson's disease patients. This case-control study was conducted on ninety children recruited from the inpatient ward and outpatient clinic of the Paediatric Hepatology, Gastroenterology, and Nutrition Department of the National Liver Institute at Menofia University, aged from 1 to 18 years. Males were 49, and females were 41. Children were divided into three groups: (Group I) consisted of thirty patients with WD; (Group II) consisted of thirty patients with chronic liver disease other than WD; (Group III) consisted of thirty age- and sex-matched healthy The exclusion criteria were patients with hyperparathyroidism, hyperthyroidism, renal failure, Cushing's syndrome, and patients on certain drugs such as chemotherapy, anticonvulsants, or steroids. All patients were subjected to the following

1- Full history-taking and clinical examination.

2-Laboratory investigations: (FBC, ALT, AST, serum albumin, total protein, total serum bilirubin, direct bilirubin, alkaline phosphatase, prothrombin time, serum creatine, parathyroid hormone, serum calcium, serum phosphorus).

3-Bone mineral density (BMD, gm/cm2) values were measured by dual-energy X-ray absorptiometry (DEXA).

The results revealed that there was a highly statistically significant difference between the three groups regarding the DEXA scan, and there was no statistically significant difference between groups I and II, but the WD group had the lowest bone mineral density. The WD group had a large number of cases of osteopenia and osteoporosis, but there was no statistically significant difference with the group II mean, while a high statistically significant difference was found when compared to group III. In the WD group, there were 20 patients with osteopenia, 4 patients with osteoporosis, and 6 patients who were normal. The percentages were 66.7%, 13.3%, and 20%, respectively. Therefore, the largest number of cases in the WD group had osteopenia. There was no statistically significant difference found between WD patients on different treatment regimens regarding DEXA scan results (Z-Score). There was no statistically significant difference found between patients in the WD group (normal, osteopenic, or osteoporotic) regarding phosphorus (mg/dL), but there was a highly statistically significant difference found between them regarding ionized Ca (mmol/L). Therefore, there was a decrease in bone mineral density when the Ca level was decreased.

In summary, Wilson's disease is associated with bone demineralization. The largest number of cases in the WD group in our study had osteopenia (66.7%). Different treatment regimens (zinc monotherapy, Artamin, and zinc) as well as different laboratory parameters have no effect on bone mineralization in WD cases. Decreased ionized Ca is associated with low BMD in WD patients. Children with WD should be investigated for BMD.

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OC43

The Impact of Rigid Infant Feeding Intentions on the Incidence of Neonatal Jaundice: an Exploratory Study by Nour Abuhwaila, Nana Anokye, Terence M. Dovey, *Brunel University London, UK.*

According to the National Institute for Health and Care Excellence (NICE) guidelines, a primary risk factor for idiopathic neonatal jaundice (INJ) is the maternal intention to breastfeed exclusively (1). This correlation has been based on actual feeding practices post-birth (2). However, the psychological interpretation of breastfeeding intention and the link with INJ has been overlooked. Therefore, this study explored the psychological interpretation of breastfeeding intention and evaluated breastfeeding outcomes, which are purported to be risk factors in the development of INJ. A cross-sectional questionnaire survey was given to mothers with jaundiced and non-jaundiced infants. The questionnaires were about childbirth experience, infant feeding intention, breastfeeding attitude, self-efficacy, neuroticism, openness, and rigidity of maternal beliefs. A machine learning approach of random forest classification was used, followed by binary logistic regression, to investigate maternal intention to breastfeed exclusively as an INJ risk factor. A correlation matrix was also conducted to assess the associations between variables. Responses from 1,131 mothers who gave birth within the last three years revealed significant predictors of INJ, including gestational age over 40 weeks, induced labour, assisted birth, and birth complications. A negative correlation was found between breastfeeding intention and INJ. However, deviation from initial feeding intentions to other feeding practices, irrespective of whether the mother was breastfeeding or not, explained the psychological connection between evaluating breastfeeding practices and INJ. Feeding differently than intention significantly correlated with INJ with a regression score of ($p=0.024$; McFR2 =0.108, odds ratio [OR] =0.606; 95% CI). Therefore, feeding differently than intention is a better predictor of INJ than the intention to solely breastfeed. Mothers' pre-birth ambivalence about sticking to a specific feeding approach may afford some protection against developing INJ, probably through more cognitive flexibility to deal with unexpected circumstances during the first hours and days of life. These findings suggest that maternal rigidity in feeding intentions, particularly when experiencing perceived traumatic childbirth, is a better direct predictor of INJ rather than the intention to solely breastfeed, which was unrelated to INJ in our data. These results indicate that the current NICE guidelines regarding infant feeding and INJ may need re-evaluation, emphasizing the psychological dimensions of breastfeeding intention.

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OC44

Predicting Ideopathic Neonatal Jaundice using the Infant Feeding Survey: Machine Learning Application by Nour Abuhwaila, Nana Anokye, Terence M. Dovey, *Brunel University London, UK.*

Maternal feeding practices and childbirth have been reported to increase the risk of developing idiopathic neonatal jaundice (INJ). However, despite the National Institute for Health and Care Excellence (NICE) guidelines suggesting that the intention to solely breastfeed is a psychological predictor for INJ, this has not been sufficiently explored from a psychological perspective (1). The Infant Feeding Survey (IFS) 2010 was conducted to understand maternal feeding practices, including the incidence, prevalence, and duration of breastfeeding, post-natal care and childcare advice received, and mothers' intentions and practices regarding infant feeding (2). The purpose of this study was to build a predictive model of determinants of INJ using the IFS data. This study aimed to replicate previously reported biological predictors of INJ and extend and explore the impact of two psychological variables - breastfeeding intention and confidence - to predict the development of INJ.

A machine learning approach of random forest classification was used to analyze 12,633 suitable cases with sufficient data identified from the IFS. During pregnancy, mothers made their intentions about their infant's feeding options clear. 2927 intended to formula feed, 6938 intended to breastfeed, 1658 decided on combination feeding, and 1078 were unsure of which feeding method to choose while pregnant. Feature selection analysis revealed that longer periods of stay at the hospital, frequency of formula feeding, and maternal perception of insufficient milk led to stopping breastfeeding were positively correlated with INJ. Meanwhile, gestational age, marital status, feeding intention and mother's socio-economic status were significantly and negatively correlated with INJ. Using the random forest classifier, the psychological model to predict INJ achieved an accuracy of 75.5%, a precision of 73.2%, and an F1 Score of 75%. A confirmatory binary logistic regression showed that longer periods of stay at the hospital and having instrumental deliveries and emergency cesarean sections are significant risk factors for INJ. Also, having a feeding intention, irrespective of the feeding option, increases the likelihood of INJ ($p=0.001$; McF $R^2 =0.214$, odds ratio [OR] =4.121; 95% CI).

In other terms, there is no difference between the intention to formula feed or breastfeed in predicting INJ. Having a predetermined feeding intention, whether it is solely breastfeeding or infant formula versus other feeding options, is a significant predictor of INJ. This is possibly linked to the rigidity of mothers' reluctance to alter feeding strategies, particularly in the context of perceived traumatic childbirth. This study highlights the importance of considering the psychological interpretation of infant feeding intention to predict INJ, with the consideration of difficult birth experiences.

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OC45

Copper deficiency in paediatric jejunal tube feeding by David Cairney[1], Catherine Paxton[1], Adele Wilson[2], Ruth Hamblin[1], Heather Grant[1], Paul Henderson[1], David Wilson[1,3], Victoria Merrick[1], *[1]Department of Paediatric Gastroenterology, Hepatology and Nutrition, Royal Hospital for Children and Young People, Edinburgh. [2]School of Medicine, University of Glasgow. [3]Child Life and Health, College of Medicine and Veterinary Medicine, University of Edinburgh, Edinburgh, UK.*

Introduction: Jejunal tube feeding (JTF) is used to deliver post-pyloric nutrition in children for a variety of indications such as reflux, foregut dysmotility and in anatomical or post-surgical gastrointestinal tract obstruction. It can be used to effectively deliver feeds, improve quality of life and may reduce the requirement for parenteral nutrition. JTF has well-known complications, primarily relating to mechanical issues such as tube displacement and rare abdominal catastrophes. There is increasing evidence that micronutrient deficiencies can arise during JTF. Copper is an essential component of numerous metalloenzymes that are required for normal metabolism, detoxification and protein synthesis. Copper is absorbed from the stomach and first part of the duodenum which is bypassed with JTF. Copper deficiency can lead to cytopenia, neurological issues and bone diseases. Serum levels can be affected by systemic inflammation[1]. We aimed to determine the rate of copper deficiency in a 21-year cohort of home JTF patients and the subsequent outcomes of management.

Methods: A retrospective cohort study was undertaken in a regional tertiary gastroenterology department with a multi-disciplinary nutrition service from 1/1/2002 to 20/4/2023. Patients were identified from a prospectively maintained departmental JTF database. Electronic records and lab results were extracted by a single reviewer using a double data entry method. Copper measurements were recorded in the year prior to starting JTF and until the earliest of: discontinuation of JTF, death, migration out of area or transition to adult services. Age variable copper normal ranges were applied to determine low values at sampling time points[2]. Copper values were excluded from analysis if the CRP was known to be >5 at the time of sampling. Replacement was administered with 0.5% copper sulphate oral solution at 50µg/kg/day gastrically (ensuring gastric drainage was clamped for 30 minutes).

Results: 91 patients (50% female) were included in the cohort; 74% (67/91) of patients had co-morbid neurodisability and 2% (2/91) had >1 period of JTF. Median (IQR) age at starting JTF was 3.6 (1.4-10.3) years. Median (IQR, range) duration of JTF was 1.7 years (0.8-5.0, 0-15). 89 patients (87%) had copper measured during their follow-up period including all patients from 01.2012 onward. After excluding measurements with a high or absent CRP level, 10 patients (11%) developed a low copper level at some point following commencement of JTF. The median (IQR, range) time from starting JTF to the first low copper level was 3.5 years (2.1-6.3, 1.5-9.6). 6 patients received copper replacement (1 for symptomatic anaemia, lymphopenia and neutropenia and 5 for worsening/persistent deficiency). Two patients required on-going daily replacement and the other 4 patients received supplementation in 1-3 month long blocks. Copper levels normalised in all patients.

Conclusions: This cohort study demonstrates that a minimum of 11% of children receiving JTF are at risk of copper deficiency and a small number may develop sequelae from this if not identified and corrected. Most patients will respond to gastric copper replacement with normalisation of copper levels and/or haematology parameters. These data reinforce the importance of routine copper measurements in jejunally fed children.

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OC46

The efficacy of DEKA® vitamin preparations in a cohort of paediatric gastroenterology patients with non-cystic fibrosis related malabsorptive disorders within a tertiary service by Alicia Gordon, *Great Ormond Street Hospital, London, UK.*

Maintaining adequate fat soluble vitamin levels prevents clinical manifestation of deficiency diseases which, untreated can significantly contribute to patient morbidity[1]. DEKA® vitamins contain fat soluble vitamins in a water soluble micelle. They are subsequently suggested to be more readily absorbed in cystic fibrosis patients compared to standard preparations[2]. The aim of this service evaluation was to assess whether these preparations are beneficial for our gastroenterology patients, who have fat soluble vitamin deficiencies refractory to standard treatments.

Data on patient demographics, vitamin and mineral supplements, pancreatic enzyme replacement therapy, adherence to treatment and serum levels of vitamin A, E, D and, prothrombin time (PT), as an indirect marker of vitamin K status, were collected retrospectively from all patients seen in gastroenterology outpatients taking DEKA® vitamins in 2022. Efficacy was assessed by comparing blood values prior to commencing DEKA® vitamins with the following two time points after starting the new treatment.

11 patients were taking DEKA® vitamins, of these 54% had a diagnosis of Schwachman-Diamond Syndrome (SDS) (Table 1), 100% of which were pancreatic insufficient (PI). The further two patients that had PI had a diagnosis of short bowel syndrome (SBS). The predominant reason for switching from standard vitamin preparations to DEKA® vitamins was "vitamin A level refractory to standard preparations" (6/10 patients). By starting the DEKA® vitamins the median dose of vitamin A increased from 500% of the RNI for age and gender to 908%, whilst vitamin K increased from 58% to 2315%. The median time (days) elapsed between baseline and the first set of blood results was 90 (range 27-247) and to the second set of blood results was 221 (range 68-421). At baseline 83% of patients had a vitamin A level below the lower reference limit of normal, compared to 50% at the second time point. However, in 5 out of 11 patients, vitamin A status worsened after starting the DEKA® vitamins. 3 out of 5 five patients in this subgroup had a primary diagnosis of SBS, 1 had SDS and 1 had Hennekam-Beemer protein losing enteropathy. PT was elevated in 55% of patients at baseline and 67% at the final time point.

Total patients in the gastroenterology outpatient cohort taking DEKA® vitamins (n)	11
Diagnosis (n)	
Schwachman-Diamond syndrome	6
Short bowel syndrome	3
Tufting enteropathy	1
Hennekam-Beemer protein losing enteropathy	2
Median age starting DEKA (years)	11.5
Pancreatic insufficiency denoted by elastse <200 ug/g (n)	8

Table 1: description of patients within the service evaluation

Our data shows that within our cohort DEKA® vitamin preparations are not effective for correcting vitamin A deficiency in malabsorptive conditions not related to PI; other methods of correcting deficiencies should be investigated for this patient group. PT did not correlate with the dose of vitamin K; whilst vitamin K provision substantially increased, the number of patients with an elevated PT increased, demonstrating the likely effect of other confounding factors. Other biomarkers of vitamin K status should be evaluated, with the DEKA® vitamins re-evaluated once a new marker has been determined.

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OC47

The measurement of resting energy expenditure in mechanically ventilated critically ill children: Evaluating the need and feasibility of introducing Indirect Calorimetry in routine dietetic practice by Sandra Fernandes Lucas[1,2], Graeme O'Connor[1,2], Samiran Ray[1,2], *[1]University College London Great Ormond Street Institute of Child Health. [2]Great Ormond Street Children's Hospital Foundation Trust, UK.*

The goal of estimating the resting energy requirements (REE) of children admitted to Paediatric Intensive Care Unit (PICU) is to tailor nutritional prescription, and prevent clinical adverse outcomes associated with over- or underfeeding (1, 2). Indirect Calorimetry (IC) is the most reliable and widely recommended method of assessing REE (3), however due to its cost and technical challenges, most PICUs use predictive equations instead (4). We aimed at evaluating the current service provided at our institution and, assess the need and feasibility of introducing IC as part of routine dietetic practice in mechanically ventilated patients.

A prospective service evaluation was performed in mechanically ventilated patients admitted to PICU over a 3-month period in 2022. We analysed the screening, eligibility process and challenges associated with IC. IC was performed in children above 10 kilograms as recommended by the metabolic monitor company. To assess our current service, we assessed the agreement between the measured REE (mREE) through Indirect Calorimetry and the REE predicted (pREE) via the Schofield equations, the method used to estimate REE in our unit. The agreement between mREE and 9 other existent equations was also assessed. A pREE within 90-110% of the mREE (i.e., a difference between methods of -10% to +10%) would be considered clinically significant.

Of the 233 PICU admissions observed in the project period, 84 (36%) were below the minimum weight criteria to have Indirect Calorimetry performed (figure 1). A total of 102 patients met the inclusion criteria, however only 21 (20.6%) had IC performed (figure 1) with a total of 26 IC measurements taken. Tidal volumes of <90mL were associated with IC measurement failure ($p<0.001$). Schofield (W) equation was accurate in (3/17) 17.7% of cases, mostly overestimating the resting energy expenditure with a mean bias of 48.2% (95%CI 22.4, 74.1), and wide limits of agreement (LoA) (-50.9%, 146.9%) (figure 2). The simplified Weir equation had the largest number of patients within the clinically acceptable range (7/17) with a mean bias of -11.4% (95% CI -14.6, -8.14), and narrower LoA (-23.8%, 1.0%). The remaining equations had wider limits of agreement with the wildest resulting from the Harris-Benedict equation.

In conclusion, valid Indirect Calorimetry measurements were only feasible in less than 10% of PICU admissions. Where performed, agreement with currently used estimation methods was poor. This demonstrates the need for better estimation techniques. The formulation of new predictive equations using advanced statistical methods is a promising area for exploration.

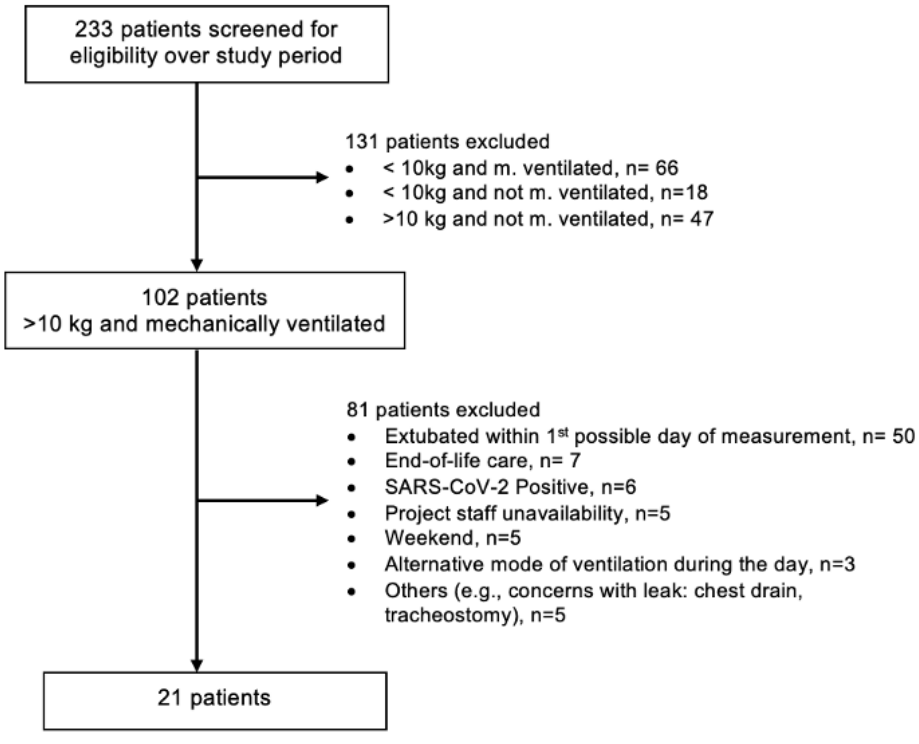

Figure 1. Flowchart of the patient screening and eligibility assessment undertaken. m. ventilated- mechanically ventilated. Extubated within 1st possible day of measurements refers to those patients who were extubated within 24-36 hours after admission or intubation.

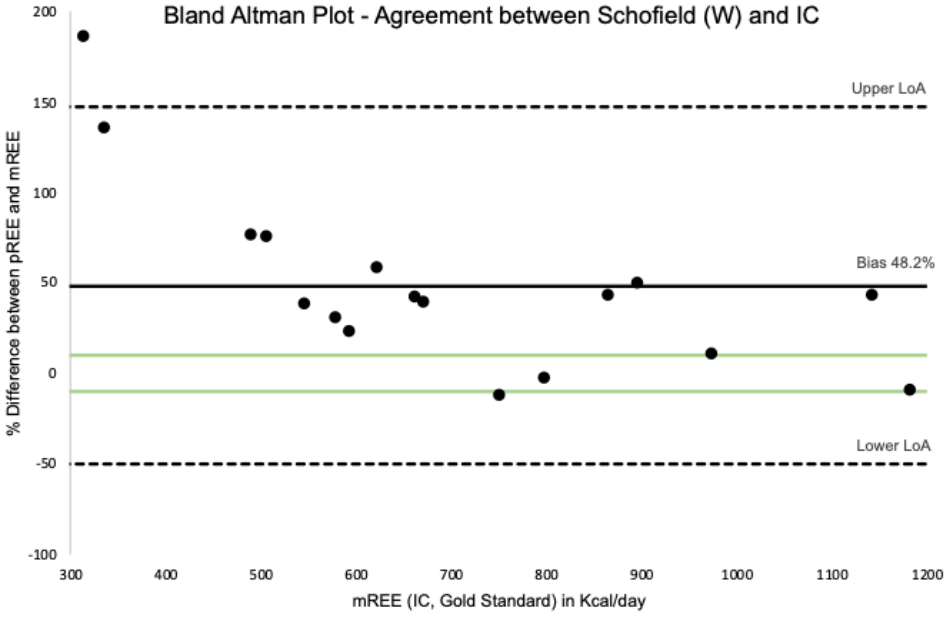

Figure 2. Bland-Altman plot displaying the agreement between the pREE from the Schofield (W) equation and the mREE via IC. The green solid lines represent the clinically acceptable limits. The dashed black lines represent the limits of agreement (LoA), and the solid black line the mean bias.

