



Report of the results for the national clinical audit of paediatric inflammatory bowel disease inpatient care in the UK

February 2012

National Report – Version 2

Prepared by the UK IBD Audit Steering Group on behalf of:



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Acknowledgements

The UK IBD Audit Steering Group would like to thank all hospital staff who contributed towards organising the collection, retrieval and inputting of data including clinical audit, information technology and clinical coding staff in addition to the members of the multidisciplinary clinical teams working in support of paediatric IBD patients.

The Royal College of Physicians of London and the UK IBD Audit Steering Group (Appendix 3) would like to also thank and acknowledge all who have participated in the piloting and development of the audit. We would also like to acknowledge the input from participating NHS hospitals for their helpful suggestions and comments on ways to improve the audit following the 2008 round of paediatric data collection.

The web based data collection tool was developed by Netsolving Ltd.

Thanks are due to the many people who have participated in the UK paediatric IBD audit (2010). The UK IBD Audit Steering Group recognises that this has involved many individuals spending time over and above an already heavy workload with no financial recompense.

Thanks are also due to:

- The Association of Coloproctology of Great Britain and Ireland
- The British Dietetic Society
- The British Society of Gastroenterology
- The British Society of Paediatric Gastroenterology, Hepatology and Nutrition
- Crohn's and Colitis UK
- The Primary Care Society for Gastroenterology
- The Royal College of Nursing Crohn's and Colitis Special Interest Group
- Royal College of Physicians
- The Royal Pharmaceutical Society of Great Britain

The UK IBD audit 3rd Round is commissioned by:

- The Health Quality Improvement Partnership
- Health Improvement Scotland

Section 1: Executive summary

Background

The Inflammatory Bowel Diseases, ulcerative colitis (UC) and Crohn's disease (CD), are common causes of gastrointestinal morbidity. The total cost of IBD to the NHS has been estimated at £720 million, based on an average cost of £3,000 per patient per year with up to half of total costs for relapsing patients¹. Up to 25% of cases will present in childhood years with a marked rise in incidence of paediatric IBD noted in the UK over the past few decades.

The [UK Inflammatory Bowel Disease audit 1st Round](#) was the first UK-wide audit performed within gastroenterology care for adults. It demonstrated a marked variation in the resources and quality of care for adult IBD patients across the UK with particular deficits in some fundamental aspects of IBD care. Following the 1st Round members of the UK IBD Audit Steering Group met with representatives of the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and agreed to include paediatric gastroenterology in the 2nd audit round so that the UK IBD audit could become a truly comprehensive audit encompassing IBD patients of all ages, this 3rd round of the audit provides the first opportunity to compare paediatric inpatient care over time.

Results from the first round of the audit were a catalyst for the development of the National Service Standards for the healthcare of people who have Inflammatory Bowel Disease (IBD) that were published in February 2009: (<http://www.ibdstandards.org.uk>). These Standards were developed for IBD patients of all ages by a collaboration of six health professional societies (including BSPGHAN) and Crohn's and Colitis UK, the IBD patients' organisation. The aim of the National IBD Service Standards is to ensure that IBD patients receive consistent, high-quality care and that IBD Services throughout the UK are knowledge-based, engaged in local and national networking, based on modern IT and meet specific minimum standards, this 3rd round of audit has used the standards as a basis for measurement wherever possible (with specific reference to Standard A12 for the purposes of this report).

Overall summary

Paediatric IBD Services took part in their second round of clinical audit as part of the UK IBD audit in 2010. This report is testament to the continued engagement of paediatric gastroenterology in the audit and offers the first opportunity to compare changes across rounds at a national level as well as offering the individual services the opportunity to both compare themselves against the national picture and identify changes at a local level between the two audits.

The UK IBD Audit Steering Group published the National Report of the Organisation of Paediatric IBD Services in the UK in May 2011, highlighting that between 2008 and 2010 there had been a significant increase in the median number of paediatric IBD nurses within each paediatric IBD Service. It is encouraging to see that this clinical audit report has shown a corresponding highly significant increase in the total number of paediatric inpatients being seen by an IBD nurse during their admission. Also worthy of note is the fact that readmission rates have fallen in both UC and CD between the 2008 and 2010 rounds of audit for paediatric IBD patients.

The deficiencies in the collection of stool samples for Standard Stool cultures (SSC) identified in the 2008 clinical audit report have improved significantly for patients admitted with ulcerative colitis and more steadily for those admitted with Crohn's disease.

Laparoscopic surgery is more common in 2010 than in 2008, with a significant increase in non-elective CD cases being undertaken this way. Rates of anticoagulation have improved for patients with both ulcerative colitis and Crohn's disease.

This report also shows that there is work to be done by the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) to address the poor levels of recording the pubertal status of patients with Crohn's disease and to encourage the widespread adoption of the

Paediatric Ulcerative Colitis Activity Index (PUCAI) in order to inform the management of acute severe ulcerative colitis.