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OC48

Safety and diagnostic yield of wireless video capsule endoscopy in early onset inflammatory bowel disease (EOIBD) in children under the age of 6 years in a tertiary paediatric IBD centre by Selina Green, Jasmine Hammond, Edward Gaynor, Kelsey Jones, Fevronia Kiparissi, *Great Ormond Street Hospital NHS Foundation Trust, London, UK.*

Wireless video capsule endoscopy (VCE) is a well-established diagnostic tool used in the evaluation of small bowel disease in paediatric IBD. Patients usually swallow the capsule. Young children are rarely able to swallow the capsule and these therefore need to be placed with the help of an OGD and an ACORN device. 2 capsule systems were used: PillCam and MiroCam.

The aim of this study was to look at the safety of capsule insertion in children less than 6 years of age and to also look at the diagnostic yield.

We conducted a retrospective review of our VCE data base over a 7-year period from April 2016 to August 2023. 22 patients (14 male) and 27 capsule episodes were included into the study with an age range at point of capsule insertion between 2 years and 5 months and 5 years and 8 months (median 5 years). All capsules were inserted with an ACORN device. All patients had a histologically proven diagnosis of EOIBD; during this period 4 patients had 2 VCEs and 1 patient 3 VCEs placed. All patients had genetic tests performed, only 1/24 patients had a monogenic mutation confirmed. 15/27 (56%) of all capsules were normal, 5/27 (19%) showed small bowel ulcerations only, 2/27 (7%) showed both small bowel and colonic ulcerations and 5/27 (19%) showed colitis only. We were able to insert the capsule in all 27 capsule episodes without any complications. All studies were completed with the capsule seen entering the colon and none of capsules got retained.

In summary wireless video capsule endoscopy in early onset inflammatory bowel disease in children under the age of 6 years is safe with a diagnostic yield of around 50%. This modality should be used in the diagnostic pathway of EOIBD.

OC49

C. Difficile in Paediatric IBD by Joseph Machta[1,2], Eliza Alexander[3], Sandhia Naik[3], *[1]Chelsea and Westminster Hospital NHS Trust. [2]Children's Clinical Research Facility, The Royal London Hospital, Barts Health NHS Trust. [3]The Royal London Hospital, Barts Health NHS Trust, UK.*

Clostridioides difficile (C.Difficile) is a spore-forming, toxin-producing, Gram-positive anaerobe and one of the most common causes of hospital-acquired and antibiotic-associated infectious diarrhoea(1). The estimated asymptomatic carriage rate of C.Difficile is approximately 5% in adults and between 15-70% in infants(2). Patients with inflammatory bowel disease (IBD) are thought to have higher prevalence of C.Difficile colonisation and C.Difficile Associated Disease (CDAD) than the general population, with associated worse outcomes(3)(4).

We performed a service evaulation study to ascertain the prevalence of C.Difficile carriage and CDAD in the regional paediatric population, comparing rates in the paediatric IBD patient population versus other groups. The hypothesis being that the rate of C.Difficile carriage and associated disease are higher in the IBD population. The study was registered with the Trust Clinical Effectiveness unit as a service evaluation project and so ethical approval was not required.

We performed retrospective analysis of all paediatric C.Difficile requests sent to the Microbiology laboratory at a major NHS Trust between 12th April 2020 to 6th November 2022. 601 samples were submitted, from the major paediatric hospital, peripheral centres, and general practice. 78.2%(n=470) tests included for analysis, from patients aged 1 to 15 years (mean 8.3 years). 21.8%(n=131) were not analysed due to being non-diarrhoeal stool, repeat samples, aged <1 year, or cancelled by requesting clinician.

32.9% (n=155) samples were from patients with known IBD. 55.5% (n=86) ulcerative colitis (UC), 36.77%(n=57) Crohn's Disease (CrD), 7.74%(n=12) IBD unclassified (IBDU). Samples were analysed for C.Difficile glutamate dehydrogenase (GDH) immunoassay, C.Difficile toxin A and B, and polymerase chain reaction (PCR) DNA extraction of C.Difficile toxigenic gene material. GDH positive: 7.74%(n=12) in IBD group vs. 20%(n=63) non-IBD.

Toxigenic gene positive: 5.8%(n=9) in IBD group vs. 9.84%(n=31) non-IBD.

C.Difficile toxin A/B: 1.29%(n=2) in IBD group vs. 3.17%(n=10) non-IBD. Both patients in IBD group received gold-standard treatment vs. 60%(n=6) in non-IBD group.

A chi-square test of independence was performed to examine the statistical significance of rates of positive GDH, Toxigenic gene, and Toxin A/B between IBD and non-IBD groups. We found a statistically significant increase in GDH positivity in the non-IBD group (p=0.02), but the differences in Toxigenic gene and Toxin A/B testing were not statistically significant (p=0.22 and 0.19 respectively).

Our findings demonstrate a lower rate of C.Difficile colonisation in the paediatric IBD group in our population, although there is no statistically significant difference in the rate of CDAD, contrary to studies demonstrating higher rates of colonisation and CDAD in IBD. Reasons for the lower rate of colonisation and the equivocal rates of CDAD could range from stringent implementation of antibiotic stewardship policies, or genetic and microbiomic variability in the East London population. However, our results also suggest over-representation of CDAD-affected paediatric IBD patients compared to the rate of asymptomatic carriage in this group, which should be borne in mind when counselling these patients on the sequelae of IBD and the risks of antibiotic treatment.

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OC50

Surveying outcomes of service user experience on the effects of emotional well-being and schooling in paediatric IBD (PIBD) patients in a tertiary PIBD centre by Catherine Lashley, Rachael Buckingham, Bonita Huggett, Terry Sawney, Sibongile Chadokufa, Fevronia Kiparissi, Aya Elzein, *Great Ormond Street Hospital, London, UK.*

We conducted a prospective survey with our PIBD patients and parents seeking outcomes in accordance with our participation goals to 'Improve and optimize the care of children and teens with IBD in underserved and underrepresented populations by addressing healthcare disparities'(1).

We sent out a survey to our PIBD patients focusing on their overall satisfaction with the service we deliver in relation to their emotional wellbeing and schooling. We prospectively sent this to our patient cohort of 280 PIBD patients, collecting both quantitative and qualitative data.

76/280 patients and parents (27%) responded, of whom 60/76 (79%) completed the entire survey. Of those responders 45 (75%) were mothers speaking on the behalf of their children aged 5-12 years (n=20 patients). 4 (7%) patients completed the survey themselves, of whom 3 (75%) were aged between 12-18 years. 39 (65%) parents and patients were overall satisfied that the IBD team spoke about getting the right help and support for the child at school. Although 39 (65%) of the patients strongly agreed that we provided information and materials on IBD and support, 21 (35%) of the patients felt that we did not provide the necessary information and education to schools to support them whilst at school.30 (50%) of the overall responders to the survey did not feel that the team had discussed with them the effect IBD has on their feelings and emotions.

Qualitative responses were the following:

Our survey has highlighted the need to provide more education at diagnosis and throughout patient care. This can be achieved by providing physical education packs for schools to be given to every child at diagnosis along with our already established welcome pack. We currently ask patients and families if they would like us to contact their school with information about IBD. This is something we can potentially change, by giving all patients a letter for school at diagnosis for them to give to schools. Caring for the patient's emotional wellbeing is essential as part of delivering a holistic approach in the care we provide. Although we do offer referral to psychology at diagnosis, this should be followed up regularly and should be included as a standard when patients seen in clinics.

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OC51

Research priorities for patients and professionals in Chronic pain (CP) associated with Inflammatory bowel disease (IBD) – a mixed methods study by Roxana Mardare[1], Mansour S Issa Abdulshafea[2], Vasiliki Sinopoulou[2], Morris Gordon[2], Ciaran Grafton-Clarke[2], *[1]Great Ormond Street Hospital. [2]University of Central Lancashire, UK.*

Introduction: In adult IBD cohorts, CP prevalence is 48% in outpatients and 38% in hospital-based cohorts with significant impact on wellbeing, psychological health, social functioning, and higher health care utilisation and costs (1, 2, 3). Recent cochrane reviews identified limited evidence for specific treatments with a need for more studies. We set out to reach a patient and professional co-produced consensus on specific priorities, key outcomes and propose a model for understanding these findings.

Methods: Initially an online delphi survey was sent out to patients and medical professionals invited from Crohn's and Colitis UK who hold a large list of patients willing to perform research. Priorities for treatments, outcome measures and reasoning were the focus, with results collated and presented for further comment.

In the second phase, four online workshops were organised over a 6-week period by 2 facilitators, each lasting approximately 1 hour, to better understand the rationales for the research priorities chosen and triangulate the findings of phase one.

Results: The survey was filled in by 128 participants (73 patients, 3 carers and 52 professionals). Diet was the top priority for both groups (although for patients equal numbers also ranked cannabis and acupuncture as their top choice). For both groups psychosocial therapies were the next priority.

Workshops were attended by 13 patients and 5 professionals. Transcripts were combined with the free text data from the delphi surveys and analysed through a three-phase qualitative technique. We identified 205 themes at the open phase, with 16 macro themes at the axial phase. These were synthetised into a novel model, displayed below, that highlights how patients and professionals made research prioritisation choices in this context.

Conclusion: Low FODMAP diet was the highest rated research priority for both professionals and patients in our survey. For patients the same score was obtained for cannabidiol and acupuncture. This was followed by psychosocial therapies. We would recommend funding bodies and researchers to consider this, as well as the findings of our model, when making choices for future research.

Treatment	MEDICAL PROFESSIONALS		PATIENTS and CARERS		Total Responses from both groups
	Research priority n(%)	Rank	Research priority n(%)	Rank	
Low FODMAP	29 (56.9)	1	26 (36.1)	1	55
Stress management course	28 (54.9)	2	19 (26.4)	5	47
Mindfulness	18 (35.3)	3	14 (19.4)	8	32
Online education	17 (33.3)	4	12 (16.7)	9	29
Relaxation therapy	13 (25.5)	5	20 (27.8)	4	33
Ororinab	11 (21.6)	6	15 (20.8)	6	26
Cannabis	10 (19.6)	7	26 (36.1)	1	36
Enteric-released GTN	10 (19.6)	7	15 (20.8)	6	25
Acupuncture	10 (19.6)	7	26 (36.1)	1	36
Yoga	6 (11.8)	10	7 (9.7)	12	13
Kefir diet	6 (11.8)	10	12 (16.7)	9	18
Stellate ganglion block	2 (3.9)	12	7 (9.7)	12	9
Transcranial DC stimulation	2 (3.9)	12	8 (11.1)	11	10
Daikenchuto	0 (0)	14	3 (4.2)	14	3

Table 1. Research priorities outlined in the survey

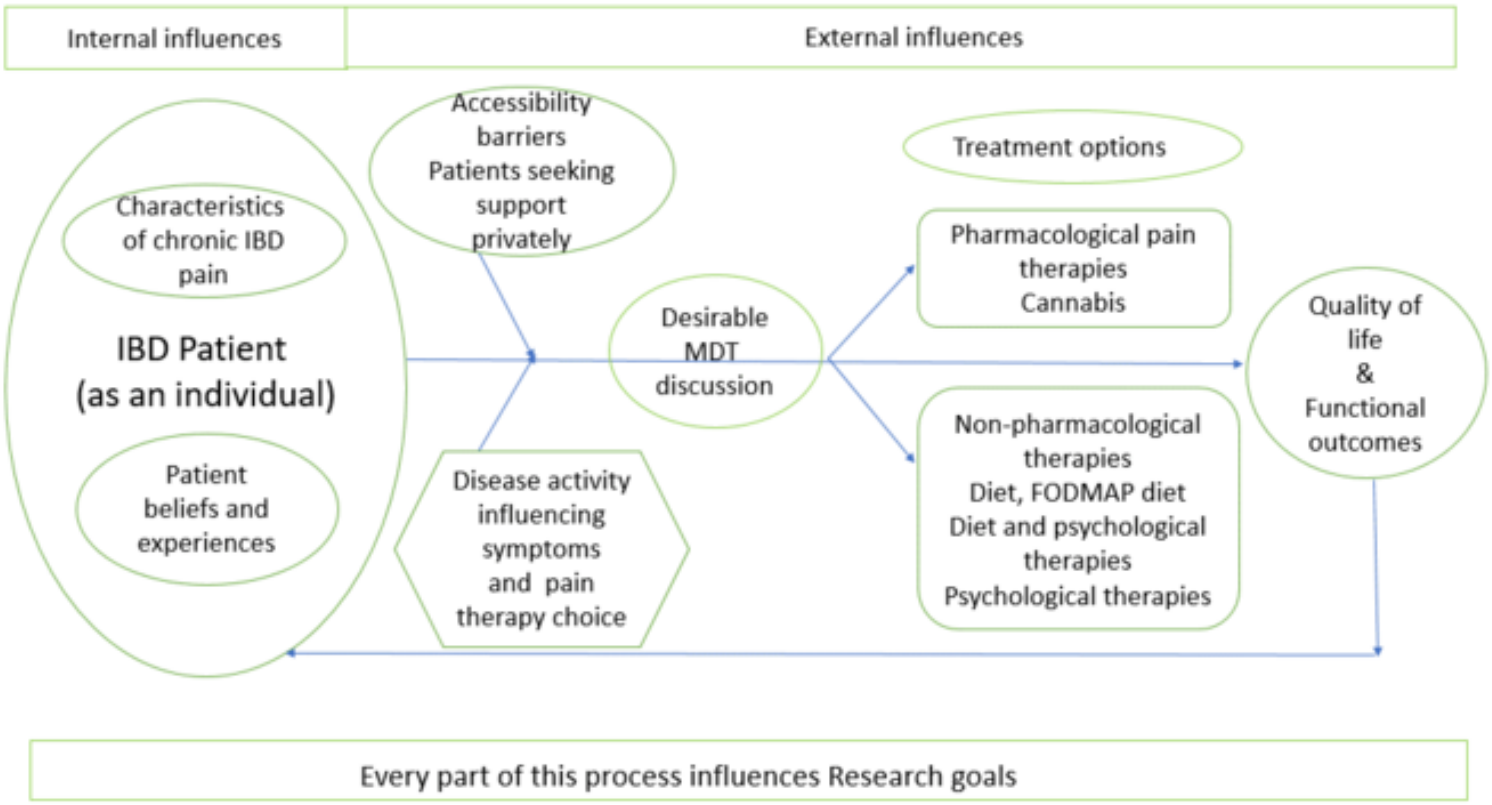

Figure 1. Internal and external influences of Research priorities in IBD associated pain by patients and professionals

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OC52

Flexible Sigmoidoscopy is an Alternative to Colonoscopy for Endoscopic Reassessment of Children with Ulcerative colitis by Akshatha Mallikarjuna, Rafeeq Muhammed, *Birmingham Children's Hospital,UK*.

Introduction: Attainment of endoscopic healing and documentation of this has been increasingly incorporated into the management of children with ulcerative colitis (UC). However the bowel preparation needed for colonoscopy is not welcomed by many children and it takes time away from school and work for children and parents. Flexible sigmoidoscopy can be done without the need of bowel preparation or laxatives.

Aim: Analysis of the colonoscopy findings of the patients with UC who had undergone colonoscopy for endoscopic activity

Methods: We reviewed the results for patients with ulcerative colitis who had colonoscopy reassessment from October 2021 to October 2022.

Results: Colonoscopies of 64 patients, 29 male (45%) and female 35 (55%), between the ages of 5-18 years (median age 15.5 years) were reviewed. Diagnostic colonoscopy of these patients showed ulcerative colitis extent E4 in 45 (70%), E3 in 5 (8%), E2 in 8 (12%) and E1 in 6 (10%) patients. Endoscopic activity of ulcerative colitis was noted using Mayo endoscopy score. Extent of colonoscopy was up to terminal ileum in 50 (80%), caecum (11%), hepatic flexure 1 (2%) and splenic flexure 1 (2%) patients.

Mayo 0 changes were seen in the rectum of 50% of colonoscopies (n=32), 61% in sigmoid colon (n=39), and 70 % in the right colon (n= 45). Out of 32 patients that scored Mayo 0 in the rectum, only 3 patients (9%) had abnormal (Mayo=1) findings in the right colon. However, 2 of these patients were known to have atypical UC with rectal sparing. Of the 30 patients who had complete endoscopic healing (Mayo score 0) of the rectum and sigmoid colon, only 2 patients (6%) had abnormal findings (Mayo score 1) in the right colon. However, one of these patients was known to have atypical UC with rectal sparing at the time of diagnosis.

Histologic activity (acute neutrophilic changes) correlated well with the endoscopic activity when complete endoscopic healing (Mayo score 0) or severe endoscopic activity (Mayo score 3) were present. Histologic activity correlated with endoscopic score of Mayo 0 in 97% patients (31/32) in the rectal biopsies, 93% patients (36/39) in the sigmoid biopsies and 93% patients (42/45) in the right colon biopsies. Histologic activity correlated with the endoscopic score of Mayo 3 in 100 % patients in the rectal biopsies (7/7) the sigmoid biopsies (3/3) and the right colon (1/1).

Conclusion: Only a small number of patients (3%) with typical ulcerative colitis at the diagnostic colonoscopy showed endoscopic activity in the right colon when complete endoscopic healing was attained either in the rectum or rectum and sigmoid colon. We propose that flexible sigmoidoscopy is a suitable alternative to colonoscopy for the assessment of endoscopic healing in children with typical ulcerative colitis distribution at their diagnostic colonoscopy.

OC53

Outcomes following biologic class switch in paediatric IBD: Three years on by Gillian Rivlin, Julia Bircheneough, Sophie Calvert, Selina Chan, Lisa Charlton, Rebecca Foulkes, Julia McKenna, Loveday Jago, Adnaan Kala, Andrew Fagbemi, Maureen Lawson, Sian Copley, Virginia Chatzidaki, *Royal Manchester Children's Hospital, UK.*

Licensed biologic therapy in the paediatric population is limited to anti-TNF therapy, infliximab (IFX) and adalimumab (ADA). Ustekinumab (UST) and vedolizumab (VZB) are unlicensed in the paediatric population but there is a growing body of real-world evidence of their safety and efficacy. We re-evaluated outcomes in our paediatric IBD cohort who had switched biologic class.

Children who switched biologic class were identified from the IBD database. Their electronic notes were scrutinised, and medication history reviewed. Outcomes following class switch were evaluated by improvement in clinical symptoms and endoscopic remission.

A total of 524 paediatric IBD patients were identified from the IBD database. 213 (41%) patients required biological therapy. 34 patients (16%) were identified from the database as having switched biological class therapy.

There was a male predominance; female [12], male [21]. Diagnosis; Crohn's [28], ulcerative colitis [3], IBD-indeterminant [5]. Mean age at diagnosis was 9 years [1.5 to 15 years] with 7 patients classified as very early-onset IBD. All patients had been on at least one immunomodulator; azathioprine [30], mesalazine [24], mercaptopurine [10], methotrexate [9]. 8 patients had documentation of poor compliance to medical therapy. Mean time to biologics was 15 months [1–60 months]. Mean age when starting biologics was 10 years [1–15 years]. Anti-TNF therapy: single agent 19 [IFX 16, ADA 3], in-class anti-TNF switch [12], no anti-TNF [3]. Anti-TNF optimisation was completed in nearly all patients on anti-TNF treatment; levels checked [30] dose optimisation [29], change to frequency [29], antibody levels [25]. 1 patient was already on anti-TNF treatment (ADA) when they were diagnosed with IBD. 3 patients were directly started on vedolizumab (1 switched to IFX following failure to respond). Mean duration on anti-TNF 31 months [1–96 months]. Re-evaluation; active disease on endoscopy [29], histological active disease [29]. Class switch reason; primary non-responder [15], loss of response [10], poor response [5], side effects [2]. Bridging therapy; PMD [3], PMD and steroids [1], steroids [15], not documented [15]. Class switch; ustekinumab [12], vedolizumab [22]. Additional biologic class switch [7]; ustekinumab [2], vedolizumab 5 [4 previously on ustekinumab, 1 previously on etrolizumab trial]. Mean duration on first agent 21 months [9–36 months]. 7 patients who required an additional change to biological therapy underwent endoscopic re-evaluation, which confirmed endoscopic and histological non-response to treatment. Patients who failed to respond to first class switch; Crohn's [7], mean age at diagnosis 8 years [3–14 years], compliance concerns [2], in-class anti-TNF switch [5].

80% [27/34] of our patients demonstrated improvement in symptoms following a biologic class switch. The remaining 20% [7/34] of our paediatric patients did not respond to a switch in biologic class, requiring an alternative biologic class. Following the COVID-19 pandemic, timely re-endoscopic evaluation remains a challenge. This cohort review is in-keeping with previously documented safety and efficacy profiles of ustekinumab and vedolizumab. Our review demonstrates the need for alternative treatments in children with challenging refractory disease.

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OC54

When are epithelioid granulomas detected in children with Crohn's disease? by Ghada Said[1,2], Rachel Mirzaali[2], Akshai Kapoor[2], Zuzana Londt[2], Natalia Nedelkopoulou[2], Prithviraj Rao[2], Dominique Schluckebier[2], Shishu Sharma[2], Mike Thomson[2], Arun Urs[2], Marta Cohen[2], Priya Narula[2], *[1]Birmingham Children's Hospital. [2]Sheffield Children's Hospital, UK.*

Background: Non-caseating epithelioid granulomas are considered the histological hallmark of Crohn's disease. (1) However, research on when and how granulomas manifest, especially in children, is still poorly understood.

Aims/objectives: This study aims at determining when granulomas are detected in children with Crohn's disease, and if they are related to clinical, endoscopic and/or histological disease activity.

Methods: This is retrospective cross-sectional study of children diagnosed with Crohn's disease under the care of the paediatric gastroenterology department at a tertiary children's hospital between 2009- 2019. Histology episodes were identified for these patients and histology reports were reviewed for the presence of granulomas and histological activity. Simple endoscopic score for Crohn's disease (SES-CD) (2) and weighted paediatric Crohn's disease activity index (wPCDAI) score (3) were calculated to determine endoscopic and clinical activity during these episodes respectively.

Results: 234 patients were identified by coding as diagnosed with Crohn's disease during the study period. The notes and histology for 75 children was reviewed and 178 histology episodes were identified. Of these 74 episodes had granulomas while 104 episodes were without granulomas. Chi-squared tests showed that the presence of granuloma was not statistically significantly related to histological activity (N =178, $\chi 2$ 3.41, p-value = .065) and clinical activity of the disease (N=54, $\chi 2$ = 2.26, p-value = .323). However, granulomas were significantly greater in those with endoscopic activity of the disease ($\chi 2$ = 5.25, P value = .022). There was no statistically significant association between granulomas and cryptitis, crypt abscesses, or ulcers. The association between the age at diagnosis and granulomas was not significant (T value 0.985 p value = .326).

Discussion/Conclusion: Granulomas were significantly associated with endoscopic disease activity. Although similar trends were seen with histological and clinical activity, this did not reach significance. This study helps gain better understanding of the disease, although more research is needed to determine the underlying factors of granuloma formation.

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OC55

Paediatric genital Crohn's disease: a combined case series by Eleni Kontaki[1], Aruna Sethuraman[1], Edward Gaynor[1], Venna Zamvar[2], Fevronia Kiparissi[1],*[1]Great Ormond Street Hospital for Children. [2]Leeds Children's Hospital, UK.*

Metastatic Crohn's disease (MCD) of the genitalia is a rare extraintestinal manifestation of Crohn's disease characterized by granulomatous inflammation of the genital skin without contact with the gastrointestinal tract. Only few paediatric cases have been reported in the literature with scanty data with regards to treatment and outcome.

To describe the clinical presentation, associated features, and response to treatment in a cohort of paediatric patients diagnosed with genital metastatic Crohn's disease.

Cases of metastatic genital Crohn's disease were retrospectively collected from two tertiary centers between 2001 and 2023.

A total of 12 patients (7 males, 5 females) were identified with metastatic genital Crohn's disease, mostly presented as genital oedema. The mean age at the time of metastatic genital Crohn's disease occurrence was 8.9 years with a range of 1.5 years to 14 years. Genital Crohn's disease was the first presentation of inflammatory bowel disease in 58% of the cases. Genital symptoms precede the onset of gastrointestinal disease in 33% of the cases whereas gastrointestinal disease presented in 42% of the cases prior to the onset of genital Crohn's disease. Perianal disease was documented in 50%. Genital Crohn's disease occurred in the absence of gastrointestinal disease in 25% of the cases. All patients underwent endoscopic and radiologic assessment. Histological confirmation of granulomas was obtained in 50% of the cases. Treatment of the patients included prednisolone, azathioprine, methotrexate, mesalazine, ciprofloxacin, metronidazole, topical tacrolimus, intralesional triamcinolone and anti-TNFa inhibitors. Eleven of twelve patients (92%) found clinical benefit of MCD from systemic anti-TNFa inhibitors monotherapy or anti-TNFa inhibitor and azathioprine combination therapy.

Metastatic Crohn's disease of the genitalia is rare. It may be the first presentation of Crohn's disease and not necessarily associated with gastrointestinal disease. Perianal disease is often present. Anti-TNFa inhibitors have exhibited a favorable response. Multicentre retrospective case series analysis would help to identify the prevalence of genital metastatic disease and formulate an integrated diagnostic and management approach.

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OC56

Coping with Inflammatory Bowel Disease: An Online Group Intervention for Young People by Tabitha Pickup, *Cambridge University Hospitals, UK.*

Quality of life (QoL) for children with Inflammatory Bowel Disease (IBD) is poorer than healthy controls and can impact upon emotional wellbeing and mental health. This in turn can impact treatment adherence, school and poor general health outcomes. Psychological support for emotional wellbeing for young people with IBD is therefore important. Cognitive behavioural therapies (CBT) and developing more positive illness perceptions can be beneficial. A paediatric gastroenterology service in a hospital developed a coping with IBD group to address this need, in the context of reduced staffing.

Young people with IBD on the waiting list were offered a video triage and opportunity to attend the group. The six-session course was run online, after school to improve accessibility and a parent was asked to attend also. The course utilised cognitive-behavioural and systemic therapies including relaxation exercises, externalising exercises, challenging negative thoughts, developing positive routines and managing flare ups. It was delivered by a clinical psychologist and a trainee psychologist. A one-month video follow up was offered after the course. Outcome measures assessing QoL, emotional wellbeing, physical health experiences were taken before and after, self-described goal-based outcomes (GBO) were also taken each session.

Eight young people and families between 12 to 14 years attended the initial video triage, five young people agreed to attend the group. Of the five that attended one young person discontinued the sessions after the first session. Each young person attended at least 4 of the 6 sessions. The GBO (on a 1-10 scale) were on average 5.6 higher at the end of sessions. Three of four of the young people needed no further support, one participant required a referral to local emotional wellbeing services. Two parents and two young people provided feedback about the course and it was rated as extremely helpful or very helpful. Hearing other people's experiences was cited as a positive as were CBT coping strategies. Outcome measures besides the GBO were poorly returned.

These findings may indicate that online group-based interventions for young people with IBD could be a feasible and acceptable intervention based on repeated attendance, good qualitative feedback and progression on GBO. The opportunity to meet other young people with IBD is a unique strength of this intervention compared to one to one therapy modalities. This 6 session course is briefer than existing CBT protocols, and group interventions may be a more efficient use of limited gastroenterology psychology resources. Replication and further feasibility and acceptability data is a future direction alongside streamlining outcomes measures and collection of these. Future research may also consider face to face interventions.

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OC57

Safety and effectiveness of IV Ferric Derisomaltose in treatment of iron deficiency anaemia - Results from two paediatric tertiary gastroenterology centres by S Emmitt[1], L Gianolio[2], RK Russell[2,3], P Narula[1,3], *[1]Department of Paediatric Gastroenterology, Sheffield Children's NHS Foundation Trust, Western Bank, Sheffield S10 2TH. [2]Department of Paediatric Gastroenterology, Royal Hospital for Children and Young People, 50 Little France Crescent, Edinburgh EH16 4TJ. [3]Joint authors*

Intravenous Ferric Derisomaltose (IV FDM) is increasingly used for the treatment of iron deficiency anaemia in paediatric gastroenterology patients. Our aim was to review the safety and effectiveness data of IV FDM in two paediatric tertiary gastroenterology centres (Hospitals A & B).

A retrospective case notes review of all paediatric gastroenterology patients receiving IV FDM between 2018 and 2023 was undertaken, following approval by the Clinical Audit and Effectiveness team. Baseline demographics, indication for IV iron, previous oral iron treatment, monitoring pre and post infusion including haematological and biochemical parameters, adverse events and need for further IV iron infusions were recorded. All patients were administered a dose of 20mg/kg IV FDM with a maximum dose of 1 gram in Hospital A and 1.5 grams in Hospital B.

A total of 65 patients who received 78 IV FDM infusions, were identified from Hospitals A and B, during this period. A majority, 49/65 (75.4%), had Inflammatory bowel disease, with a median age at iron infusion of 12.8 years (IQR: 9.6-15.2) and a median weight of 36.5Kg (IQR: 24.1-58.5). A significant, rapid and well-maintained increase in median Haemoglobin (HB) levels was observed after IV FDM, paralleled by MCV trends (Table 1). No alterations in phosphate levels were reported after the IV FDM infusion, with data available for 80% of the entire cohort. There were no alterations noted in liver and renal function tests. Overall, 53/65 (81%) patients recovered their anaemia after IV FDM with 9/53 (17%) re-dropping HB and requiring further iron supplementation. Regarding IV FDM safety, 3/65 (4.5%) patients had to discontinue the infusion, only one due to an allergic reaction with chest pain, decreased O2 saturations and cutaneous rash.

Overall, our multicentre real-world data showed that IV FDM was safe, well tolerated and demonstrated good clinical effectiveness in paediatric gastroenterology with no significant biochemical changes induced post infusion.

Table 1

FDM Infusion	Median Hb (IQR)	P value	Median MCV (IQR)	P value
Pre FDM infusion	92 g/L (IQR 85-108)		72 fL (IQR 67-79)	
1 month post-FDM	126 g/L (IQR 115-132)	<0.001	80 fL (IQR 77-83)	0.038
3 months post-FDM	128.5 g/L (IQR 121-140)	<0.001	82 fL (IQR 77-86)	0.005
6 months post-FDM	131 g/L (IQR 123-140)	<0.001	83 fL (IQR 80-87)	<0.001
12 months post-FDM	134 g/L (IQR 125-142)	<0.001	84 fL (IQR 79-88)	<0.001

OC58

Evaluation of Functional Dyspepsia in Children: Prevalence, Risk Factors and Clinical Outcome by Stanley Goodbody[1], Dinesh Rawat[2], Zaynab Ahmed[1], *[1]School of Medicine, University of Leeds. [2]Leeds Children's Hospital, UK.*

Functional dyspepsia (FD) is a common disorder of gut brain interaction in the paediatric population and is responsible for significant disruption to a child's physical, emotional and social wellbeing (1,2). Limited research exists on the efficacy of the different management options and no guidelines are available for the management of FD in children. We aim to characterise the symptoms, associated conditions as well as evaluate the response to treatment for children with FD.

A prospective longitudinal study design was adopted to recruit patients who were attending a paediatric gastroenterology clinic over a 6-month period. Participants were required to meet the ROME-IV criteria for FD and were followed up after 3 months to assess clinical outcome. Data collected with a pre-designed proforma included symptoms (primary and secondary), relevant family history, associated conditions (food intolerance, atopy, joint hypermobility, obesity, autism etc.). Children were investigated and managed as per agreed pathway while response to treatment was assessed using binary outcome measures (3).

Thirty participants (56.7% female, 43.3% male) were recruited who met the ROME-IV criteria after negative screening for organic conditions including helicobacter pylori infection, coeliac disease, inflammatory bowel disease. The commonest primary symptoms – defined as the presenting complaint – were regurgitation (76.7%), nausea (73.3%) and abdominal pain (70%). The commonest secondary symptoms – defined as those which must be elicited from the patient – were postprandial fullness and early satiety (96.7%), postprandial discomfort (86.7%) and constipation (63.3%). Delayed colonic transit (colonic transit time > 48 hours) was noted in 55%. Upper GI endoscopy (42%) and pH studies (33%) were normal. Clinical outcome was recorded as no change (36.7%), improvement or resolution of symptoms (63.3%). Management included dietary change, anti-reflux medications, prokinetics, antispasmodics as well as laxatives. Chi-square analysis demonstrated that no single intervention was significantly associated with a positive clinical outcome ($p<0.05$) compared to alternatives, though majority of children demonstrated improvement or complete resolution of symptoms (63%).

These findings emphasise the need to elicit FD defining symptoms in children which can often co-exist with other disorders of gut brain interaction. Constipation can coexist in these patients and addressing colonic transit can help in symptom alleviation as part of biological approach within the biopsychosocial model. This approach will help minimise invasive investigations like endoscopy and support development of management guidelines.

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OC59

Functional Gastrointestinal disorders in Children with Autism Spectrum Disorders; a systematic review of published literature by Hayah Taimuri[1], Azzra Maricar[1], Annabelle Turner[1], Kylie Austin[1], Mohamed Mutalib[2], *[1]King's College London. [2]Guy's and St. Thomas' Hospital, London, UK.*

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by impairments in social communication behaviours and skill. Functional Gastrointestinal (GI) disorders FGID as defined in Rome criteria are common in children with ASD. We aimed to systematically review the literature for the prevalence of FGID in children with ASD.

Systematic search of Embase, MEDLINE, Global Health and American Psychological Association (APA) PsycInfo databases following PRISMA guidelines for FGID and their subtypes and ASD.

3431 articles were identified, 527 were duplicate. 2860 were excluded by abstract and full text screen. 44 articles were included, 2 added from reference search. FGID data was collected from 17924 children with ASD from 18 countries. Overall prevalence was 22.7 – 93.2%. Constipation was 29.8%, functional abdominal pain was 14.5% were most prevalent with a wide reported range. Other types of FGID are less frequently reported.

FGID are prevalent in children with ASD with constipation and abdominal pain are the predominant types. There were wide heterogenicity in the reported prevalence with some studies reporting near universal prevalence.

Summary box

- What is already known on this topic

Gastrointestinal disorders are commonly reported in children with autistic spectrum disorders

There is a wide variation in the reported prevalence of functional gastrointestinal disorders (FGID) in autism

- What this study adds

Systematically reviewed the literature on the prevalence of FGID using the Rome criteria in children with autism and accurately describing the true prevalence of disorders subtypes.

- How this study might affect research, practice or policy

Providing an up to date prevalence of FGID in autism.

Highlighting the need for detailed analysis of FGID in autism

OC60

Functional Gastrointestinal Disorders in Children with Autism Spectrum Disorders; a systematic review of published literature: Prevalence of specific FGID by Kylie Austin[1], Annabelle Turner[1], Azzra Maricar[1], Hayah Taimuri[1], Mohamed Mutalib[1,2], *[1]King's College London. [2]Evelina London, UK.*

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by impairments in social communication, behaviours and skills. Functional Gastrointestinal Disorders (FGID), as defined by ROME criteria, are gastrointestinal disorders such as constipation and abdominal pain, without structural or organic pathology. FGIDs are also known as disorders of gut-brain interaction, and result from disordered signalling between enteric and central nervous systems. FGIDs are widely prevalent in children with ASD. This study performed a systematic literature review aiming to review global prevalence of FGID in children with ASD.

Key databases including MEDLINE, Global Health and American Psychological Association (APA) PsycInfo were searched using keywords. The search was limited to human studies published in English language, from 1992 - ≤2021. Children were defined as ≤18 years of age. Articles were screened by abstract and full text, with duplicates removed. ROME IV criteria for FGIDs guided the inclusion criteria. Studies involving gastrointestinal disorders with a structural or organic cause were excluded.

The initial search yielded 3,431 results of which 527 were duplicates. These were screened by title, abstract and full text, after which 44 records remained including 2 papers extracted from a review. From the included studies, FGID data was collected of 17,924 children with ASD across 18 different countries in total.

Data on prevalence of specific FGIDs, was collected in children and adolescents, and infants and toddlers as categorised by ROME IV criteria. The majority of data was available for FGIDs in children/ adolescents, as the range of participant groups often incorporated ages that applied to both categories of children. Functional constipation and functional abdominal pain - not otherwise specified, were the most prevalent with a mean result of 29.8% and 14.5% respectively. Prevalence of irritable bowel syndrome was relatively low, however had a higher reported prevalence compared to other FGIDs, with 3 studies showing over 10% prevalence. similarly, prevalence of non-retentive faecal incontinence ranged from 0.3-11%, except in one study which reported 33% prevalence. Functional dyspepsia had a similar prevalence, with 3 studies reporting over 10%. Abdominal migraine, aerophagia, rumination syndrome, cyclical vomiting syndrome, and functional nausea and vomiting all showed a comparably low prevalence, with almost all studies reporting under 10%. No data was recorded for rumination syndrome, cyclical vomiting syndrome, infant dyschezia, and functional constipation in neonates/ infants. In neonates/ infants, functional diarrhoea was the predominant FGID, and average prevalence of FGIDs was 5.4% in this group.

In conclusion, functional abdominal pain and functional constipation were the most prevalent FGIDs in children with ASD. Stress, social deficits and behavioural differences can contribute to disruption of enteric and central nervous system. Features of ASD such as restrictiveness to change may sustain symptoms of FGID. Conditions commonly occurring alongside ASD, such as ADHD, have resulted in difficulty isolating ASD, therefore increased GI related symptoms may have been caused by other factors. Recorded prevalence of FGID is likely to underestimate the global picture in children with ASD due to challenges in reporting of symptoms in children with ASD.

OC61

Evaluating the Clinical Psychology Service in Paediatric Gastroenterology: A Year-Long Retrospective Study at a Tertiary Hospital by Sophie Velleman, Harry Martin, *Bristol Royal Hospital for Children, UK.*

The integration of clinical psychology in paediatric gastroenterology is critical due to the biopsychosocial nature of paediatric gastrointestinal disorders and the psychological impact of chronic conditions. Despite the growing need, there is a notable disparity between the demand for and availability of psychology services in paediatric gastroenterology settings.

This study aims to provide a detailed retrospective analysis of clinical psychology referrals in a high-volume paediatric gastroenterology, hepatology, and nutrition service in England. We sought to identify patterns in referral, conditions treated, and service capacity, as well as to outline areas for future research and service development.