This audit has provided a large amount of useful contemporary data for each participating paediatric IBD Service to compare with other UK sites. It will also allow them to identify and address any areas where they may be falling short of professionally agreed IBD standards and guidelines²

Two key action points follow:

- Health departments in England, Northern Ireland, Scotland and Wales must support future rounds of the UK IBD audit to ensure that quality improvement in paediatric IBD care is continued
- All NHS Trusts/Health Boards should review their local audit results in relation to the recognised standards and guidelines² and take any necessary action to continue improving their paediatric IBD Service.

Key results

The key results detailed below in Table 1 show corresponding results from the 2008 and 2010 rounds of the UK IBD audit, wherever directly comparable. These data were compiled by comparing only the results from the 22 sites that took part in both these rounds (ensuring that they also had the same site composition). The last two rows in bold font in both the UC and CD key findings refer to questions asked only in the 2010 round of audit and therefore use the full 2010 case cohort. The figures shown within the tables indicate the percentage and number where the response was 'yes' to the question. Statistically significant change is indicated by an asterix (*) in the 2010 data column

Table 1: Key results for paediatric IBD care across 2 rounds of the UK IBD audit

		Ulcerative colitis	
		2008 248 comparable cases of which 215 were non-elective	2010 173 comparable cases of which 150 were non-elective
Were Standard Stool culture (SSC) and Clostridium Difficile Toxin (CDT) samples requested in non-elective patients with diarrhoea recorded during the first full day following admission?		SSC 48.3% (71/147) CDT 32.7% (48/147)	SSC 71.1% (86/121) * CDT 46.3% (56/121)
Did the patient see an IBD nurse during the admission? (In non-elective patients)		61.9% (133/215)	70.7% (106/150)
Did the patient have a previous admission in the last 2 years (in patients with a pre-admission diagnosis)		71.2% (111/156)	60.6% (60/99)
Was prophylactic Heparin prescribed? (In non-elective patients)		2.3% (5/215)	10% (15/150) *
If the patient underwent surgery, was it undertaken laparoscopically?	Non-Elective	27.3% (3/11)	36.4% (4/11)
	Elective	27.3% (9/33)	43.5% (10/23)
Was a PUCAI score recorded on Day 1 in emergency admissions?		Not asked	20% (13/66) Median score = 65
Did the patient experience a thrombotic episode during the admission?		Not asked	2% (3/176)

Crohn's disease			
		2008 350 comparable cases of which 297 were non-elective	2010 339 comparable cases of which 285 were non-elective
Were Standard Stool culture (SSC) and Clostridium Difficile Toxin (CDT) samples requested in non-elective patients with diarrhoea recorded during the first full day following admission?		SSC 41.5% (51/123) CDT 26.0% (32/123)	SSC 44.7% (88/197) CDT 31.3% (60/192)
Did the patient see an IBD nurse during the admission? (In non-elective patients)		58.3% (173/297)	71.6% (204/285) *
Did the patient have a previous admission in the last 2 years (in patients with a pre-admission diagnosis)		65.4% (159/243)	51.9% (123/237) *
Was prophylactic Heparin prescribed? (In non-elective patients)		2.0% (6/297)	3.9% (11/285)
If the patient underwent surgery, was it undertaken laparoscopically?	Non-Elective	8.8% (3/34)	35.7% (10/28) *
	Elective	28.9% (15/52)	27.5% (14/51)
Was the patient's weight measured during the admission? (In non-elective patients)		97.0% (288/297)	99.3% (283/285) *
Did a dietician see the patient? (In non-elective patients)		71.7% (213/297)	80.4% (229/285) *
Percentage of patients aged 12 and over that were not asked about their smoking status		55.0% (126/229)	52.1% (134/257)
Was pubertal status recorded in the 12 months prior to admission? (In patients aged 10 at the time of their last outpatient appointment)		Not asked	25% (59/237)
Did the patient experience a thrombotic episode during the admission?		Not asked	0.3% (1/342)

Table 2 – Key results for paediatric IBD care, 'UK results' versus 'Your Site' – 2010 only

Here you are able to identify 'your site' results for 2010 and compare them directly against the combined UK results from all of the 23 paediatric specialist sites that participated in the 3rd Round of the UK IBD audit. To get the full view of how your site data compares against the complete 3rd round datasets see the full 2010 audit results (section 4)

Table 2: Key results for paediatric IBD care. UK results v Your Site 2010 only

Ulcerative colitis			
		2010 UK results 176 cases of which 153 were non-elective	Your Site 2010
Were Standard Stool culture (SSC) and Clostridium Difficile Toxin (CDT) samples requested in non-elective patients with diarrhoea recorded during the first full day following admission?		SSC 70% (88/126) CDT 45% (57/126)	
Did the patient see an IBD nurse during the admission? (In non-elective patients)		71% (109/153)	
Did the patient have a previous admission in the last 2 years (in patients with a pre-admission diagnosis)		61% (62/102)	
Was prophylactic Heparin prescribed? (In non-elective patients)		11% (20/176)	
If the patient underwent surgery, was it undertaken laparoscopically?	Non-Elective	42% (5/12)	
	Elective	43% (10/23)	
Was a PUCAI score recorded on Day 1 in emergency admissions?		20% (13/66) Median score = 65	
Did the patient experience a thrombotic episode during the admission?		2% (3/176)	

Crohn's disease			2010 UK results	Your Site 2010
			342 cases of which 288 were non-elective	
Were Standard Stool culture (SSC) and Clostridium Difficile Toxin (CDT) samples requested in non-elective patients with diarrhoea recorded during the first full day following admission?			SSC 41% (88/214) CDT 28% (60/214)	
Did the patient see an IBD nurse during the admission? (In non-elective patients)			72% (207/288)	
Did the patient have a previous admission in the last 2 years (in patients with a pre-admission diagnosis)			52% (124/238)	
Was prophylactic Heparin prescribed? (In non-elective patients)			7% (24/342)	
If the patient underwent surgery, was it undertaken laparoscopically?	Non-Elective		36% (10/28)	
	Elective		27% (14/51)	
Was the patient's weight measured during the admission? (In non-elective patients)			99% (286/288)	
Did a dietician see the patient? (In non-elective patients)			81% (232/288)	
Percentage of patients aged 12 and over that were not asked about their smoking status			53% (136/259)	
Was pubertal status recorded in 12months prior to admission? (In patients aged over 10 at the time of the last outpatient appointment)			25% (59/237)	
Did the patient experience a thrombotic episode during the admission?			0.3% (1/342)	

Key findings

1. There has been a very positive increase in the numbers of paediatric IBD patients being seen by specialist paediatric IBD nurses during their admission
2. There is a significant increase in the rates of stool sample collection in UC patients
3. Prescription of prophylactic Heparin although increased remains low. Paediatric inpatients continue to experience thrombotic phenomenon during their admission
4. Only 20% (13/66) of ulcerative colitis patients admitted as an emergency had a Paediatric Ulcerative Colitis Activity Index (PUCAI) score recorded on Day 1 of their admission
5. There are more surgical procedures now being undertaken laparoscopically or laparoscopically-assisted
6. Readmission rates in the two years prior to the audited admission have fallen significantly in CD patients, with a numerical but not statistically significant fall also demonstrated for UC patients
7. The increase in inpatients being seen by a dietician would suggest that important dietary factors in CD are continuing to be given further emphasis in patient care.

Recommendations

1. As highlighted in the 2010 paediatric organisational audit report, 71% of sites do not have formal arrangements for annual review. The implementation at a national level, of an agreed systematic annual review would avoid the likelihood of routine data collection items such as smoking and pubertal status being overlooked.
2. The local policy for thrombus prevention (including use of heparin) in paediatric patients with IBD should be reviewed by each paediatric IBD service
3. In line with ESPGHAN/ECCO recommendations, every paediatric patient admitted as an emergency with ulcerative colitis should have a PUCAI score recorded on admission and daily thereafter as a guide to the need for medical rescue therapy or colectomy
4. Local hospitals should develop a practice where testing for Clostridium difficile toxin is routinely carried out alongside tests for SSC in all stool samples sent for IBD patients admitted with diarrhoea
5. All paediatric CD inpatients should have growth and nutrition reviewed during their admission to ensure that any growth faltering is not overlooked

Section 2: Background information and introduction

The burden of inflammatory bowel disease

Although ignored by the National Service Framework program, the Inflammatory Bowel Diseases, ulcerative colitis (UC) and Crohn's disease (CD), are common causes of gastrointestinal morbidity in the western world. The incidence of IBD has risen dramatically in recent decades with a combined incidence now of over 400/100 000. It is estimated that up to 0.5% of European and North American populations are affected. IBD most commonly first presents in the second and third decade but much of the recent increase has been observed in childhood, notably with CD in children increasing 3 fold in 30 years. IBD is not curable, UC and CD are lifelong conditions following an unpredictable relapsing and remitting course. 25% of UC patients will require colectomy and approximately 80% of CD patients require surgery over their lifetime. The main symptoms are diarrhoea, abdominal pain and an overwhelming sense of fatigue but associated features such as arthritis, anal disease, fistulae, abscess and skin problems can also contribute to a poor quality of life. In addition, there are wide ranging effects on growth and pubertal development, psychological health, education and employment, family life and pregnancy and fertility. Effective multidisciplinary care can attenuate relapse, prolong remission, treat complications and improve quality of life.

UK IBD audit aims

The UK IBD audit seeks to improve the quality and safety of care for all IBD patients in hospitals throughout the UK by auditing individual patient care and the provision and organisation of IBD service resources.

As with the 1st (adult only) and 2nd Round reports this UK paediatric IBD audit report (2010) enables each participating site to compare or benchmark their performance against national statistics. Following the previous rounds of the audit the UK IBD Audit Steering Group looked to develop intervention strategies to improve the provision and quality of IBD patient care. This comprised the widespread dissemination of results to participating sites through registered site clinical leads and hospital management. The results of all national reports were available publicly via the UK IBD audit web page within the Clinical Effectiveness and Evaluation Unit section of the Royal College of Physicians website. The UK IBD audit hosted well-attended regional meetings throughout the UK discuss the audit results following both previous rounds of the audit. Data from the both rounds was also presented at key professional and patient meetings including those of the British Society of Gastroenterology, Association of Coloproctology of Great Britain & Ireland, British Dietetic Association, Royal College of Nursing (IBD Nurse Forum) and Crohn's and Colitis UK.