Data from April 2022 to April 2023 were collected, encompassing referrals to the psychology team consisting of 1.6 FTE staff. This study analysed demographics, conditions, reasons for referral, waiting times, session numbers, and outcomes for referred children and young people (CYP) aged 1-17 years.

A total of 147 CYP were referred, with a majority (84%) being outpatients. The most common conditions included Inflammatory Bowel Disease (30%), Coeliac Disease (20%), and Functional GI Disorders (16%). Key reasons for referral were adjustment difficulties to diagnosis (26%), symptom management (22%), and child anxiety (20%). Notably, 17% of outpatients did not engage with the service post-referral. The waiting period for initial triage ranged from 30 to 130 days (mean 81 days), and subsequent intervention wait times were between 20 to 150 days. Most CYP received 2 to 8 sessions (average 4.19 sessions), with the service facing capacity challenges.

The data highlight a significant demand for psychological services in paediatric gastroenterology, with diverse needs across a range of conditions. The long waiting times underscore the necessity for additional resources and streamlined processes. Furthermore, the disengagement of a portion of the referred CYP indicates a need to explore barriers to service uptake.

The retrospective nature and single-centre focus of the study limit the generalisability of the findings. Future research should involve multiple centres and prospective data collection.

This study emphasises the critical role and high demand for clinical psychology within paediatric gastroenterology services. It points to the need for increased resources and more efficient referral processes. Future research should investigate patient and family experiences to enhance service delivery and meet the diverse needs of this population more effectively.

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OC62

"Please write to me not about me" – what is our practice, and should we change? by Anne Willmott, *Leicester Childrens Hospital, UHL, UK.*

Introduction: In 2018 the Academy of Royal Colleges published guidance "Please, write to me" This recommended that we should be writing clinic letters to patients (or parents) and copy GP rather than the other way round. This was endorsed by RCPCH. It was also a recommendation of the Patterson Inquiry in 2020. In 2023 NCEPOD report "Transition from child into adult healthcare" recommended writing to the young person once they are older, rather than parents. This was not my current practice, and I was aware most colleagues were still writing to GP and cc family. This project was to look into this further, and to see reasons why practice has not changed, and consider changing my own practice.

Aims and objectives: to confirm current practice amongst consultant colleagues, and to look at potential barriers to change

Subjects and methods: a survey was sent to all paediatric consultants at Leicester childrens hospital asking who they write to, is it GP, parents, or young person themselves; I also asked regarding comments and concerns about writing direct to parents or young person. There was then a face to face education meeting.

Results: A survey was sent to the paediatric consultants generic email address, which is distributed to 80 people. There are some (eg ICU team) for whom this was not relevant, and replies not expected. There were 19 replies (24%).

A message to a few GPs adhoc gave response that they are happy for letter cc to them, as long as any GP action is clearly stated, and that if no GP action then admin staff file the letters which are then not read by GP

Write to parent and copy GP	18/19 (95%)
Write to parent or YP and copy GP	1/19 (5%)
Comments and concerns	habit, this is communication between health professionals, I am writing to myself for next clinic, medical information may worry parents or YP, will GP get any action plan, will simplifying language mean it is not useful for GP.
consultant who already writes to parents	no issues, family see the medical information anyway, language needs altering but this gets quicker

Summary and conclusions:

1. There is a clear recommendation to write to patients or parents, and copy to GP.
2. Almost all consultants (who responded) are not following this recommendation.
3. Concerns about language, GP response, and reaction to medical information are not felt an issue by the consultant (an oncologist) who writes to family.
4. The GPs asked (adhoc) were happy for us to write to parents and cc them provided action plan clear.

Since this project I have changed my practice, and so far have had no negative feedback. A patient / family survey is planned.

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OC63

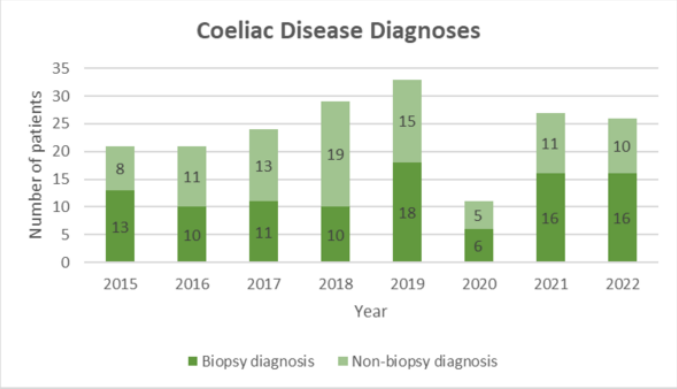
Coeliac disease 2005-2011 vs 2015-2022; more cases, more symptoms and fewer biopsies than before by Lydia Chapman[1], Joe Chan[2], David Tuthill[2], [1]*Cardiff University.* [2]*CVUHB, UK.*

Coeliac Disease (CD) occurs in around 1% of children, but most remain undiagnosed. Historically, diagnosis required demonstration of typical small intestinal biopsy abnormalities ESPGHAN 1980/91(1). Since BSPGHAN 2013(2) & ESPGHAN guidelines 2012(3), no biopsy is necessary if immunoglobulin-A tissue transglutaminase (IgA-TTG) is >10 times upper limit of normal(>10xULN). Using contemporaneous guidelines as standards we aimed to:

- Audit practice in Cardiff and Vale University Health Board (CAVUHB) 2015-2022
- Compare the rate of detected CD to our previous study 2005-2011 (4)
- Identify numbers diagnosed via biopsy and non-biopsy

Patients aged 0-16(Population<17 around 92,000) investigated for CD between 01/01/2015-31/12/2022 were sought. Data was obtained from 3 different sources to maximize patient capture: laboratory IgA-TTG results, biopsy lists and dietetic records. Duplications were discounted. Electronic case notes were analysed for demographics, symptoms and blood results.

From the 246 individuals identified as possible cases, 192 children (69 male:123 female) were diagnosed. Graph 1 shows that pre-pandemic (2015-2019) 21-33 cases/year were diagnosed; during the pandemic this fell to 11/year(2020). Mean annual incidence was 28/100,000 pre-pandemic and 21/100,000 peri-pandemic.



Graph 1 - Coeliac Disease Diagnoses 2015-2022

Most patients were symptomatic 153(79.7%); commonest symptoms being, abdominal pain(50.5%), diarrhoea(25.5%), fatigue(17.7%) and constipation(15.6%).

92 patients had an IgA-TTG result >10xULN and were diagnosed without biopsy, leaving 100 requiring biopsy. 19 had an IgA-TTG result <10xULN but >5xULN. 6 of these declined endoscopy. The remaining 13 all received a CD diagnosis after biopsy. See Table 1.

IgA-TTG results and outcomes for patients investigated for Coeliac Disease					
TTG result	Number of patients:	Biopsy	Refused declined biopsy	Diagnosed with CD	Following investigations: Not diagnosed with CD
>10xULN	92	NO	-	92	-
<10xULN	33	NO	-	0	33
>10xULN	22	YES	0	21	1
<10xULN but >5xULN	19	YES	6	13	0
<5xULN	80	YES	3	66	11
Total:	246	-	9	192	45

Table 1 - IgA-TTG results and outcomes for patients investigated for Coeliac Disease

Pre-pandemic CD incidence was steadily rising, but halved during the COVID pandemic. Compared to our previous study 2005-2011vs2015-2022, the mean rate of diagnosis is slightly higher despite COVID 23 vs 26/year, higher female: male ratio continues 58:42% to 64:36%, whilst asymptomatic diagnoses have decreased from 36% to 20%. Half of diagnoses are now made without biopsy. Virtually all patients biopsied with an IgA-TTG >5xULN were diagnosed with CD. Should threshold for non-biopsy diagnosis fall to >5xULN?

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OC64

The importance of taking proximal duodenal biopsies during the endoscopic diagnosis of Coeliac Disease in children by Ieuan Davies, Namor Williams, *Bwrdd Iechyd Prifysgol Bae Abertawe*

Introduction: The diagnosis of Coeliac Disease for children is standardised according to the ESPGHAN 2020 (1) criteria. When the diagnosis is made without the need for a biopsy, the IgA tissue transglutaminase (tTG) antibodies must be greater than 10 times the upper limit of normal (ULN). For children who require an endoscopy to investigate the condition, it is recognised that biopsies should be taken from the duodenal bulb (D1) and the more distal duodenum (D2).

Aims: To review the level of IgA tTG antibodies in cases of biopsy confirmed Coeliac Disease and to investigate the importance of D1 biopsies in making the diagnosis.

Methods: In a unit offering endoscopy as a satellite to the main regional centre, the prospective data base integral to the clinical pathway was used to identify all children investigated over a 12 month period. These data were analysed against the diagnosis confirmed after the histology meeting.

Results: 27 children had abnormal tTG antibodies and were investigated by endoscopy. Following the histology meeting, 24 were diagnosed with Coeliac Disease (14 female). Their ages ranged from 2 – 15 years (median 8 / 9). The 22 abnormal IgA tTG antibody results ranged from less than 2 times the ULN to less than 8 times the ULN. 2 children had low or absent IgA levels and both cases had an IgG tTG antibody greater than 10 times the ULN. All 24 children diagnosed with Coeliac Disease had histological changes that confirmed the condition in D1. 5 / 24 had histological changes only in D1 with normal D2 biopsies. In these 24 children with Coeliac Disease, their presenting symptoms included: abdominal pain (12), fatigue (5), diarrhoea (5) and vomiting (4). 6 children were asymptomatic, 3 of these were targeted for screening because of a family history of Coeliac Disease, a diagnosis of Diabetes or a diagnosis of Thyroid Disease. Of the 3 children who did not have Coeliac Disease, one has gone on to have a further endoscopy and has now been diagnosed and the other two remain under follow up.

Conclusions: The numbers in this series are very small. Clearly, similar studies involving larger centres should be encouraged. However, we emphasise:

1. Taking both D1 and D2 biopsies is crucial to making the diagnosis. In this sample the D1 biopsies were the most important and were abnormal in every case of Coeliac Disease. Therefore, we recommend at least two D1 biopsies every procedure.
2. A quarter of these children with Coeliac Disease had no obvious presenting problems.
3. The IgA tTG antibody results were only marginally abnormal (i.e. less than 2 times the ULN) in 7 / 24 confirmed cases. Therefore, a marginally abnormal IgA tTG antibody result cannot be ignored.
4. We suggest that all children with chronic abdominal pain should be screened for this prevalent autoimmune disease.
5. Robust follow up should be arranged for any child with abnormal tTG antibodies who does not have Coeliac Disease confirmed on their first endoscopy.

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OC65

Understanding the psychological experiences of children and young people with coeliac disease and their relationship with food by Heather Maddison-Roberts[1,2], Chrissie Jones[1], Rosie Satherley[1], *[1]University of Surrey. [2]South West London and St George's Mental Health NHS Trust, UK.*

Individuals with Coeliac Disease (CD) are required to follow a lifelong strict gluten-free diet (GFD). Hypervigilance around the GFD may contribute to disordered eating, increase the risk of mental health difficulties, and impair quality-of-life (1, 2, 3). However, research has focused on adults (4, 5), and little is known about children and young people's (CYP) approaches to managing the GFD. This study explored CYP with CD interactions and experiences with food. Fifteen CYP with CD, aged 8-13 years, who were following the GFD for at least one year, were interviewed with their caregiver about their management of the GFD. Reflexive thematic analysis was used to analyse the data. CYP described a need for control over others and the environment to effectively manage the GFD, and a heightened sense of threat and hypervigilance around food, characterised by persistent thoughts about CD symptoms, preoccupation with a chain of events leading to gluten-contamination, and extensive risk assessments. A continuum of approaches to managing the GFD was apparent, ranging from pragmatism to hypervigilance. The findings were applied to an existing model of gluten-related distress and hypervigilance developed from research with adults (5), which was adapted to reflect the experiences of CYP in the current study. Implications to monitor gluten-related distress, beliefs, and behaviours in CYP with CD, and proposed psychological interventions are discussed, as well as limitations of the study.

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OC66

Eosinophilic oesophagitis occurs rarely in an incident cohort of paediatric coeliac disease with a median of over 5 years follow-up

by Megan Barr[1], Anna Wilson[2], Anna Richards[1], Sarah McDonald[1], Gemma Oversby[1], David Wilson[1,3], Peter Gillett[1], *[1]Department of Paediatric Gastroenterology, Hepatology and Nutrition, Royal Hospital for Children and Young People, Edinburgh, Scotland, UK. [2]University of Glasgow Medical School, Glasgow, Scotland, UK. [3]Child Life and Health, Centre for Inflammation Research, University of Edinburgh, Edinburgh, Scotland, UK.*

Introduction and aim: Paediatric coeliac disease (CD) continues to increase in incidence in the UK. Eosinophilic oesophagitis (EO) has also shown a marked incident rise in paediatric patients. A connection between paediatric CD and EO has been proposed but with a scanty evidence base. We aimed to determine the rate of co-morbid EO in an incident cohort of paediatric CD patients.

Methods: We have a regional PGHAN network based on 1 tertiary PGHAN centre sharing care for CD and all other chronic PGHAN conditions with 3 paediatric district general hospitals. Our incident paediatric CD database is based on pathology and biochemistry results, with ongoing capture-recapture efforts (liasion with paediatric diabetes services and community child health for T1DM and other relevant patient groups) to ensure that all “no biopsy“ CD diagnoses are also included. We interrogated the incident CD cohort over 2014 to 2017 to identify patients diagnosed with CD less than 16 years of age with also a strict endoscopic and histopathological diagnosis of EO; case notes were thoroughly reviewed. Follow up was to the soonest of 31.08.23, age 18.0 years, transition to adult CD services, emigration from our region or death. Our regional standard at endoscopy of suspected incident CD is to take 2 gastric antral biopsies, three duodenal cap biopsies and four biopsies from the second part of the duodenum. Suspicious clinical history of oesophageal disease or atypical macroscopic features in the oesophagus are our only prompt to also obtain oesophageal biopsies at this endoscopy for possible CD. Our regional standard at endoscopy of suspected incident EO in 2014 was to take multiple proximal and distal oesophageal biopsies; more recently we also take biopsies from mid-oesophagus.

Results: There were 276 patients in our 2014-2017 incident CD cohort. Six also had a confirmed diagnosis of EO, a cumulative incidence rate of 2.2%. These 6 patients included 2 (33%) females and had CD diagnosed at a median (range) age of 9.9 (8.1) years of age. Their median (range) duration of follow up after CD diagnosis was 5.5 (4.6) years. Four were diagnosed at the same time during the same endoscopy as CD (simultaneous diagnosis) with relevant history and/or macroscopic features; two were diagnosed at endoscopy at 1.0 and 7.2 years after CD diagnosis. These 6 CD-EO patients had a median (range) duration of follow up after EO diagnosis of 5.1 (4.7) years.

Conclusions: The cumulative incidence rate of EO diagnosis in our regional 2014-2017 paediatric CD incident cohort followed up while in paediatric services was 2.2%. We cannot rule out that patients in this cohort have still undiagnosed EO so we present a minimum value of 2.2%. No region of the UK has published incidence rates of paediatric EO to place our result in context of the non-CD population. Further large population-based studies of EO in CD with complete accrual of CD, strict diagnostic criteria for EO and longer duration of follow up are needed to determine if there is a connection between paediatric CD and EO.

OC67

Esophageal dysphagia in children: 16-year experience of a single center

OC68

The State of Paediatric Gastroenterology, Hepatology and Nutrition Training in the U.K. by Kushila Rupasinghe[1], Nkem Onyeador[2], Lucy Howarth[3], Christopher Bakewell[4], *[1]King's College Hospital NHS Trust. [2]St.George's Hospital NHS Trust. [3]Oxford Children's Hospital. [4]Southampton Hospital, UK.*

Background: The Paediatric Gastroenterology, Hepatology and Nutrition (PGHAN) GRID is the U.K. pathway for training. Training is overseen by the College Specialist Advisory Committee and monitored in previous years through surveys, which have been used as a springboard to implement improvement and change.

Aim:

- Evaluate PGHAN training in the U.K. from a trainee viewpoint.
- Evaluate the state of paediatric endoscopy training in the U.K.
- To highlight challenges and positive practices.
- Compare these data from previous surveys.

Subject and methods: Trainees working between March 2023 and September 2023, were surveyed anonymously using an electronic form. The survey included a combination of question types, including Likert scales, yes/no and sections for free text. The survey was distributed August 2023 and closed in September 2023.

Results: 19 PGHAN trainees completed the survey (83%). 47% of trainees were less than full time (LTFT), an increase of 4% from 2021 (44%). 79% of trainees reported working >70% of their time managing sub-specialty patients, up from 65% (2021). Local departmental teaching was felt to meet trainees' needs for 79% of trainees, an increase of 40% from 2021 (39%). Less trainees found online teaching useful (74%), than in 2021 (87%). The Trainees' Day was found to be useful to 91% of trainees. 84% attended >1 clinic per week. Parenteral nutrition (PN) clinic and transition clinic attendance were 42% and 32% respectively, down from 47% and 57% in 2021.
68% of trainees have access to >2 endoscopy lists per month, less than 2021 (74%). 32% had completed >100 gastroscopy (OGD) procedures on Joint Advisory Group (JAG) Endoscopy Training System (JETS). Two trainees (11%) had >100 colonoscopies logged, and 1 trainee had been signed off. The primary reason for not achieving accreditation for colonoscopy was lifetime procedure count (78%), followed by requiring assistance (50%) and not attending a course (39%). 58% of trainees had come in on a non-clinical day to attend a list.

Table 1 Endoscopy

	Strongly disagree (%)		Disagree (%)		Neutral (%)		Agree (%)		Strongly agree (%)	
	2021	2023	2021	2023	2021	2023	2021	2023	2021	2023
OGD confident	4.3	10.5	4.3	0	13	5.3	21.7	36.8	56.5	47.4
Colonoscopy confident	56.5	42.1	13	26.3	17.4	21.1	13	10.5	0	0
	0-20	21-40	41-60	61-80	81-100	101-120	>120			
OGD numbers (%)	10.5	15.8	5.3	10.5	26.3	15.8	15.8			
Colonoscopy numbers (%)	57.9	21.1	10.5	5.3	0	5.3	5.3			

Summary and Conclusion: The trend of trainees training LTFT has continued to rise. Changes since the pandemic show an increase in the time trainees spent managing sub-speciality patients and an improved perception of local departmental teaching.
Poor attendance of PN and transition clinics could represent clinic availability, high trainee workload and/or trainee awareness of this speciality learning objective.
Surveys in both 2021 and 2023 show an aggregate of 97% of trainees are not JAG accredited for paediatric colonoscopy at CCT. With the lifetime procedure count requirement set to rise to 150, trainees will universally be completing PGHAN training without accreditation. Support systems should be available to new consultants to achieve this competence.

OC69

Safety and diagnostic yield of the remote access video capsule endoscopy system CapsoCam® in paediatric and adolescent patients in a tertiary paediatric Gastroenterology centre by Selina Green, Jasmine Hammond, Kelsey Jones, Edward Gaynor, Fevronia Kiparissi, *Great Ormond Street Hospital NHS Foundation Trust, UK.*

Video capsule endoscopy is a well-established diagnostic tool in the evaluation of small bowel disease especially in paediatric IBD, however can also be useful in other gastrointestinal conditions. The CapsoCam® remote video capsule endoscopy system uses four cameras to produce a panoramic view of the small bowel. This system can be self-administered at home, following instructions provided, as patients usually swallow the capsule. Patient selection needs to be considered carefully.

Our aim was to evaluate safety and diagnostic yield of this novel system and to determine how feasible this is, in a paediatric and adolescent population.

We conducted a retrospective review of our VCE data base over a 4-year period from April 2019 to August 2023. 49 patients (32 male) were included into the study, 6 capsules (5 male) were inserted with an ACORN device, due to the age of the patient and difficulties in swallowing, age range 4 years and 4 months to 15 years and 7 months, median 11year and 4 months. 42 (27 male) out of 43 capsules were sent back, only 1/42 (Female, 10 years and 9 months, AXR did not show capsule) capsule was flushed down the toilet, although the kit provides a sieve to collect the stool. The age range at point of capsule study for the remote capsule swallows ranged between 9 years and 3 months and 19 years and 3 months, median 15 years. The indications were as follows: Suspected IBD: n=10: 9 normal, 1 ulcers in SB; Small bowel Crohn's disease monitoring: n=16: 8 normal SB, 6 ulcers in SB, 2 normal SB but colitis seen; Autoimmune enteropathy n=1, normal; Behcet n=1, normal; Blue rubber bleb syndrome n=1, Blue rubber bleb lesions scattered throughout the small bowel; Cystic fibrosis n=1, gastritis; XIAP n=2, normal; x-linked agammaglobulinemia n=1, gastritis; DGBI n=1, normal; EGID n=2, normal; Perianal disease only n=2, normal; GI bleed n=1, normal; IBDU n=3, normal; OFG only n=1, failed study as patient ate after 4 hours whilst capsule still in stomach; OGD and Crohn's disease n=4, 2 normal and 2 with ulcers in SB; Vascular EDS n=1, blood clots in SB, no source seen. Overall, 31/48 (64.5%) capsules were reported as normal. 47/49 studies were completed (1 lost and 1 failed study due to food debris) with the capsule seen entering the colon and none of capsules got retained.

Is summary CapsoCam® in Paediatric and Adolescent Gastroenterology patients is safe in a variety of indications. Patients can administer it themselves at home with a very high degree of success. Due to possible selection bias the diagnostic yield is under 40%. In selected patients with difficult access to hospital settings this modality should be considered in the diagnostic pathway of paediatric gastrointestinal conditions.

OC70

Outcomes of Diagnostic Endoscopy in Newly Presenting Children With Gastrointestinal Symptoms during and after COVID pandemic by Joseph Machta[1,2], Sandhia Naik[3], Ahmed Kadir[4], David Rawat[3], Protima Deb[3], Marco Gasparetto[5], Nicholas M Croft[2], *[1]Chelsea and Westminster Hospital NHS Trust. [2]Children's Clinical Research Facility, The Royal London Hospital, Barts Health NHS Trust. [3]The Royal London Hospital, Barts Health NHS Trust. [4]The Royal London Hospital, Barts. [5]Norwich and Norfolk University Hospital, UK.*

Paediatric endoscopy is an important tool in diagnosing and ruling out gastrointestinal pathology. However, little published data exists to guide selection of patients for endoscopy. Existing guidance contains weak recommendations based on low quality evidence (1). We have previously published data showing the diagnostic yield of macroscopic and histological abnormalities in children undergoing first diagnostic endoscopy (2) including 218 procedures in 164 children, of which 49.4% were macroscopically and histologically normal, and only 35% were histologically abnormal.

The aim of this project was to assess how the Covid-19 pandemic affected diagnostic yields in paediatric endoscopy. Using the same methodology we analysed first diagnostic endoscopies over two 6-month periods: during the Covid-19 pandemic peak (including lockdowns), and two years later once restrictions were lifted. Clinical factors, endoscopic, and histological findings were assessed. Biopsies were reviewed in weekly histopathology multidisciplinary meetings with final agreed outcomes. Abnormal histology was used as the criterion standard for abnormality.

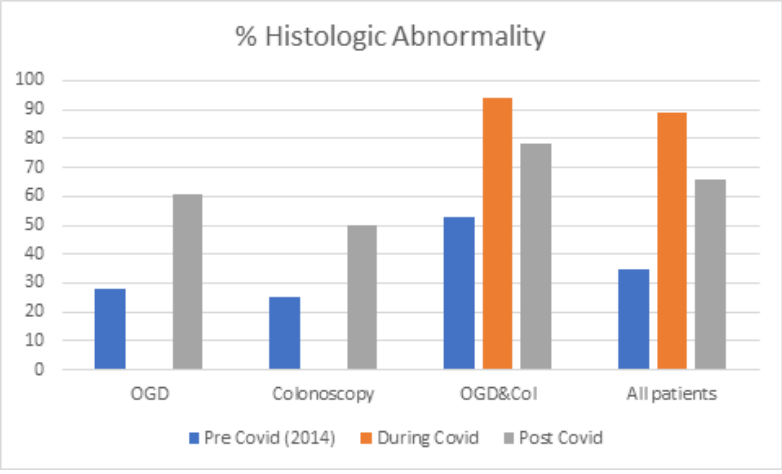
During COVID-19: 69 procedures in 37 children. 65%(n=24) male. 86%(n=32) underwent OGD&Colon/Sigm, small numbers had OGD(n=3) or Colonoscopy(n=2) alone. Mean age 10.9 years. 89%(n=33) had histological abnormality.

Macroscopic and histological abnormalities (respectively) were 94%&94% of those undergoing both OGD and colonoscopy (OGD&Col) plus 2 of 2 colonoscopy alone and 1 of 3 OGD alone.

Post-Pandemic: 194 procedures in 138 children. 54%(n=75) male. 55%(n=76) underwent OGD; 41%(n=56) underwent OGD&Col/Sigm; 4%(n=6) Colon. Mean age 9.5 years. 66%(n=91) had histological abnormality.

Macroscopic and histological abnormalities (respectively): 47%&61% of OGD, 50%&50% of colonoscopy alone, and 76%&78% in OGD&Col.

Figure 1 shows the abnormality rates (defined by macroscopic and histologic abnormality), the % column for OGD or colonoscopy alone during Covid was not included due to n<3.



The most common symptoms and laboratory tests prompting endoscopy were chronic diarrhoea (19%, n=26), rectal bleeding (20%, n=27), abdominal pain (33%, n=46), raised calprotectin (18%, n=25), positive TTG/EMA (17%, n=24), anaemia (20% of all negative TTG/EMA, n=23), and raised CRP/ESR (38% of all negative TTG/EMA, n=43). While clinical and laboratory abnormalities mostly correlated with high rates of macroscopic and histological abnormalities, features associated with low rates of macroscopic and histological abnormality were heartburn (38%&46% respectively) and dysphagia (44%&33% respectively). Features most predictive of macroscopic and histological abnormality (respectively) were chronic diarrhoea (88%&86%), rectal bleeding (70%&78%), raised calprotectin (88%&96%), anaemia (87%&91%), raised ESR (90%&100%), and raised CRP (86%&90%).

Conclusions: As expected, the number of first diagnostic endoscopies reduced greatly during the COVID-19 pandemic but post-pandemic returned to similar numbers to the previous study. There was a striking increase in histological abnormalities identified during the pandemic (from 35% of patients in 2014 to 84%). Post-pandemic this has remained high (66%), suggesting a lasting change in practice since the original study. No delayed diagnoses or patient complaints have been noted since this change. Further work will examine reasons for this.

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OC71

Eating Disorder and Inflammatory Bowel Disease: Double Barrel Disorder or Coincidence by Ehinomen Imoisili[1], Odillha Maglalang-Reed[1], Sharon Probert[1], Anirban Mukhopadhyay[2], *[1]University Hospital of North Durham. [2]Great North Children Hospital, Newcastle, UK.*

A male pre-teen was referred to the paediatric gastroenterology team at a district general hospital following a finding of high faecal calprotectin. This child had long-term feeding problems which had started in infancy. Refuses foods, initially being very unsettled at younger ages, as he grew older his feed aversion worsened and eventually stopped eating with significant weight loss. In the three months preceding referral to the team, the child was passing loose stools (2-3 episodes per day), including nocturnal stools. The child also had occasional vomiting, increased anxiety, and personality change. His weight was on the second centile at referral. He was initially admitted at another hospital, diagnosed as an eating disorder (ED), for nasogastric feeding support. His bloods showed mildly elevated inflammatory markers and platelet count, low iron levels and albumin. An additional faecal calprotectin done for completeness came back as markedly raised (>10 times the upper limit of normal). He was eventually sent to our tertiary paediatric gastroenterology centre where an urgent endoscopy was done. This showed serpiginous ulceration and cobble stone appearance throughout the large bowel with terminal ileal ulceration. He was then started on infliximab and azathioprine as maintenance.

There have been a number of case reports on patients with eating disorders and IBD.[1] The vast majority of these cases have had symptoms develop in their teenage years, our case seems to have developed symptoms at a much younger age, although there was no unifying diagnosis for many years. Some authors have associated eating disorders with a higher risk of Crohn's disease in particular, similar to our index case.[2] The relationship between IBD and ED remains unclear, with uncertainty about whether one condition leads to the other or if the association is bidirectional.[3] A systematic review highlighted the risk of delayed diagnosis given the overlapping nature of symptoms.[1] The article also explores potential risk factors for developing ED in IBD patients, including delayed growth, preoccupation with dietary management, fear of abdominal discomfort, and body image concerns.[1] On the other hand, disturbance of gut microbiota from restrictive eating, laxative use and immune modulatory factors have been suggested as possible risk for IBD in ED patients.[2]

Most of the available literature and evidence focuses on how IBD might lead to an ED, there is paucity of data on when the reverse occurs such as in our case. This report highlights the challenges in diagnosing co-morbid cases and the importance of considering IBD in patients with ED. While more research is needed to establish the causality, eating disorders units and general paediatricians should strongly consider testing for IBD in patients with ED.

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OC72

Optimising the efficiency of infliximab infusions in paediatric inflammatory bowel disease: single centre audit to assess safety and practice by Elena Gil-Zaragozano[1], Pippa Taylor[2], *[1]University Hospital Bristol and Weston NHS Foundation Trust. [2]University Hospitals Bristol and Weston NHS Foundation Trust, UK.*

Infliximab is a common biologic therapy for paediatric Inflammatory Bowel Disease (PIBD) patients. There is no consensus on the administration protocols. There is variation on the length of the infusion and the observation period post infusion. In addition, premedication including antihistamines, corticosteroids and antipyretics, are commonly used (1, 2). We reviewed the current literature and developed an updated protocol (Figure 1). In both protocols, only patients who had a previous reaction to infliximab, restarting infliximab or deemed to need it, receive premedication. The aim of this study was to assess the safety of the updated protocol and to understand the operational time created.

Figure 1. Comparison of protocols

Initial protocol			Updated protocol		
	Infusion time	Observation post infusion time		Infusion time	Observation post infusion time
-First 3 induction doses -Doses of 10mg/kg -Previous reaction	2 hours	2 hours	-First 3 induction doses -Previous reactions	2 hours	30 minutes
-Maintenance doses of 5mg/kg with no previous reaction	1 hour	1 hour	-Maintenance doses (5mg/kg and 10mg/kg) with no previous reaction	1 hour	30 minutes

We compared the experience of the initial protocol with the updated protocol in a tertiary hospital in the United Kingdom. Patients attending the infusion unit for infliximab were identified from 01/01/2019 to 31/12/2019 and compared to patients attending from 01/01/2022 to 31/12/2022. The period of the pandemia was avoided to minimise bias. Inclusion criteria was PIBD patients admitted for infusion of infliximab. The data was collated using the individual's medical records.

In 2019, a total of 35 patients had infusions, a total of 205 infliximab infusions. 154 (75%) infusions over 2 hours with 2 hours observation time and 51 (25%) infusions over 1 hour with 1 hour post infusion observation time. Total of 718 hours. 7 (20%) patients received premedication, a total of 38 events (19%). 1 (0.5%) reaction reported.

In 2022, a total of 32 patients had infusions, a total of 194 infusions. 70 (36%) infusions over 2 hours, 124 (64%) infusions over 1 hour. All 194 infusions had 30 minutes post infusion observation time. Total of 361 hours. 4 patients (13%) received premedication, a total of 32 events (16%). No reactions were reported (0%) (Figure 2).

Figure 2. Comparison of number of reaction and operational time

	Total number of infusions	Infusion reactions	Total infusion and post infusion observation time (hours)
Initial protocol	205	1	718
Updated protocol	194	0	361

This study confirms the safety of shortened infusion time for maintenance doses regardless of the dose, as well as supporting a short observation time post infusion of 30 min for all infliximab infusions for PIBD patients. It also confirms that it safely increases operational capacity and reduces patient's time spent during infusions. This study highlights the safety of only administering premedication for specific patient group when infusing infliximab. With emerging evidence on the use of accelerated protocols infusion over 30 min, more paediatric studies are needed to understand the safety of these protocols and the benefit for the patient and their families.

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OC73

Descriptive analysis of Primary Sclerosing Cholangitis in patients with Inflammatory Bowel Disease in paediatric population: A single centre study by Priyanka Bhakta[1,2], Aravind Manoj[1,2], Shishu Sharma[2], Akshay Kapoor[2], Natalia Nedelkopoulou[2], Priya Narula[2], Prithviraj Rao[2], Zuzana Londt[2], Dominique Schluckebier[2], Marta Cohen[2], Mike Thomson[2]
[1]University of Sheffield. [2]Sheffield Children's Hospital, UK.

PSC-IBD has chronic progressive course with an increased risk of hepatic decompensation and colorectal neoplasia. To review the clinical presentation and outcomes of children with PSC-IBD at a tertiary referral centre. A nine-year (2014-2023) retrospective analysis of medical records at a tertiary paediatric centre, analysing relevant clinical presentations, laboratory markers, imaging, histopathology and relevant clinical outcomes. Fifteen patients were identified (see Table 1.) The predominant presenting complaints related to underlying IBD included abdominal pain (60.0%), diarrhoea (86.6%), and melaena (60.0%). At presentation, all patients presented with raised faecal calprotectin, (93.3% GGT, 80.0% ALT, 80.0% unconjugated bilirubin), and elevated inflammatory markers (33.3% CRP, 66.7% ESR). 20% of patients had rectal sparing. The primary diagnostic modality for PSC was MRCP (73.3%). MRI and Liver biopsy were needed for diagnostic clarification in the remaining cohort (26.7%). Radiological findings (Table 2) highlighted common bile duct (CBD) dilatation, intrahepatic duct dilatation and stricturing as the most prevalent abnormalities across all modalities. Changes on liver biopsy included: portal fibrosis (83.3%), lymphoplasmacytic infiltrate (83.3%), and autoimmune hepatitis (50.0%), periportal eosinophilic infiltrate (33.3%) and onion-skin fibrosis (16.7%). Pharmacological therapies for PSC-IBD were categorised into 3 groups: those receiving steroid treatment without biologics (20.0%), sequential therapy of steroids followed by biologics (53.3%), and azathioprine (66.7%). Infliximab was the predominant biologic (40.0%). Among those on biologics (53.3%), 50% required a change in biologic: half for LOR and half for allergic reaction. Ursodeoxycholic acid (UDCA) was prescribed to a significant majority (80.0%). Laparoscopic subtotal colectomy was required in 1 patient due to chronic active colitis despite maximal medical therapy. No patients progressed to colorectal carcinoma or liver failure. Assessment from initial to recent clinic visits showed symptom improvement (80.0%). 33.3% received annual endoscopic surveillance post-diagnosis of IBD. Patients with PSC-IBD presented with colitic symptoms. Hepatic impairment was diagnosed on routine bloods. IBD was treated to target to achieve clinical and biomarker remission. UDCA was initiated to normalise liver enzymes. No adverse long-term complications were seen. Majority of the PSC patients are diagnosed incidentally on routine bloods. It is important to entertain the diagnosis of PSC as it is an important prognostic factor for poor outcomes related to intestinal and hepatic neoplasia.

Table 1: Patient characteristics

Mean age at referral	11.4 years
Mean age at diagnosis of IBD	11.4 years
Mean age at diagnosis of PSC	12.3 years
M:F	11:4
Family H/O IBD or autoimmunity	7/15 (46.7 %)
Ulcerative Colitis Pancolitis Left sided colitis Right sided colitis	60 % 50 % 20 % 10 %
Crohn's disease	33.3 %
IBD-U	6.7 %

Table 2: Radiological findings

Radiological findings	CBD dilatation	Intrahepatic duct dilatation	Hepatic duct stricturing
Ultrasound	42.9 %	28.6 %	
MRI	30%		20 %
MRCP	50 %	41.7 %	16.7 %

Acknowledgment - Both co-authors 1 and 2 are 1st authors.

OC74

Validation of the IMPACT-III quality of life questionnaire in Sinhalese for children with inflammatory bowel disease in Sri Lanka by Sayeeshan Thiruchelvanathan[1], Shaman Rajindrajith[1,2], Wathsala Hathagoda[1,2], Sandeepa Wijerathne[2], *[1]Lady Ridgeway hospital for Children, Colombo, Sri Lanka. [2]Faculty of Medicine, University of Colombo, Sri Lanka.*

Pediatric Inflammatory Bowel Disease (PIBD) is becoming more common, even in middle-income countries like those in South Asia. The increase in diagnosed patients of PIBD reflects a global trend of Inflammatory Bowel Disease (IBD) affecting regions where its incidence was previously low. It is important to understand how PIBD affects the quality of life of patients in these areas to optimize their care and outcomes. To assess the quality of life in children with IBD, the Inflammatory Bowel Disease Questionnaire (IMPACT III) is often used. Adapting and validating this tool in the Sinhalese language could greatly benefit the local healthcare system by providing a standard way to evaluate the impact of IBD on children's lives in that specific cultural and linguistic context. Therefore, this study aimed to assess the reliability and validity of the Sinhalese version of IMPACT III for children with inflammatory bowel disease in the region.

A cross-sectional study was conducted at the Gastroenterology and Stoma care clinic in Sri Lanka's sole tertiary care specialized centre for IBD in children, catering to both medical and surgical patients with IBD.

The study included 33 participants, comprising 16 males (48.5%) and 17 females (51.5%), with predominant diagnoses of Crohn's disease (26, 78.8%), Ulcerative colitis (6, 18.2%), and IBD-unclassified (1, 3.0%). Internal reliability was assessed, revealing a high Cronbach's alpha of 0.918. Confirmatory factor analysis was performed to evaluate the appropriateness of the proposed four-factor structure (well-being, emotional functioning, social functioning, and body image). Robust positive correlations (coefficients > 0.3) among variables within each factor supported the suitability of the model for our cohort. Concurrent validity was established through correlation with the Pediatric Quality of Life Inventory (PedsQL), revealing a strong correlation coefficient of 0.733 ($p < 0.001$). Discriminant validity was demonstrated by comparing mean IMPACT III scores across disease activity groups (Clinical remission, mild disease, and moderate to severe disease), with statistical significance observed ($p = 0.004$).

Thereby, this study presents a validated Sinhalese-language health-related quality of life instrument, IMPACT – III, for children with IBD aiming to enhance the quality of care by offering a comprehensive assessment tool tailored to the unique needs of this population.

OC75

Age based clinical phenotype and complications of pediatric Inflammatory bowel disease in Sri Lanka by Wathsala Hathagoda[1,2], Shaman Rajindrajith[1,2], Sayeeshan Thiruchelvanathan[1], Sandeepa Wijerathne[2], *[1]Lady Ridgeway Hospital for Children, Colombo,Sri Lanka. [2]Faculty of Medicine, University of Colombo, Sri Lanka.*

Pediatric inflammatory bowel disease (PIBD) has traditionally been prevalent in Western regions, but its incidence is rising globally, particularly in pediatric cases. Our study, conducted in Sri Lanka, a developing country in South Asia experiencing a surge in PIBD cases, aims to address the unique clinical presentations and the complications at different age of onset categorized according to the Paris Classification.