A number of participating sites collaborated with members of the UK IBD Audit Steering Group to develop a model 'action plan' for IBD Services that addressed the key messages from the 1st round report. The model action plan was accessible via the internet and contained freely adaptable reference documents such as care pathways, model business cases for IBD clinical nurse specialist posts and patient information leaflets that could be downloaded and edited to meet local requirements. Visits to 23 randomly-selected hospitals that participated in the 1st round of the IBD audit were carried out, during which a clinical member of the IBD Audit Steering Group worked alongside the health professional team responsible for IBD care to develop an action plan for their IBD Service that would address areas identified in their 1st round site specific report as requiring improvement.

The specific aims of the UK IBD audit set out at the inception of the project were to:

1. Assess processes and outcomes of care delivery (inpatient and outpatient) in IBD
2. Enable Trusts to compare their performance against national standards
3. Identify resource and organisational factors that may account for observed variations in care
4. Facilitate, develop and institute an intervention strategy to improve quality of care.
5. Repeat the audit to prove that change has occurred
6. Establish measures for healthcare services to use to compare quality of IBD services
7. Develop a sustainability programme to maintain quality of care.

Further information on the work of the UK IBD audit project can be accessed via the [Clinical Effectiveness & Evaluation Unit section](#) of the Royal College of Physicians website.

Explanation of the 'Your Site' terminology appearing in this national report

For individual participating specialist paediatric gastroenterology sites these tables show data specific to their hospital, indicated as 'Your Site' compared against the combined 'national averages' for all of the specialist paediatric gastroenterology sites. In the case of this 'Generic Hospital Report' no data will appear under the 'Your Site' headings but these have been left in to show the format of the site reports received by the participating sites.

The full report is supported by the UK IBD Audit Steering Group.

Availability of audit results in the public domain

Full and executive summary copies of the UK IBD 3rd round national results for the clinical care of paediatric IBD patients in the UK will be available in the public domain via the Royal College of Physicians, London external website: www.rcplondon.ac.uk. The national report of results will be made available to the Department of Health in England, NHS Quality Improvement Scotland, NHS Wales Health & Social Care Department and the Department of Health, Social Services and Public Safety in Northern Ireland.

A limited number of key data results for each of the 23 individual sites participating in this round will be published in the public domain in section 5 of this report as agreed upon registration for this audit. These data items were agreed by the Steering Group as giving an indication of how individual sites are performing based on a selection of those data items considered to be key messages.

Section 3: Further highlighted results

Ulcerative colitis

Table 3. Displays all non-elective UC cases that received corticosteroids but failed to respond, identifies those that were then prescribed Ciclosporin or Anti TNF as rescue therapy (along with their response to this treatment) and whether or not they underwent surgery over the two rounds of audit

Table 3: Non-elective UC patients: response to steroids, prescription and response to Ciclosporin and Anti TNF and progression to surgery		
	2008	2010
Number of patients that received corticosteroids during their admission	78.6% (169/215)	76% (114/150)
Number of patients that failed to respond to corticosteroids	22.5% (38/169)	29% (33/114)
How many of the patients that failed to respond to corticosteroids, progressed to undergoing surgery during the admission?	26.3% (10/38)	18.2% (6/33)
If the patient was prescribed corticosteroids but failed to respond, how many were then prescribed Ciclosporin?	21.1% (8/38)	36.4% (12/33)
How many patients prescribed Ciclosporin responded to this treatment?	87.5% (7/8)	91.7% (11/12)
If the patient was prescribed corticosteroids but failed to respond, how many were then prescribed Anti TNF?	5.3% (2/38)	18.2% (6/33)
How many patients prescribed Anti TNF responded to this treatment?	100% (2/2)	100% (6/6)

Table 4. Depicting section 3.2 of the UC 2010 proforma- steroid therapy in non-elective UC patients, with all responses from cases identified as 'new diagnosis' excluded.

Table 4: Section 3.2 Steroid therapy in all non-elective patients except 'new diagnoses' (n=106)		National results 2010 Excluding New Diagnosis	
		N	%
3.2.1	Were corticosteroids administered during this admission?	76/106	72%
	a) iv corticosteroids initially prescribed	59/76	78%
	b) oral corticosteroids initially prescribed	17/76	22%
3.2.2	Which of the following steroids were prescribed?		
	a) Prednisolone	19/76	25%
	b) Methylprednisolone	37/76	49%
	c) Budesonide	0/76	0%
	d) Hydrocortisone	20/76	26%
3.2.2i	Initial dose (mg/day)	Median 60	IQR 36 - 90
3.2.2ii	Time between admission and initiation	0	0 - 1
3.2.2iii	Was therapy increased during this admission?	N 8/76	% 11%
3.2.2iv	Time between initiation and increase	Median 3	IQR 1 - 7
3.2.3	Did the patient respond to corticosteroids and not require any other significant therapy for ulcerative colitis?	52/76	68%

Crohn's disease

Response rates to Anti TNF when prescribed during admission in CD

Table 5. Represents all non-elective CD cases, where a patient was prescribed Anti TNF and their response rate to this treatment. This table excludes any patients recorded as being on Anti TNF on admission

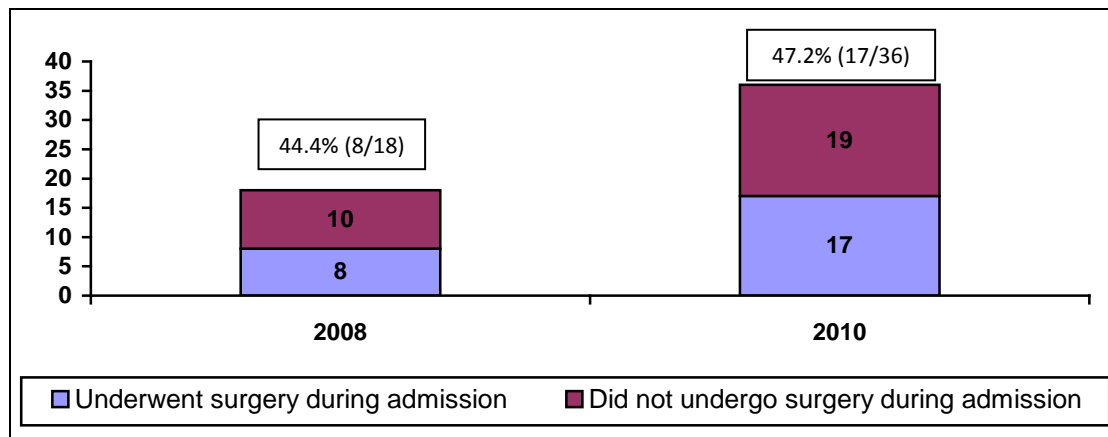
Table 5: Non-elective CD patients: prescription and response to Anti TNF in those prescribed Anti TNF as an inpatient		
	2008	2010
Number of cases where Anti TNF was prescribed during the admission?	3.5% (10/283)	7.7% (20/261) *
Number of patients that responded to Anti TNF treatment	Not asked	95% (19/20)

Use of immunomodulators in 2010

In 2010, on admission 43% (147/342) of all Crohn's disease patients were taking either: Azathioprine, Mercaptopurine or Methotrexate

Anti TNF prescription and progression to surgical intervention

Graph 1. Depicts the number CD patients recorded as being admitted on Anti TNF that then went on to have surgery, for both 2008 and 2010. Includes both elective and non-elective admissions



Recording of patient height during admission 2008 and 2010

Recording of patient height during admission has risen statistically significantly between the 2008 and 2010 rounds of audit. In 2008 29.3% (87/297) of inpatients had their height recorded during admission and in 2010 59.0% (168/285)

Combined data for both UC and CD

Seen by an IBD nurse during the admission

In 2008 60% (306/512) non-elective inpatients were seen by an IBD nurse during admission, in 2010 this had risen to 71% (310/435), giving a highly statistically significant increase between rounds of audit.

Surgery in 2008 and 2010

Table 6: Rates of elective and non-elective surgery undertaken in UC and CD patients 2008 and 2010 (in sites that participated in both rounds of audit)		
Ulcerative colitis		
	2008	2010
Number of cases where surgery was undertaken	17.7% (44/248)	19.7% (34/173)
Number of elective procedures	75% (33/44)	67.7% (23/34)
Number of non-elective procedures	25% (11/44)	32.4% (11/34)
Crohn's disease		
	2008	2010
Number of cases where surgery was undertaken	24.6% (86/350)	23.4% (79/338)
Number of elective procedures	60.5% (52/86)	64.6% (51/79)
Number of non-elective procedures	39.5% (34/86)	35.4% (28/79)

The UK IBD Audit Steering Group would welcome approaches via ibd.audit@rcplondon.ac.uk to join a writing group that will be established to produce academic papers from the data collected from this 3rd round of the UK IBD audit.

Suggested topics for further investigation of the audit data could include:

1. An investigation into the trends in treatment of acute severe ulcerative colitis between 2008 and 2010
2. An investigation into the demographics of IBD inpatients who experience thromboembolic phenomenon
3. An examination into the timeliness of surgical intervention in IBD patients: how are outcomes affected in cases with delayed surgical intervention
4. Laparoscopic versus non-laparoscopic surgery in IBD
5. An investigation into the medications provided to IBD inpatients
6. A correlation between the provision of an IBD nurse specialist and standards of treatment

Section 4: Full 2010 audit results

Clinical audit ulcerative colitis

2010 In total data were collected for **176** paediatric ulcerative colitis patients (from 23 sites) median (IQR) of 8 (3-10) per site, range 2-16.