A retrospective analysis was conducted using clinic registry data from children with PIBD at the Gastroenterology Clinic in Sri Lanka's sole tertiary specialized children's hospital from May 2019 to May 2023. The study encompassed patients diagnosed with Crohn's Disease (CD), Ulcerative colitis (UC), and indeterminate colitis (IC), confirmed through clinical, biochemical, endoscopic, and histopathological criteria. Stratified by age of onset, demographic information, clinical presentations, laboratory parameters, and complication development during follow-up were extracted from medical records. Data were analyzed using IBM SPSS Statistics version 27, employing descriptive statistics and relevant statistical tests.

There were 91 patients in total, including CD (61, 67.03%), UC (25, 27.47%) and IC (5, 5.50%), among which 43 (47.25%) pediatric onset inflammatory bowel disease (IBD), 24 (26.37%) early onset IBD, 14 (15.38%) very early onset IBD, 10 (10.99%) infantile onset IBD and no cases of neonatal IBD. Mean age of onset of CD was 8.80 months while 11.80 months for UC. CD was diagnosed at a mean age of 9.07 months with an average delay of 8.25 months, while UC was diagnosed at a mean age of 7.92 months with an average delay of 10.73 months. The duration of symptoms before diagnosis had a statistically significant association with the severity of the disease ($p<0.05$).

In CD abdominal pain (48, 78.69%), loss of weight (47, 77.05%), and loss of appetite (44, 72.13%) were frequent presentations, while indolent perianal fistula (3, 4.92%), perianal abscess (3, 4.92%), and active draining fistula (2, 3.28%) were seen less commonly. Bloody diarrhoea (21,84.0%), mucoid stools (20, 80.0%) and chronic diarrhea (20, 80.0%) were common in UC. Arthritis (CD – 9.83%, UC – 8.0%) and erythema nodosum (CD – 3.28%, UC – 12.0%) were found to be associated with both CD and UC whereas iritis/ uveitis was seen only in CD (2, 3.28%).

The mean hemoglobin level in CD was 10.174g/dl whereas 10.317g/dl in UC. In CD, mean platelet count was 611.30×10^3 /mm^3 whereas 548.58×10^3 /mm^3 in UC. Mean albumin level in CD was 28.76g/l whereas 35.814g/l in UC. The platelet count, c-reactive protein level and serum albumin showed statistically significant association with the histological subtypes of PIBD ($p<0.05$).

Biologics were indicated to 32 patients including CD (24, 39.34%) and UC (8, 32.0%). Azathioprine was the principal immunomodulator administered to 89 (97.80%) patients. There was no statistically significant correlation observed between the age of onset of symptoms (early-onset IBD and Late-onset IBD) and the indication of biologics ($p>0.05$).

Therefore, the study shows a higher prevalence of CD along with a significant association of perianal manifestations. Patients with CD exhibited a greater propensity to utilize biologics and had undergone colectomy procedures.

OC76

Magnetic Resonance Enterography Profiles in Pediatric Inflammatory Bowel Disease: A Comprehensive Overview of Imaging Features and Symptomatology by Wathsala Hathagoda[1,2], Shaman Rajindrajith[1,2], Sayeeshan Thiruchelvanathan[1], Sandeepa Wijerathne[2],[1]*Lady Ridgeway Hospital for Children, Colombo, Sri Lanka.* [2]*Faculty of Medicine, University of Colombo, Sri Lanka.*

In children, the prevalence of Inflammatory Bowel Disease (IBD) is on the rise, presenting a diagnostic challenge. Magnetic resonance enterography (MRE) is a highly effective and non-invasive technique for evaluating and monitoring intestines in IBD patients. MRE facilitates intestine visualization enabling accurate diagnosis, assessment of disease involvement, monitoring of disease activity, and evaluation of treatment response. It plays a crucial role in guiding treatment choices and evaluating therapy effectiveness in children and adolescents with IBD. Although there is existing research on MRE-based indices in adults, there is a need to gather more data specific to the pediatric population. This study investigates the correlation between clinical presentation and Magnetic Resonance Enterography findings in Crohn's Disease (CD).

A retrospective study was done using the clinic registry data of patients with IBD who attended the Gastroenterology Clinic at Sri Lanka's sole tertiary care specialized centre for IBD in children between 2019 May and 2023 May. The study encompassed patients diagnosed with CD, confirmed by clinical, biochemical and endoscopic criteria. Demographic information of the patient such as gender and age, medical history, clinical and endoscopic activity, and MRE findings, were extracted from electronic medical records. Data were analyzed using descriptive statistics and statistical tests, as applicable, with IBM SPSS statistics version 27.

Of the 24 patients included in the study, 15 (62.5%) were female, and 9 (37.5%) were male. Infantile-onset CD occurred in 01 patient (4.1%), early onset in 06 (25.0%), and late-onset in 17 (70.8%). The mean age of diagnosis was 10.79 years (SD = 2.93). The mean duration of symptoms from the onset to diagnosis was 6.62 months (SD=5.41). Loss of weight (22, 91.6%), loss of appetite (22, 91.6%) and abdominal pain (21, 87.5%) were the predominant symptoms, and perianal CD was seen in 13 (54.0%) of patients. MRE findings showed active inflammation in 11 (45.8%) of patients. The mean duration of MRE from the initial diagnosis was five months (SD=3.22). Proximal small bowel thickness was seen only in 2 (8.3%) patients, whereas distal small bowel thickness was seen in 13 (54.1%) and ileo-caecal valve thickening was seen in 5 (20.8%). Strictures were present only in 2 (8.3%) patients, and a fistula was seen in one patient (4.2%).

Thus, the study sheds light on managing IBD in resource-poor settings using diagnostic methods like MRE. The findings indicate that small bowel involvement is prevalent in most patients, but only half of the study population showed active inflammation. Although we were able to appreciate the intestinal changes, the varying time duration since diagnosis has limited us from differentiating initial changes from changes following response to ongoing medications. We recommend future studies in analyzing initial changes from the follow-up.

OC77

Unveiling Infantile Onset – Inflammatory Bowel Disease : Insights from the first Reported Cohort from Sri Lanka – A Case series by Sandeepa Wijerathne[1], Shaman Rajindrajith[2,1], Wathsala Hathagoda[2,1], Sayeeshan Thiruchelvanathan[2],
[1]Faculty of Medicine, University of Colombo, Sri Lanka. [2]Lady Ridgeway Hospital for Children, Colombo, Sri Lanka.

Infantile onset-Inflammatory Bowel Disease (IO-IBD), diagnosed before two years of age, exhibits elevated familial predisposition and primarily colon involvement, as evidenced by previous literature. Moreover, limited therapeutic efficacy and heightened surgical interventions are observed relative to late onset-IBD. We presents ten cases identified at Sri Lanka's sole specialized pediatric tertiary care center for IBD.

A cross-sectional study was conducted from May 2019 to June 2023. Patient information was retrieved from the clinic's registry.

Over the past four years, ten patients were diagnosed with IO-IBD, with an average age of diagnosis at 8.4 months, including seven females and three males with six cases of crohn's disease (CD), three of ulcerative colitis (UC) and one of indeterminate colitis (IC). One patient had a family history of IBD. Chronic diarrhea with blood and mucus stools was the frequent presentation. Treatment approaches varied: two patients received exclusive enteral nutrition therapy, one patient received sulphasalazine while the remaining seven achieved remission through corticosteroid therapy. Five patients required biologics therapy where two patients experienced ongoing symptoms during the maintenance phase despite using biologics such as Infliximab, Adalimumab and Vedolizumab. Complications included failure to thrive in eight cases; none required any surgical complications.

Therefore, this study highlights the clinical spectrum and management diversity of IO-IBD. The findings underscore the challenges in achieving remission in some cases despite biologics therapy and highlight the importance of tailored approaches in addressing the complications associated with IO-IBD.

	Diagnosed age	Gender	Family History	Initial clinical presentation	Diagnosis	Region/s involved * Ascending colon (AC), Transverse colon (TC), Descending colon(DC), Sigmoid colon (SC), Rectum (R), Pancolitis (P)	Induction agent	Maintenance agent (Biologics)	Complications
Patient 01	01 year 04 months	Female	No	Fever, oral ulcers, Abdominal pain, Mucoid stools, Chronic diarrhea, Bloody diarrhea, Loss of appetite (LOA), Loss of weight (LOW), Failure to thrive (FTT)	CD	P	IV Methyl prednisolone	Infliximab	FTT
Patient 02	11 months	Female	Yes	Abdominal pain, Mucoid stools, Chronic diarrhea, Bloody diarrhea,	CD	AC, TC, DC, SC	Exclusive enteral nutrition	Infliximab, Adalimumab, Vedolizumab	None
Patient 03	06 months	Male	No	Mucoid stools, Chronic diarrhea, Bloody diarrhea, LOW, FTT	CD	P	Oral prednisolone	Infliximab	FTT
Patient 04	11 months	Female	No	Mucoid stools, Chronic diarrhea, bloody diarrhea, LOW, LOA, FTT	CD	P	Oral prednisolone	No	FTT
Patient 05	04 months	Female	No	Mucoid stools, Chronic diarrhea, Bloody diarrhea, LOW, FTT	UC	P	Exclusive enteral nutrition	No	FTT
Patient 06	12 months	Female	No	Fever, Abdominal pain, LOA, LOW, FTT	CD	AC, TC	IV Methyl prednisolone	Infliximab	FTT

Patient 07	01 year 10 months	Female	No	FTT	UC	DC, SC, R	IV Methyl prednisolone	Infliximab	FTT
Patient 08	02 years 0 months	Female	No	Chronic diarrhoea, LOW, FTT	IC	AC	Oral prednisolone	No	FTT
Patient 09	01 year 02 months	Male	No	Oral ulcers, Mucoid stools, Chronic diarrhoea, Bloody diarrhoea, LOA, LOW	CD	AC, TC, DC, SC	IV Methyl prednisolone	Azathioprine	None
Patient 10	01 year 06 months	Male	No	Fever, Mucoid stools, Bloody diarrhoea, LOW, FTT	UC	P	Sulphasalazine	Sulphasalazine	FTT

OC78

Reflux/Eosinophilic Oesophagitis Overlap Syndrome in a Paediatric Population: Treatment Responses, and Diagnostic Utility of ALOX15 Immunostaining WSW by Fong[1,2], S. Sharma[2], A. Manoj[1,2], S. Sonmez-Ajtai[2], E. Minshall[2], M. Cohen[2], M. Thomson[2], P. Rao[2], N. Nedelkopoulou[2], P. Narula[2], A. Urs[2], Z. Londt[2], D. Schluckebier[2], *[1]University of Sheffield Medical School. [2]Sheffield Children's NHS Foundation Trust, UK.*

Eosinophilic oesophagitis (EoE) is a chronic inflammatory disorder characterised by substantial eosinophilic infiltration of the oesophageal mucosa, presenting with symptoms such as dysphagia, regurgitation, and food impaction[1]. Clinical, endoscopic, and histopathological characteristics of gastroesophageal reflux disease (GORD) and EoE often coincide, with a subcohort of paediatric patients having reflux/EoE overlap syndrome[2].

We conducted a retrospective observational study to compare treatment responses to proton pump inhibitors (PPI) as an adjunct treatment, target elimination diets (TED), and oral viscous budesonide (OVB), between EoE and reflux/EoE overlap syndrome, and the diagnostic utility of ALOX15 immunostaining in borderline histological findings of EoE in a paediatric cohort.

The medical records of all patients from a paediatric tertiary centre who had a diagnosis of EoE, with >1 oesophageal biopsy and >15 eosinophils/high-power field (HPF), from 2020-2023 were reviewed. Exclusion criteria included previous fundoplication procedures, diagnoses of tracheo-oesophageal fistula, and oesophageal atresia.

Relevant patient data was collected and anonymised, to evaluate:

- Patient Demographics
- Symptoms of EoE
- Atopic Comorbidities & IgE-mediated food allergies
- Reflux/EoE overlap diagnosis from significant pH studies, defined as reflux index (RI) >4 or Demeester Score >14.7 in relation to number of reflux events.
- Cytoplasmic expression of ALOX15 immunostaining
- Treatment response (histological remission) to PPI as an adjunct treatment, OVB, and TED

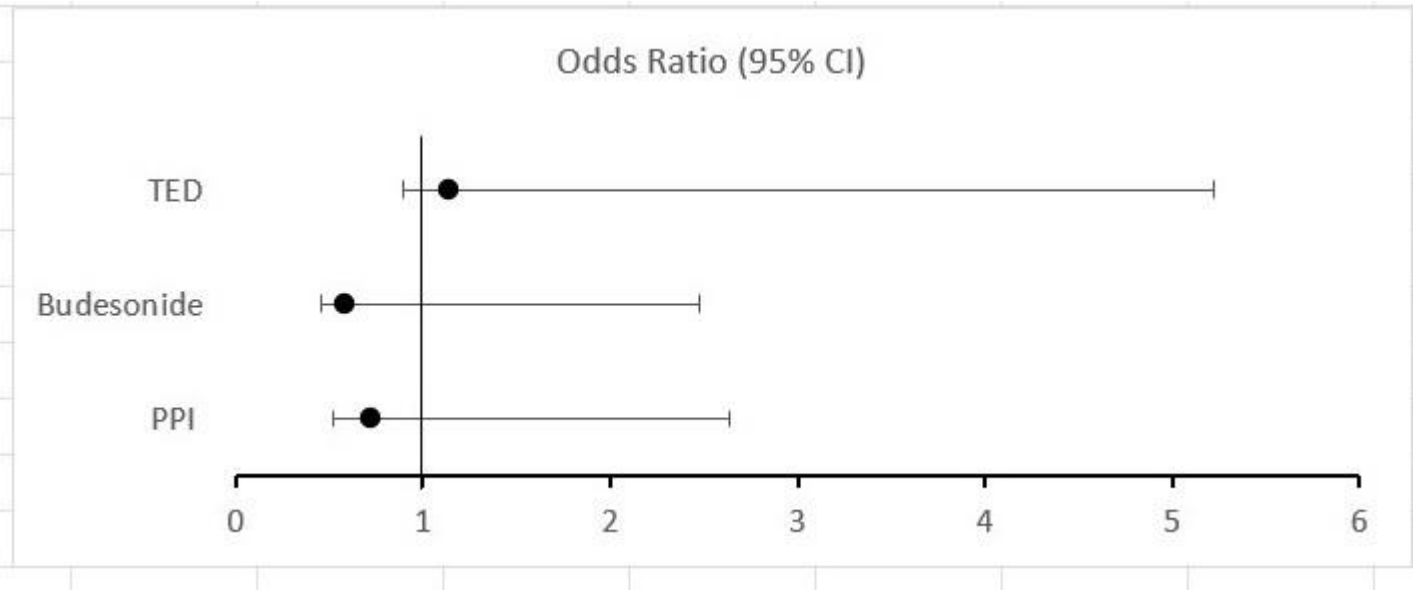
Our results show 47 patients (68.1% male) having a diagnosis of EoE, with a mean age of 8.8. The most common reported symptom was regurgitation/vomiting (37, 78.7%), followed by dysphagia (30, 63.8%). 27 patients had at least one atopic comorbidity, with allergic rhinoconjunctivitis being the most common (18, 38.2%); 13 patients were sensitised to seasonal aero-allergens. 15 patients had IgE-mediated food allergies, primarily to peanuts (10, 66.7%).

Among the 47 patients, 23 (48.9%) had a diagnosis of reflux/EoE overlap, from a significant RI or Demeester Score, with a median of 7.60, and 20.4 respectively. Alox15 immunostaining was performed on 16 patients, with 10 (62.5%) patients demonstrating cytoplasmic expression. Among the positive findings, ALOX15 immunostaining diagnosed EoE in 50% of patients. 1 patient had a borderline endoscopic result of EoE (13 eosinophils/HPF); 4 patients originally diagnosed with GORD had a revised diagnosis of reflux/EoE overlap syndrome, with significant eosinophils only in the distal sample.

Table 1: Treatment Responses

Treatment Response	Reflux/EoE Overlap	EoE	Overall
PPI as an Adjunct Treatment	13/22 (59.1%)	12/18 (66.7%)	25/40 (62.5%)
OVB	6/15 (40%)	8/15 (53.3%)	14/30 (46.7%)
TED	8/15 (53.3)	6/12 (50%)	14/27 (51.9%)

Figure 1: Effect of Reflux Overlap in EoE on Treatment Responses



Acknowledging the large confidence intervals in this pilot study, reflux/Eoe overlap patients are shown to have poorer outcomes with currently available treatment, excluding TED; PPI is shown to be an effective adjunct treatment in both cohorts. ALOX15 immunostaining demonstrated valuable utility in diagnosing both EoE & reflux/EoE overlap, in patients with only significant eosinophils in the distal sample, and borderline histological findings. Prospective studies should evaluate outcomes of oro-dispersible budesonide in treating paediatric patients with EoE, which may reduce need for multiple endoscopic evaluations.

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OC79

Differences of health related quality of life in children with EoE – implications for patients, parents and professionals by Helen Garrett[1], Cennet Tezgel[2], Jean Spinty[2], Marcus K H Auth[2], *[1]Alder Hey Children's NHS Foundations Trust. [2]Alder Hey Children's NHS Foundation Trust, UK.*

There is a recognised significant negative effect on health related quality of life (QoL) in patients with eosinophilic eosophagitis (EOE) (1). Attributed to the chronicity of disease, diagnostic procedures, impact of treatment, and communication obstacles (1).

In one calendar year 2022, all (n=121) patients with EOE from this tertiary centre were invited to participate via QR code link for a Microsoft Forms questionnaire in a pilot feasibility study. This included both a PEESS Pediatric Eosinophilic Esophagitis (EoE) Symptom Severity Module version 2.0 (20 questions, maximal score of severity 80) and a PedsQL ™ Eosinophilic Esophagitis Symptoms Scales Standard Version 3.0 which is validated for QoL in children with EoE for patients in different age groups and carers.

N=27 completed forms were received (22%), 70% were males (n=19), age range data, 2-7 years of age n=2 (8%), age 8-17 years n= 25 (93%).

Table 1 – PEESS scores and predominant symptoms for whole cohort and the subgroups

	< 8 years of age carers	> 8 years of age carers
PEESS activity score all responders -median	52	29
Highest scoring PEESS symptom all responders	Needing to vomit	Needs more time than other children their age to eat

Results were received from carers (n=18) and patients over 8yrs (n=14) with scores from both in (n=5)

Table 2 – QoL data for questions receiving the highest frequency of 'almost always effecting' for full cohort and sub groups

	< 8 years of age carers	> 8 years of age carers	> 8 years of age patients
QOL all responders – most prevalent always scores	Throwing up	Needing more time than other children their age to eat	Needing to drink to swallow food
QoL all responders- most prevalent always & often scores	Throwing up & needing more time to eat	Food coming back up in the throat	Needing to drink to swallow food
QoL – diet treatment most prevalent always scores	Throwing up	Food coming back up in throat.	Needing to drink to swallow food
QoL – medicine treatment – most prevalent always scores	N/A	Food coming back up in throat.	Food coming back up in throat

For the group receiving combined diet and medicine treatment n=4, no single question showed a dominance, although 75% of responders in this group report the highest level of impact.

Obtaining data is a known challenge in qualitative studies and health related quality of life measurements are logistically difficult to get. Using a QR code questionnaire provided a good response rate of 22%. Provided much insightful information from the patients perspectives with significant implications for health care professionals and carers.

From our data, the impact on quality of life felt by the child or young person changes over time and may not mirror the opinion of their carer. These pilot study findings highlight the need for patient engagement during their medical care and the need to empower them as part of a service delivery to address all aspects of their symptoms and health related problems.