PRE-SECTION PATIENT DEMOGRAPHICS (n=176)	National results 2010		YOUR SITE 2010
Auditor discipline	N	%	
Consultant	23/176	13%	
Other medical staff	105/176	60%	
Nurse	36/176	20%	
Manager	0/176	0%	
Clinical audit	14/176	8%	
Other	5/176	3%	
What was the patient's age at admission?	Median	IQR	
	13	10 - 13	
Gender	N	%	
Female	78/176	44%	
Male	98/176	56%	

SECTION 1: ADMISSION / MORTALITY

1.1	ADMISSION (n=176)	National results 2010		YOUR SITE 2010
1.1.2	What was the primary reason for admission?	N	%	
	a) Emergency admission for active ulcerative colitis	66/176	38%	
	b) Planned admission for active ulcerative colitis	26/176	15%	
	c) Elective admission for surgery	22/176	13%	
	d) New diagnosis of ulcerative colitis	47/176	27%	
	e) Transferred from another site for surgery	1/176	0.6%	
	f) Transferred from another site for further medical management	14/176	8%	
The rest of this table excludes elective admissions ie those where options c) or e) were chosen in Q1.1.2 n=153				
1.1.3	Which specialty was responsible for the patient's care 24 hours after admission?	N	%	
	a) Acute Medicine	6/153	4%	
	b) Paediatric gastroenterology	130/153	85%	
	c) Paediatric Surgery	3/153	2%	
	d) General paediatrics within a paediatric GI Network	8/153	5%	
	e) Adult Surgery	0/153	0%	
	f) Colorectal Surgery	1/153	0.7%	
	g) General paediatrics	4/153	3%	
	h) Other	1/153	0.7%	
1.1.4	What date was the patient first seen by a consultant paediatric gastroenterologist?	N	%	
	Number of patients seen	147/153	96%	
	Days from admission (if seen)	Median	IQR	
		0	0 - 1	
	Not seen	N	%	
		4	3%	
	Not required	2	1%	
1.1.5	What date was the patient first seen by a consultant colorectal paediatric surgeon?	N	%	

Number of patients seen	20/153	13%	
	Median	IQR	
Days from admission (if seen)	2	1 - 4	
	N	%	
Not seen	39	25%	
Not required	94	61%	
Not seen by either consultant gastroenterologist or consultant colorectal surgeon (patients noted as 'not required' have been removed from this calculation)	3/152	2%	
1.1.6 Was the patient seen by a paediatric IBD nurse specialist during the admission?	109/153	71%	
1.1.7 Was the patient transferred to a specialist paediatric gastroenterology ward?	48/153	31%	
1.1.7i If yes, which type of ward?			
a) Medical	19/48	40%	
b) Joint Medical/Surgical	28/48	58%	
c) Surgical	1/48	2%	

1.2 COMORBIDITY (n=176)	National results 2010		YOUR SITE 2010
	N	%	
1.2.1 Did the patient have any significant co-morbid diseases?			
a) Respiratory	1/176	0.6%	
b) Stroke	1/176	0.6%	
c) Liver Disease	18/176	10.2%	
d) None	135/176	76.7%	
e) Other	22/176	12.5%	

Other included: Allergic Rhino / Arachnoid cyst / Arginase deficiency / Autism / Cerebral Palsy / Coeliac disease x2 / 'Confidential' / Cow's milk protein allergy / Cyclical vomiting / Cystoperitoneal shunt / Depression / Eczema / Epilepsy / Gall stones / Hereditary Spherocytosis / Learning difficulties / Microcephaly / Optic atrophy / Pancreatitis x2 / Polyarthrititis / Proximal myopathy / Scoliosis x2 / Spastic quadriplegia / Thyroid disease x2 / Ventricular Septal Defect

1.3 DISCHARGE / MORTALITY (n=176)	National results 2010		YOUR SITE 2010
	N	%	
1.3.1 Did the patient die during admission?	0/176	0%	
1.3.1i Days from admission (if died)	NA	NA	
1.3.1ii If yes, please write the cause of death	NA	NA	
1.3.1iv Length of stay (if discharged)	Median	IQR	
	6	3 - 10	
1.3.1v Discharge destination	N	%	
a) Discharged home	173/176	98%	
b) Transferred to another site for surgery	0/176	0%	
c) Transferred to another site for further medical management	3/176	2%	

SECTION 2: ASSESSING THE EXTENT OF ULCERATIVE COLITIS

Tables in Section 2 exclude elective patients ie those that were indicated as Q1.1.2 a) or e)

2.1 PATIENT HISTORY (n=153)	National results 2010		YOUR SITE 2010
	N	%	
2.1.1 Did the patient have a pre-admission diagnosis of ulcerative colitis?	102/153	67%	
2.1.2 What was the extent of the colitis?			
a) Proctitis (E1)	7/102	7%	
b) Left sided (E2)	10/102	10%	

	c) Extensive (E3)	8/102	8%	
	d) Pan Colitis (E4)	73/102	72%	
	e) Unknown	4/102	3%	
2.1.3	Has the patient had previous admissions with ulcerative colitis in the two years prior to this admission?	62/102	61%	
2.1.3i	Number of admissions in the two years prior to this admission?	Median 2	IQR 1 - 3	

2.2	SEVERITY OF DISEASE (n=153)	National results 2010		YOUR SITE 2010
2.2.1	How many loose or bloody stools were passed in the first full day following admission?	N	%	
	No loose or bloody stools	5/153	3%	
	1 or more loose or bloody stools	126/153	82%	
		Median	IQR	
		5	2 - 8	
		N	%	
	NA	6/153	4%	
	Not documented	16/153	10%	
2.2.2	What was the highest recorded pulse rate during the first full day following admission? (BPM)	103	90 - 118	
	Not documented	1	0.7%	
2.2.3	What was the highest temperature recorded during the first full day following admission? (°C)	37.1	36.9 - 37.5	
	Not documented	1	0.7%	
	In patients with 1 or more loose or bloody stools (Q2.2.1)	N	%	
2.2.4	Was a stool sample sent for Standard Stool Culture?	88/126	70%	
	No	35/126	28%	
	NA	3/126	2%	
		Median	IQR	
2.2.4i	Days from admission until sample sent	0	0 - 1	
		N	%	
2.2.4ii	Was it positive?	2/88	2%	
		Median	IQR	
2.2.4iii	Days between sample sent and reported positive	5	4-5	
	In patients with 1 or more loose or bloody stools (Q2.2.1)	N	%	
2.2.5	Was a stool sample sent for CDT?	57/126	45%	
	No	66/126	52%	
	NA	3/126	2%	
		Median	IQR	
2.2.5i	Days from admission until sample sent	0	0 - 1	
		N	%	
2.2.5ii	Was it positive?	0/57	0%	
2.2.5iii	Days between sample sent and reported positive	NA	NA	

2.3	MONITORING OF COLITIS - RADIOLOGY (n=153)	National results 2010		YOUR SITE 2010
2.3.1	Was a plain abdominal X-Ray performed?	N	%	
		45/153	29%	
		Median	IQR	
2.3.1i	Days from admission to request	0	0 - 2	
2.3.1ii	Days from request to x-ray	0	0 - 0	
2.3.1iii	Days from x-ray to report by radiologist	1	0 - 1	

2.3.2	Was toxic megacolon present in the x-ray?	N	%	
		2/45	4%	
2.3.2i	Was a repeat x-ray or CT Scan or MRI Scan performed?	0/2	0%	
2.3.2ii	Days from original x-ray reported to repeat x-ray	NA	NA	

SECTION 3: MEDICAL INTERVENTIONS

3.1	USE OF ANTITHROMBOTIC THERAPY (n=176)	National results 2010		YOUR SITE 2010
		N	%	
3.1.1	Did the patient have a thrombotic episode during this admission?	3/176	2%	
3.1.2	Was the patient given prophylactic heparin?	20/176	11%	

Section 3.2 excludes elective patients ie those that were indicated as Q1.1.2 a) or e)

3.2	STEROID THERAPY (n=153)	National results 2010		YOUR SITE 2010
		N	%	
3.2.1	Were corticosteroids administered during this admission?	116/153	76%	
	a) iv corticosteroids initially prescribed	89/116	77%	
	b) oral corticosteroids initially prescribed	27/116	23%	
3.2.2	Which of the following steroids were prescribed?			
	a) Prednisolone	29/116	25%	
	b) Methylprednisolone	54/116	47%	
	c) Budesonide	0/116	0%	
	d) Hydrocortisone	33/116	28%	
3.2.2i	Initial dose (mg/day)	Median	IQR	
		60	40 - 100	
3.2.2ii	Days between admission and initiation	N	%	
		1	0 - 2	
3.2.2iii	Was therapy increased during this admission?	N	%	
		11	9%	
3.2.2iv	Days between initiation and increase	Median	IQR	
		2	0 - 5	
3.2.3	Did the patient respond to corticosteroids and not require any other significant therapy for ulcerative colitis?	81/116	70%	

3.3	WHICH OTHER THERAPIES DID THE PATIENT RECEIVE? n=72	National results 2010		YOUR SITE 2010
	The findings below (Q3.3.1-Q3.3.4) have been calculated to include the 35 cases where corticosteroids were prescribed but there was no response to this treatment (Q3.2.3) and the 37 cases where a patient was not recorded as receiving corticosteroids (Q3.2.1) n=72			
		N	%	
3.3.1	Received Ciclosporin therapy	12/72	17%	
3.3.1ii	Did the patient respond?	11/12	92%	
		Median	IQR	
3.3.1i	Days between admission and starting treatment	5	1 - 10	
3.3.2	Received Anti TNF therapy	N	%	
		9/72	13%	
3.3.2ii	Did the patient respond?	8/9	89%	
		Median	IQR	
3.3.2i	Days between admission and starting treatment	3	3 - 8	
3.3.3	Received therapy as part of a clinical trial	N	%	
		0/72	0%	
3.3.3ii	Days between admission and starting treatment	NA	NA	

3.3.3iii	Did the patient respond?	NA	NA	
		N	%	
3.3.4	Received other significant therapy	42/72	58%	
3.3.4ii	Did the patient respond?	32/42	76%	