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OC80

Histological remission impacts oesophageal dilatation rates in children with oesophageal atresia and eosinophilic oesophagitis. A single centre review by Lucy Jackman[1], Kezia Kite[1], Leanne Goh[1,2], Edward Gaynor[1], Osvaldo Borrelli[1], Anna Rybak[1], [1]*Great Ormond Street Hospital.* [2]*Imperial College Hospital, UK.*

An increased prevalence of eosinophilic oesophagitis (EoE) is reported in children with oesophageal atresia (OA). Although the underlying pathophysiology remains unknown; oesophageal dysmotility, sensory disruption, mechanical disruption and stasis of toxins/antigens, on an atopic background, could explain the increased risk.

The diagnosis of EoE in OA may be delayed due to the overlapping symptom profile of feeding difficulties, food bolus obstruction, treatment-resistant gastroesophageal reflux disease; coupled with anticipated oesophageal dysmotility and anastomotic stenosis(2).

Oesophageal strictures are rare in children with EoE without concomitant OA, although reported in up to 71% of adults with a 20 year diagnostic delay(1). Conversely, recurrent oesophageal strictures are the most frequent post-operative complication in OA, occurring in 18-60% of patients(3).

We aimed to explore the impact of histological remission on dilatation rates in children with OA and concomitant EoE.

We performed a retrospective analysis of patients with OA and confirmed EoE in our specialist children's hospital. Data collected included: age, age at EoE diagnosis, gender, and current treatment for EoE. The number of oesophageal dilatations were evaluated pre and post treatment annually for the three years pre-diagnosis and three years' post-histological remission. A paired t-test was used to assess statistical significance.

Sixteen patients (12 males), with mean age of 9 years (range 3 – 15 years) with OA-EoE were reviewed. All patients within this cohort had diagnosis of EoE made while on PPI treatment; mean age of diagnosis was 5.5 years (range 2 – 13 years). Two patients were excluded as they were not in histological remission at the time of analysis and one patient was excluded as an outlier not representative of the study population due to an excessive number of dilatations.

7 patients (44%) were managed with an increased PPI, 4 patients (25%) a combination of PPI & swallowed topical steroids (STS) & 5 (31%) patients were managed with PPI & food exclusion diets (FEDs). The average time between diagnosis & achieving histological remission was 16 months.

The average number of oesophageal dilatations in the 3 years preceding diagnosis was 0.3 per year (range 0 - 4) & the average number of oesophageal dilatations in the 3 years post achieving histological remission was 0.2 per year (range 0 – 2); resulting in a 33% reduction in dilatation rate ($P = 0.01$). Of note, the excluded outlier, required 21 dilatations (SD = 14.6) in one year prior to histological remission, whilst in the 3 years following remission, they have not required further dilatation. There was no difference in dilatation rates between the mode of treatment (PPI, STS or FED).

Our results suggest that histological remission of EoE in children with OA resulted in a significant (33%) reduction in the frequency of oesophageal dilatations required in the following 3 years. These results are similar to those reported by Chan et al in 2016, which demonstrated a dilatation frequency of reduction of 55% annually post treatment.

Further data is required to fully understand if histological remission in this cohort, reduces dilatations, to understand if guidance should differ from non-OA EoE management.

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OC81

Eosinophilic esophagitis successfully treated with elimination diet and proton pump inhibitors in a patient with glycogen storage disease type 9c by **Francesco Pellegrino[1,2], Aimee Wiseman[1], Lucy Jackman[1], Leanne Goh[3], Edward Gaynor[1],** *[1]Department of Paediatric Gastroenterology, Great Ormond Street Hospital, London UK. [2]Department of Pediatric and Public Health Sciences, Postgraduate School of Pediatrics, Regina Margherita Children Hospital, University of Turin, Turin, Italy. [3]Department of Paeditric Allergy. St. Mary, Imperial College Healthcare, London, UK*

We present the case of a pediatric patient with glycogen storage disease type 9c (GSD9c) who introduced cornstarch into dietary regimen to keep blood glucose levels within safe limits and avoid hypoglycemia. After the introduction of cornstarch, the patient developed dysphagia and growth impairment (weight 22 kg, z-score -1.12 and height 123 cm, z-score -1.21) and struggled to control his glucose levels properly. Following multiple admissions, an esophagogastroduodenoscopy revealed eosinophilic esophagitis (EoE). His symptoms slightly improved after a three-months proton pump inhibitor treatment, but the next endoscopy revealed persistent macroscopic changes of the esophagus and absence of histological remission. After replacement of cornstarch with tapioca starch, his symptoms and his growth improved (weight 33.7 kg, z-score -0.45 and height 140.6 cm, z-score -0.77).
In patients with GSD, slow digestion and absorption of cornstarch is essential to maintain adequate blood glucose levels [1], but in our case its introduction in patient's diet was associated to EoE development, poor control of metabolic symptoms and poor growth. This is the second case reported in literature of GSD developing EoE after cornstarch introduction to diet [2], with clinical and histological remission after identification of corn as a main allergen trigger and its subsequent elimination [3].

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OC82

Candida esophagitis in paediatric patients with Eosinophilic oesophagitis: a monocentric case - control study by Francesco Pellegrino[1,2], Edward Gaynor[1], Liina Palm[3], *[1]Department of Paediatric Gastroenterology, Great Ormond Street Hospital, London, UK. [2]Department of Pediatric and Public Health Sciences, Regina Margherita Children's Hospital, Postgraduate School of Pediatrics, University of Turin, Piazza Polonia 64, Turin, Italy. [3]Department of Histopathology, Great Ormond Street Hospital for Children, London, UK.*

Eosinophilic oesophagitis (EoE) is a chronic inflammatory condition of the oesophagus, which presents in children and adults with swallowing difficulties, abdominal and chest pain, vomiting, nausea and/or with symptoms affecting eating and appetite. [1]

EoE can present a white exudate or plaques in the oesophagus - a finding not dissimilar to those with oesophageal candidiasis (OC). To exclude OC, Periodic acid-Schiff (PAS) staining is recommended. [2] The aim of the study is to report the incidence of positive PAS staining in patients with EoE and idenitify possible risk factors for OC.

A single-center retrospective case-control study was conducted. We reviewed all patients with a diagnosis of EoE (n = 111). We excluded those which had other possible risk factors for OC, as oesophageal atresia (n= 20) and severe immunodeficiency (n=1) and we selected only patients for which we required at least one time PAS staining for suspected OC (n=36, 40%) either at the time of endoscopy or due to associated features on oesophageal histology such as infiltration of the surface with mononuclear cells.

We enrolled a total of 26 patients, 3 with positive PAS staining and 23 with negative PAS staining. The prevalence of OC in patients with EoE, without known risk factors is 3.3%, greater than in non-immunosuppressed population as reported in the literature (0.32-0.4%). [3,4]

Those children who underwent PAS-staining due to suspected of OC was principally due to the presence of white exudate or plaques in the oesophagus at the oesophagogastroduodenoscopy (n= 22 patients, 85%), isolated or with other oesophageal macroscopic changes.

In order to find possible risks factors for OC in patients with EoE, we compared patients with confirmed OC with those with suspected OC but not confirmed with PAS-staining.

We identified those with known IgA deficiency and on recent antibiotics therapy and H. pylori infection. We also assessed length of therapies with proton pump inhibitors (PPI) and topical steroids (inhaled or swallowed) for EoE; significant statistical correlation was not found with any of these factors.

Our study suggests that OC prevalence in EoE is increased compared to reported prevalence of OC in non-immunosuppressed population, but no clear risk factors were detected. Due to the small number of cases observed, further studies on larger populations are needed to assess the indications for PAS staining in EoE patients and real risk of OC in this population.

PAS staing is recommended to aid diagnosis of OC with children with known EOE.

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OC83

A regional rare disease experience: How children with Megacystis Microcolon Intestinal Hypoperistalsis Syndrome are diagnosed and managed by Laura Kelly, Karen Knight, Selena Curkovic, Huda Atta, *Noah's Ark Children's Hospital for Wales, UK.*

Megacystis microcolon intestinal hypoperistalsis syndrome (MMIHS) is a rare disease, characterised by abdominal distension caused by a dilated, but generally non-obstructed bladder, combined with a very small colon and globally decreased or absent gastrointestinal peristalsis. It is associated with several genetic causes, most often with de novo autosomal dominant mutations in the ACTG2 gene. A rare disease is defined as one that affects less than 1 in 2000 people[1]. However, by these standards, MMIHS is extremely rare, with only 450 recorded cases in the literature[2]. Most clinicians working in paediatric Gastroenterology are therefore likely to have limited experience of caring for patients with MMIHS.

Our aim was to undertake a service evaluation of our regional management of seven children with MMIHS during the last five years. A retrospective review was carried out for all paediatric patients with MMIHS within our region during the last five years. Patients were excluded if they did not have a confirmed genetic diagnosis or a consensus multidisciplinary clinical diagnosis of MMIHS (with or without pending genetic results).

Out of eleven patients who were reviewed, seven children (five female) were included. Six patients are still cared for in our region, with one patient having died aged 15 months old. Table1 shows the age at presentation and the outcomes of genetic testing.

Table 1. Age At presentation and Genetic testing Outcomes

Number of patients	3 patients	2 patients		2 patients	
Age at presentation	Neonatal	Early Infancy (3-5 months)		Early Childhood (2-3 years)	
Genetic characteristics	All found to have pathogenic mutations in ACTG2 gene	1 patient awaiting genetic testing results	1 patient with a likely significant ACTG2 gene variant	1 patient clinical diagnosis, no significant genetic variant	1 patient awaiting genetic testing results

Management of these patients involves a large multi-disciplinary team. Most of these children have benefitted from joint MDT clinics in a specialist motility clinic or a joint gastro-surgical clinic. Table 2 illustrates the teams providing input into these children's medical care.

Table 2. Specialty team input

Specialty	Number of children receiving input from specialty
Paediatric Urology	7
Specialist Continence Nursing Teams	7
General Paediatrics	7
Paediatric Gastroenterology	6
Paediatric Nephrology	5
Community Paediatrics	3
Paediatric Colorectal Surgery	2
National GI Motility Specialist team	2

The breadth of symptom type and severity means patient management does vary, but there is a consistent stepwise approach to managing bladder and bowel symptoms. Table 3 illustrates strategies used and how many patients they have been used for.

Table 3. Management Strategies

Intervention	Number of patients receiving intervention
Laxatives	5
Bowel irrigation	2
Ileostomy	2
ACE	1
Intermittent Catheterisation	5
Suprapubic Catheterisation	1
Enteral nutrition supplementation	3
Parenteral Nutrition	1

Our experiences with age of presentation and genetic diagnosis for these children mirror the literature[3]. We propose that close multidisciplinary working with joint clinics may be a factor in a relatively high diagnosis rate. We also recognise that having a continence nursing network has also aided in highlighting where bowel and bladder symptoms warrant further investigation.

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OC84

Diagnostic Yield of Manometry in Paediatric Patients in a Tertiary Centre by Aravind Manoj[1,2], Shun Hui Yeoh[1,2], Shishu Sharma[2], Caroline Race[3], *[1]University of Sheffield. [2]Sheffield Children's Hospital. [3]Sheffield Teaching Hospitals, UK.*

High-resolution oesophageal manometry (HROM) and anorectal manometry (ARM) are invaluable diagnostic tools that significantly enhance our understanding of complex paediatric gastrointestinal (GI) motility disorders, providing detailed information into the neuromuscular coordination and physiological function of the GI tracts. HROM is particularly useful for screening patients for anti-reflux interventions e.g. Fundoplication or STRETTA®, while ARM also plays a crucial role in the screening process for Hirschsprung's disease. This diagnostic capability enables clinicians to create personalised treatment plans, thereby optimising GI health outcomes for their patients.

Our study aims to evaluate the motility services at a tertiary paediatric centre where it was first introduced in 2018. Specifically, we aim to assess the diagnostic yield of manometry and investigate whether new motility diagnoses have resulted in changes in management and/ or improved health outcomes.

A 5-year retrospective analysis from 2018 to 2023 of medical records from a tertiary paediatric centre was conducted. The study targeted patients aged 0 to 18 years who had undergone HROM or ARM. Exclusion criteria were applied to cases with unavailable records (n=21), patients unable to tolerate the procedures (n=2), and those who had previously undergone manometry at a different hospital (n=1). The final cohort included 121 patients, of whom 53 underwent HROM and 68 underwent ARM.

The mean referral age was 11.1 years for HROM and 6.15 years for ARM. Gender ratios (M:F) were 24:29 ratio for HROM and a balanced 1:1 ratio for ARM. Common HROM indications included gastroesophageal reflux disease (GORD) evaluation (37.7%), dysphagia (28.3%), regurgitation (18.9%), food bolus impaction(5.66%), haematemesis (3.77%), vomiting (3.77%) and abdominal pain (1.89%). ARM was primarily used for constipation (39.7%), faecal incontinence (30.4%), overflow diarrhoea (24.6%), abdominal pain (2.94%) and rectal bleeding (1.45%).

The diagnostic yield of HROM and ARM in the paediatric population studied was calculated at 95.7% and 56.5% respectively. In HROM, management changes occurred in 87.2%, with 59.6% showing improved outcomes. In the ARM group, 89.5% of patients experienced a change in management and 61.1% reported symptom improvement.

Interestingly, despite the absence of the Recto-Anal Inhibitory Reflex (RAIR) in ARM, patients exhibited normal results in rectal strip biopsies. This emphasises that ARM alone is not sufficient for Hirschsprung's disease screening. Additionally, 23% of patients initially considered for fundoplication had their diagnoses reassessed to rumination syndrome through oesophageal manometry, which prompted a shift from anti-reflux procedure to biofeedback techniques.

The service evaluation highlights the importance of HROM in evaluating cases referred for anti-reflux procedures, especially to exclude conditions like a short oesophagus and oesophageal dysmotility. It is emphasised that relying solely on ARM as a screening test for Hirschsprung's disease may not be sufficient. Prospective studies are required to assess the diagnostic yield of ARM for Hirschsprung's Disease. In light of these considerations, it is recommended to make GI physiology services more widely accessible and integrate GI physiology training into the UK gastroenterology GRID programme.

Acknowledgement - Both Authors 1 and 2 are 1st Co-authors and have contributed equally to this project

OC85

Diagnostic Yield of High-Resolution Oesophageal Manometry (HROM) in Paediatric Patients in a Tertiary Centre

by Shun Hui Yeoh[1,2], Aravind Manoj[1,2], Shishu Sharma[2], Caroline Race[3], *[1]University of Sheffield. [2]Sheffield Children's Hospital. [3]Sheffield Teaching Hospitals, UK.*

High-resolution oesophageal manometry (HROM) has been used as a valuable diagnostic tool for patients with persisting gastrointestinal (GI) symptoms and as a screening tool before anti-reflux surgery. This non-invasive procedure provides insight into the neuromuscular coordination and peristaltic function of the oesophagus, enabling clinicians to gain a better understanding of the underlying causes of upper GI disorders and tailor treatment plans to optimise GI health for their patients.

This study evaluates the diagnostic performance of HROM in a paediatric population treated at a large tertiary centre, where manometry was first introduced in 2018. The primary aim of this project is to examine its ability to identify oesophageal motility disorders and understand its impact on patient care and outcomes.

A retrospective analysis of medical records from a tertiary paediatric centre from 2018 to 2023 was carried out. The study centred on patients aged between 0 and 18 years who had undergone HROM to assess upper gastrointestinal symptoms. From the initial group of 58 patients, exclusion criteria were applied for cases with unavailable records (n=4) and patients unable to tolerate the procedures (n=1). Consequently, the final cohort consisted of 53 patients.

The mean age at referral for HROM was established at 11.1 years with a male-to-female (M:F) ratio of 24:29. The predominant indications for oesophageal manometry included the evaluation of gastroesophageal reflux disease (GORD) (37.7%), dysphagia (28.3%), regurgitation (18.9%) and others (15.1%).

Primary symptoms	**Number of patients (n)**	**Percentage (%)**
Gastroesophageal reflux disease (GORD)	20	37.7
Dysphagia	15	28.3
Regurgitation	10	18.9
Food bolus obstruction	3	5.66
Haematemesis	2	3.77
Vomiting	2	3.77
Abdominal Pain	1	1.89
Total	**53**	

HROM exhibited a remarkable sensitivity and specificity, culminating in a diagnostic yield of 95.7%, indicating strong diagnostic evidence of positive test results in those who had undergone the procedure. These results prompted changes in patient management in 87.2% of cases, with 59.6% of these cases witnessing a tangible improvement in patient outcomes. Notably, 6 patients out of 26 (23%) patients who were previously referred for anti-reflux procedures such as STRETTA® or Fundoplication had a change in management plan following manometry results suggesting rumination syndrome.

Results	**Percentages (%)**
Sensitivity	91.7
Specificity	96.6
Positive Predictive Value	95.7
Negative Predictive Value	93.3

Diagnostic Accuracy	94.3
Diagnostic Yield	95.7

The study underscores the crucial role of HROM in assessing cases referred for anti-reflux procedures, particularly to rule out conditions such as a short oesophagus and oesophageal motility disorder. Prospective studies are needed to validate these findings and establish comprehensive guidelines for its optimal use in paediatric clinical practice, with the potential to enhance paediatric healthcare and improve patient outcomes. It is recommended to improve the accessibility of GI physiology services and integrate GI physiology training into the UK gastroenterology GRID programme.

Acknowledgement - Both Authors 1 and 2 are 1st Co-authors and have contributed equally to this project

OC86

Diagnostic Yield of Anorectal Manometry (ARM) in Paediatric Patients in a Tertiary Centre by Shun Hui Yeoh[1,2], Aravind Manoj[1,2], Shishu Sharma[2], Caroline Race[3],[1]*University of Sheffield.* [2]*Sheffield Children's Hospital.* [3]*Sheffield Teaching Hospitals, UK.*

Anorectal manometry (ARM) is a crucial diagnostic tool in the field of paediatric gastroenterology, aimed at assessing the functional aspects of the anus and rectum in children. By evaluating the coordination and strength of the muscles responsible for bowel movements, ARM aids in diagnosing underlying pathophysiology of these disorders such as Hirschsprung's disease.

The aim of the study was to assess the diagnostic yield of manometry in a paediatric population in a large tertiary centre and to determine if a new diagnosis of motility disorder would result in changes in management, leading to better health outcomes for these patients with gastrointestinal symptoms.

A 5-year retrospective analysis from 2018 to 2023 was conducted using medical records obtained from a tertiary paediatric centre. The primary focus of this study was to investigate patients aged 0 to 18 years who had undergone ARM as part of their evaluation for GI symptoms. Out of the initial cohort of 85 patients, exclusions were made for cases with inaccessible records (n=15), patients unable to tolerate the procedures (n=1), and those who had previously undergone manometry at a different hospital (n=1). This resulted in a final sample size of 68 patients.

The mean age at referral for ARM was 6.15 years, with an equal male-to-female (M:F) ratio. Anorectal manometry was primarily used to investigate symptoms like constipation (39.7%), faecal incontinence (30.4%), overflow diarrhoea (24.6%) and other related concerns (5.30%).

Primary Symptoms	**Number of Patients (n)**	**Percentage (%)**
Constipation	27	39.7
Faecal incontinence	21	30.4
Overflow diarrhoea/ diarrhoea	17	24.6
Abdominal pain	2	2.94
Rectal Bleeding	1	1.45
Total	**68**	

Overall, ARM demonstrated a sensitivity of 81.3% and a specificity of 80.8%. The diagnostic yield of ARM in the paediatric population was calculated at 56.5%. Of the patients on our ARM list, 89.5% experienced a change in management plan, with 61.1% of these cases showing improvement. Notably, six patients had absent RAIR but normal biopsy results, proving that Hirschsprung's disease is not always present in patients with absent RAIR alone.

Results	Percentages (%)
Sensitivity	81.3
Specificity	80.8
PPV	56.5
NPV	93.3
Diagnostic Accuracy	80.9
Diagnostic Yield	56.5

The study emphasises how important anorectal manometry is for tertiary healthcare settings' diagnosis of paediatric gastrointestinal diseases. It is highlighted that using ARM alone to screen for Hirschsprung's disease might not be adequate. To evaluate the diagnostic yield of ARM for Hirschsprung's disease, future studies are necessary. ARM techniques yield accurate diagnoses as well as insightful information about the underlying pathology. Their high values of sensitivity and specificity make them essential for comprehensive assessment and management. In light of these factors, it is advised to increase the accessibility of GI physiology services and incorporate GI physiology education into the UK gastroenterology GRID programme.

Acknowledgement - Both Authors 1 and 2 are 1st Co-authors and have contributed equally to this project

OC87

Cost effectiveness of routine monitoring of vitamin B12 and folate in paediatric home parenteral nutrition patients

by Cameron Hogg[1,2], Elena Cernat[1], Lilianne Gomez-Lopez[1], Natalia Iglesias[1], Julie Steele[1], Jenny Goldthorpe[1], *[1]Leeds Teaching Hospitals NHS Trust. [2]Yorkshire and Humber Foundation School, UK.*

Patients on home parenteral nutrition (HPN) receive 5µg of vitamin B12 and 400µg of folate with every bag of PN and require regular monitoring of micronutrients[1], including serum vitamin B12 and folate levels. A review of the literature and guidelines highlighted a discrepancy in the recommended frequency of the monitoring for these vitamins between different societies[2] and NICE guidelines[3]. The dose recommended by NICE guidelines is 1000µg IM hydroxocobalamin every 3 months (equivalent to approximately 11µg/day) and 5 mg daily for 4 months of oral folate, in case of deficiency. Also, NICE guidelines state that 'ongoing monitoring (of vitamin B12 and folate) is unnecessary unless a lack of compliance with treatment is suspected' in case of anaemia secondary to vitamin B12 or folate deficiency[2]. In our hospital, the cost of measuring serum vitamin B12 is £0.95 and for folate is £0.51.

The objective of the study was to determine the cost effectiveness of regular monitoring of vitamin B12 and folate on HPN patients and explore if it can be safely reduced to prevent unnecessary expenditure of healthcare resources without causing harm to patients.

We retrospectively reviewed 24 patients (age range 11 months - 18 years) over a 2-year period (2020-2022). The minimum number of days on PN per week was 2 and maximum 7. 68.2% of vitamin B12 samples were above the reference range, 30.7% within the reference range and 1.1% below the reference range. For folate, 39.4% were above the reference range, 60.1% were within the reference range and 0.5% were below the reference range. Any low results were further investigated, and it showed that patients were not using PN at that time. For each patient, the total cost of monitoring vitamin B12 and folate during those 2 years was £261.50 on average.

Conclusions:

1. Vitamin B12 and folate levels were all above or within the reference range in this cohort in 98.9-99.5% of the sample.
2. The dose of vitamin B12 given with every PN bag (5 µg/bag) was less than the recommended by NICE for patients that need IM treatment (11µg/day); potentially better levels are reached with IV administration.
3. The dose of folate given with every PN bag (400µg/bag) was less than the recommended by NICE for patients that required oral supplementation (5mg/day/7 days a week/4 months); potentially better levels are reached with IV administration.
4. The annual total cost of vitamin B12 and folate monitoring per year per patient in this study was £131.
5. We recommend to decrease the measurement of serum vitamin B12 and folate from three monthly to once a year for patients receiving PN at least 2 days per week. This would be an estimated cost saving of 75%.

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OC88

Teduglutide use in England outside clinical trials - single centre experience by E. Cernat, J. Steele, O. Harvey, N. Iglesias, J. Goldthorpe, H. Brogan, L. Gomez Lopez, *Leeds Teaching Hospitals NHS Trust, Leeds, UK*

Teduglutide is a synthetic analogue of the glucagon-like peptide type 2 used to promote intestinal adaptation in patients with short bowel syndrome (SBS) dependent on parenteral nutrition (PN). Although used in paediatric clinical trials for the last 10 years (1,2), the treatment was approved by NICE in England, Wales and Northern Ireland in June 2022.

The objective of our study was to describe our experience in using Teduglutide in two patients.

The dose of Teduglutide used was 0.05mg/kg given as a daily subcutaneous injection.

Patient 1: 12 years old boy, SBS secondary to complex gastroschisis - initial anatomy 10 cm small bowel, after several lengthening procedures, 85 cm. D-lactic acidosis, last episode in 2019. PN 7 nights a week over 14 hours (5 fat free nights), tolerating a normal diet. Patient started Teduglutide in February 2023.

After 39 weeks 2 days on Teduglutide, PN was stopped (see table 1). The bloods have been stable during this period. Loperamide was stopped after 3 weeks of treatment.

There was also an improvement in body mass composition - Body fat 19.5%, Muscle mass 76.1% before treatment compared with Body fat 16.4% and Muscle mass 79.1% when PN stopped.

Table 1:

Date	Weight (kg)	Height (cm)	PN (ml)	PN days/week	Average PN (kcal/day)	EAR PN (%)
06/02/23	31.3	143.4	2600	7	820	42
13/02/23	31.6		2600	7	820	42
20/02/23	32.1		2600	7	820	42
27/02/23	32.5		2300	7	725	35
13/03/23	32.7	143.7	2000	7	630	31
27/03/23	32.6		1800	7	567	28
24/04/23	33.9		1500	7	428	20
22/05/23	34.5	145.6	1200	7	378	18
14/06/23	34.7		900	6	335	16
25/07/23	32.9		900	5	292	14
23/08/23	34.3		900	5	292	14
18/09/23	34.1	148.3	900	4	246	12
11/10/23	35.4	148.8	900	3	205	10
08/11/23	35.1	150	900	2	124	6

PN stopped 8/11/23.

Patient 2: 18 years old girl with SBS secondary to neonatal volvulus - remaining anatomy 10 cm small bowel. D-lactic acidosis with multiple admissions since 2016. PN 4 nights/week, over 12 hours. Patient started Teduglutide in July 2023.

After 7 weeks on treatment, PN was stopped (see Table 2). Loperamide stopped after 3 weeks.

Patient off PN for the last 13 weeks, continued to have ongoing episodes of D-lactic acidosis and hypomagnesemia for which she was started on Magnesium infusions twice weekly. She has been transitioned in September.

Table 2:

Date	Weight (kg)	Height (cm)	PN (ml)	PN (days/week)	Average PN (kcal/day)	EAR PN (%)
03/07/23	58.3	167.5	1645	4	1019	40
10/07/23	58.7		1645	4	1019	40
17/07/23	58.5		1645	4	1019	40
24/07/23	61.3		1645	4	1019	38
07/08/23	59.6		1485	4	920	36
14/07/23	59.1		1100	4	681	27
21/08/23	58.6		700	4	434	17
01/09/23			0	0	0	0
10/10/23	55	168	0	0	0	0
21/11/23	54.5			Mg infusion		

In conclusion, Teduglutide appears safe and effective in reducing PN requirements in paediatric patients but more data is needed to understand it´s long term efficacy and results after discontinuation (3).

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OC89

Effectiveness of annual surveillance chest radiographs to assess central venous catheter position in paediatric home parenteral nutrition patients by Shalu Jain, Imran Kasli, Elena Cernat, Helen Brogan, Lilianne Gomez-Lopez, *Leeds Teaching Hospital, UK.*

Paediatric intestinal failure (IF) is characterised by the inability of the gastrointestinal tract to absorb adequate nutrition and fluid to maintain hydration and growth. This results in the need for long-term parenteral nutrition (PN) delivered via a central venous catheter (CVC)1. There are several CVC related complications like fracture, occlusion and dislodgement. There are recommendations for regular radiographic surveillance, however these vary in different hospitals and have limited scientific evidence2,3.

The objective of our study was to review the utility and cost effectiveness of performing annual surveillance chest radiographs to assess CVC position routinely, i.e. without clinical evidence of central line complications.

We performed an observational retrospective study including 27 paediatric patients aged 0 to 18 years, currently on home PN (HPN) under the care of a tertiary Intestinal Failure centre. The information collected included demographic details, number of years on PN, weight and height at the time of CVC insertions and CVC changes, number of chests-radiographs and if any CVC manipulation or change was required following the chest radiographs.

The average age in our cohort was 8.8 years +/- 4.95SD, with 51.8% (n=14) being females and 48.1% (n=13) males. The average number of years on HPN was 5.3 years+/- 3.82SD. None of the children required manipulation or change of their CVC after radiographic surveillance. There was an average CVC lifespan of 1.1years+/- 0.99SD secondary to various complications like accidental dislodgement, fracture, line sepsis or occlusion. There were no instances of a child's growth necessitating a CVC change. 2 patients had an increase in height of 25cm and 22 cm respectively and non-changes in their standard deviation (SD) body mass index (BMI) with their CVC being in correct position.

We concluded that routine annual surveillance chest radiographs have not been deemed useful in our cohort. Continuous use of CVCs in HPN patients renders them vulnerable to have CVC changes due to other complications and hence not lasting long enough for them to outgrow of. Additionally, it increases the burden on families due to hospital attendances, increased radiation in a population that already has high levels of exposure and increases the financial and resource burden of healthcare facilities. The role of chest radiographs are mainly to see if the CVC is intravascular which is checked bedside by bleeding back from the line before use, which is the gold standard to check a line is still intravascular. Our hypothesis is that increase in height is probably not a useful indicator of line movement especially if the patient has not changed his BMI SD.

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OC90

Outcomes of two different approaches to central venous catheter repairs in children on home parenteral nutrition: preliminary results by Alessandra Mari, Mihaela Stoian, Sophie Montgomery-Stuart, Hannah Littlechild, Jutta Koeglmeier, Susan Hill, Rulla Al-Araji, *Department of Gastroenterology, Great Ormond Street Hospital, London, UK.*

Children on home parenteral nutrition (HPN) may experience central venous catheter (CVC) breakage, which could lead to infection. To preserve vascular access sites, CVC repairs are preferred to CVC substitutions (1,2).

Aim of this study is to evaluate whether routine blood culture (BC) is needed for all children undergoing CVC repair or if, in absence of specific risk factors, cultures can be avoided without an increased incidence of central line associated blood stream infection (CLABSI).

Children (0-17 years) enrolled in the HPN program of a large tertiary referral center who underwent a CVC repair between January 2021 and October 2023 were included in the study. During period-A (01/01/2021-30/06/2022) a BC was performed for every repair. During period-B (1/07/2022-31/10/2023) BC was not performed in absence of risk factors for infection (repair done in >12 hours, signs of systemic or local infection, breakage due to biting).

During period-A, among fifty children (median age 11-years) in the HPN program seventeen breakages were reported. Median age for breakage was 6-years. BC was performed in 100% patients. Three BC were positive, all three children had at least one of the risk factors.

During period-B, twenty breakages were reported among forty-five children (median age 11-years). For nine children (45%) without risk factors for sepsis, BC was not obtained. None of them developed CLABSI.

In absence of risk factors, avoiding routine BC during CVC repairs does not seem to be associated with an increased risk of CLABSI. This approach can help reducing unnecessary line accesses, laboratory resources, and hospitalization.

Table 1.

Characteristics	**Period A**	**Period B**
Number of patients	50	45
F, n (%)	27 (54%)	29 (49%)
Age, median (25°-75° QI)	11 (7-15)	11 (7-16)
Number of breakages	17 (in 13 patients)	20 (in 11 patients)
Breakages/ 1000 catheter days	0,77	1,04
Age at line breakages, median (25°-75° QI)	6 (4-11)	5 (5-11)
Patients who had BC	17 (100% of breakages)	11 (55% of breakages)
Repair in > 12 hours	NA	10 (90,1% of patients with BC)
Breakage due to biting	1 (5,9 of patient with BC)	4 (36,3% of patients with BC)
Signs of infections	2 (11,8% of patient with BC)	2 (18,8% of patients with BC)
BC positive	3 (18% of breakages)	4 (20% of breakages)

Repair in > 12 hours	NA	4 (100% of positive BC)
Breakage due to biting	1 (33,3% of positive BC)	4 (100% of positive BC)
Signs of infections	3 (100% of positive BC)	2 (50% of positive BC)
Patients who did not have BC	0 (0% of breakages)	9 (45% of breakages)
CLABSI in patients who did not have BC	NA	0 (0%)

Legend. BC = blood culture; CLABSI = central line associated blood stream infection. NA = not applicable

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OC91

Trends in catheter related blood stream infections rates in children on home parenteral nutrition by Hannah Littlechild, Sophie Montgomery-Stuart, Alessandra Mari, Micol Sonnino, Amrita Gill, Rulla Al-Araji, Jutta Koeglmeier, Susan Hill, *Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK.*

Children receiving long term parental nutrition (PN) are at risk of catheter related blood stream infections (CRBSI), a potentially life-threatening complication. The CRBSI rate for our centre was 1,88/1000 catheter days from year 2015 to 2019 (1). The aim of this study was to assess and compare our current rate of CRBSI.

Patients aged 0-18 years enrolled in our tertiary intestinal failure (IF) rehabilitation home PN service from 1stOctober 2022- 1st October 2023 were included. Data regarding episodes and potential risk factors for CRBSI were prospectively recorded.

48 patients were included. Median (25th-75th Q.I.) age was 11,5 (7,5 – 16) years. 22/48 (45,8%) were female. Indication for PN was short bowel syndrome (SBS) in 13/48 (27,1%), gastrointestinal motility disorder in 18/48 (37,5%), intestinal mucosal disorders 6/48 (12,5%), immune-onco-haematologic disorders for 7/48 (14,6%), and neurologic disability for 4/48 (8,3%). Characteristic of patients are summarized in table 1.

17 episodes of CRBSI were recorded in 12/48, 25% patients. Two patients had 3 episodes of CRBSI, and 2 patients had 2. Median (25th-75th Q.I.) age of patients with CRBSI was 9 (4,7-13,5) years. 5/12 (41,6%) were female. 10/48 (20,8%) families were identified as psycho-socially vulnerable and had difficulty prioritising the child's health needs, for example resulting in delayed presentation with suspected CRBSI.

The number of children with CRBSI according to IF diagnosis was 8/13 (61,5%) with SBS, 4/18 (22,2%) with motility disorders, 2/6 (33,3%) with mucosal disorders, 2/4 (50%) with neurological disability, 1/7 (14,3%) with immune-onco-haematologic disorders.

Overall CRBSI rate was 1,17/1000 catheter days, not significantly lower than the previous rate of infection ($p = 0.69$).

The CRBSI rate was 1,92/1000 catheter days for SBS, 1,36/1000 catheter days for motility disorders, 0,97/1000 catheter days for mucosal disorders, 0,61/1000 catheter days for immune-onco-haematologic disorders, 1,51/1000 catheter days for neurological disability. Among the vulnerable children, CRBSI rate was 3,86/1000 catheter compared to a rate of 1,17/1000 catheter days for all patients, ($p=0.001$).

One of the two children who had 3 episodes of CRBSI, had a cutaneous granuloma at the CVC exit site, and both were SBS patients from vulnerable families.

In summary, our overall CRBSI rate of 1,17/1000 catheter days was lower than the rate of 1,88/1000 catheter days reported previously and there was a significant association with a higher CRBSI rate in patients with vulnerable families. In conclusion, particular attention should be paid to children from families known to have difficulties in managing their child's care, since they appear to be at greater risk of septicaemia.

Table 1. Characteristics of children in the home PN programme

	n	%
Patients	48	
Females	22	45,8
Median age	11,5	
25th Q.I age	7,5	
75th Q.I. age	16	
SBS	13	27,1
Motility	18	37,5
Mucosal	6	12,5
Immuno-Haem-Onco	7	14,6

Neuro-disability	4	8,3
Vulnerable families*	10	20,8
CVC care with gloves	22	45,8
Single lumen	40	83,3
Taurolock	31	64,6

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

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OC92

Single centre experience of parenteral nutrition in patients with Mitochondrial Neurogastrointestinal Encephalomyopathy (MNGIE) after liver transplant by Kirn Sandhu, Enes Coskun, Sabrina Gurung, Kate O'Leary, Jonathan Hind, Harween Dogra, *King's College Hospital NHS Trust, UK.*

Mitochondrial neurogastrointestinal encephalomyopathy (MNGIE) is a rare condition characterised by gastrointestinal dysmotility and neurological manifestations such as ptosis, external ophthalmoplegia, peripheral neuropathy and leukoencephalopathy. It is caused by mutations in the TYMP (thymidine phosphorylase) gene resulting in toxic levels of plasma thymidine causing deoxyribonucleoside imbalances impairing DNA replication and over-time disabling mitochondrial function. It typically occurs in the second decade and patients usually die from severe malnutrition and gastrointestinal (GI) complications.

Current therapeutic strategies aim to normalise metabolic derangement by removing toxic metabolites or restoring thymidine phosphorylase activity. Hepatic tissue has a high expression of thymidine phosphorylase therefore liver transplant (LT) may restore the biochemical imbalance.

We describe three patients with MNGIE who have undergone LT for chronic liver disease but have persistent gastrointestinal dysmotility resulting in intestinal failure requiring parenteral nutrition(PN). Two of the patients (A and B) are siblings with B having a more severe phenotype. Attempts were made to feed the patients enterally via jejunal route but there were problems with recurrent nasojejunal, gastro-jejunal tubes displacement likely due to dysmotility and poor feed tolerance (high gastrostomy losses, vomiting and abdominal pain).

Table: Demographics of MNGIE patients

Patient	Age	Sex	Weight/BMI (Z-score)	Age at LT	Pre-transplant nutrition	Enteral intake post transplant	PN composition
A	16yrs	F	27.7kg/ 12.75kg/m^2 (Z: -5.20)	15yrs	Normal diet, fortisips	3 meals a day, snacks plus 100-200mls fortisips	1600ml over 12hrs PN 4 nights a week, nitrogen 0.28g/kg/day glucose 6.9g/kg/day, lipid 1.1g/kg/day, PN providing 57% of EAR
B	13yrs	M	23.5kg 11.1kg/m^2 (Z: -6.67)	12yrs	Normal diet (trialled NG feeds, 250mls of Paediasure Compact with poor tolerance)	1 meal a day (chicken and rice)	600ml over 18hrs nitrogen 0.39g/kg/day, glucose: 9.6g/kg/day, lipid 1.5g/kg/day (4x week) PN providing 102% of EAR
C	18yrs	M	41.6kg/ 14.7kg/m^2 (Z: -4.04)	17yrs	1300ml Nutrini peptisorb energy with vitajoule via NG tube	1 bottle of Peptisip, orange juice, fizzy drinks, food intake can be 2-3 meals a day	PN volume varies from lipid to non lipid days 2100/1700mls nitrogen 0.25g/kg/day, glucose 8g/kg/day, lipid 0.3g/kg/day (3x week) PN providing 72% of EAR

(NG:nasogastric, EAR:estimated average requirement)

MNGIE patients are known to have hyperlipidaemia, this maybe because the lipid components are metabolised by the mitochondrion. All three patients experienced hypertriglyceridaemia requiring tailored PN with reduced lipids. Triglyceride levels during PN ranged from 0.74 to 21.7mmol/l. Patient B had pancreatitis, likely secondary to hypertriglyceridaemia.

Reduced calorie delivery, while managing hypertriglyceridaemia even with PN manages to maintain nutritional status but no catch up weight or normalisation of Z-score has been demonstrated since LT. Patient B and C have developed insulin dependent diabetes since LT. All 3 patients have established some oral intake, however there is limited progress with enteral intake meeting calorie requirements.

In MNGIE patients, despite undergoing LT, GI symptoms persist and these patients require PN. However, managing PN is challenging due to hyperlipidaemia and hyperglycaemia with no improvement in nutritional status or tolerance of enteral feeding. In our experience LT has not reversed intestinal failure.

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