3.4	RESPONSE TO TREATMENT (n=153)	National results 2010		YOUR SITE 2010
3.4.1	Day 1 PUCAI score Where LOS = ≥ 0 days (n=153)	Median	IQR	
		65	50 - 70	
		N	%	
	Completed	29/153	19%	
	NA	13/153	9%	
	Not documented	111/153	73%	
3.4.2	Day 3 PUCAI score Where LOS = ≥ 2 days (n=135)	Median	IQR	
		50	20 - 55	
		N	%	
	Completed	23/135	17%	
	NA	19/135	14%	
	Not documented	93/135	69%	
3.4.3	Day 5 PUCAI score Where LOS = ≥ 4 days (n=104)	Median	IQR	
		30	25 - 55	
		N	%	
	Completed	15/104	14%	
	NA	13/104	13%	
	Not documented	76/104	73%	
3.4.4	Discharge PUCAI score Where LOS = ≥ 0 days (n=153)	Median	IQR	
		25	15 - 30	
		N	%	
	Completed	19/153	12%	
	Not documented	107/153	70%	
	NA	27/153	18%	

SECTION 4: SURGICAL INTERVENTIONS

Site level results will be provided split by elective and emergency admissions based on admission reason provided in Q1.1.2. Cases noted as transferred to another site for surgery are excluded (Q1.3.1v) from all of the Section 4 tables

4.1	SURGICAL THERAPY n=176	ELECTIVE ADMISSIONS		NON-ELECTIVE ADMISSIONS	
		N	%	N	%
4.1.1	Did the patient have surgery on this admission?	23/23	100%	12/153	8%
		Median	IQR	Median	IQR
4.1.2	Days between admission and surgical decision	-42	-80, -15	1	0 - 10
4.1.3	Days between admission and surgery	1	0 - 1	2	2 - 11
4.1.4	Was there a delay of more than 24 hours between decision to operate and surgery for non-elective patients?	N	%	N	%
		3/23	13%	2/12	17%
4.1.4i	Reason for delay	N	%	N	%
	a) Improvement in severity of UC	0/3	0%	0/2	0%
	b) Cancelled due to lack of theatre time	0/3	0%	1/2	50%
	c) Cancelled for other clinical reasons	0/3	0%	1/2	50%
	d) Patient declined surgery or needed time to consider	0/3	0%	0/2	0%
	e) Other	3/3	100%	0/2	0%
4.1.5	Was the patient seen by a stoma nurse during this admission?	13/23	57%	8/12	67%

	Median	IQR	Median	IQR
4.1.5i Days between admission and seeing stoma nurse	1	0 – 3	5	2 - 14
4.1.6 What was the grade of the senior surgeon present during surgery?	N	%	N	%
a) Consultant paediatric surgeon	17/23	74%	7/12	58%
b) Consultant colorectal surgeon	5/23	22%	3/12	25%
c) Consultant CI surgeon (non-colorectal)	0/23	0%	0/12	0%
d) Consultant General surgeon	0/23	0%	0/12	0%
e) Other consultant surgeon	0/23	0%	0/12	0%
f) Specialist registrar	0/23	0%	0/12	0%
g) Other	1/23	4%	2/12	17%
4.1.7 What were the indications for surgery?	N	%	N	%
a) Failure of Medical Therapy	10/23	44%	8/12	67%
b) Toxic megacolon	0/23	0%	3/12	25%
c) Bleeding	3/23	13%	5/12	42%
d) Obstruction	0/23	0%	0/12	0%
e) Completion Proctectomy	2/23	9%	1/12	8%
f) High Grade Dysplasia	0/23	0%	0/12	0%
g) Low Grade Dysplasia	0/23	0%	0/12	0%
h) Ungraded Dysplasia	0/23	0%	0/12	0%
i) Cancer	0/23	0%	0/12	0%
j) Perforation	0/23	0%	0/12	0%
k) Abscess	0/23	0%	0/12	0%
l) Formation of Ileostomy	3/23	13%	1/12	8%
m) Closure of stoma	7/23	30%	0/12	0%
n) Other indication	4/23	17%	3/12	25%
4.1.8 Type of intervention	N	%	N	%
a) Subtotal colectomy	10/23	43%	8/12	67%
b) Proctocolectomy	0/23	0%	0/12	0%
c) Proctectomy	0/23	0%	0/12	0%
d) Ileoanal pouch with stoma	5/23	22%	0/12	0%
e) Ileoanal pouch without stoma	1/23	4%	0/12	0%
f) Formation of Ileostomy	7/23	30%	4/12	33%
g) Other	8/23	35%	4/12	33%
4.1.8i Was the surgery done laparoscopically / laparoscopically-assisted?	N	%	N	%
	10/23	43%	5/12	42%
4.1.9 Was the ASA status recorded pre-operatively?	N	%	N	%
Yes	7/23	30%	8/12	67%
1	1/7	14%	0/12	0%
2	4/7	57%	5/12	63%
3	1/7	14%	2/12	25%
4	1/7	14%	1/12	13%
5	0/7	0%	0/12	0%
NA	0/7	0%	0/12	0%

4.2 SURGICAL COMPLICATIONS	ELECTIVE ADMISSIONS		NON-ELECTIVE ADMISSIONS	
	N	%	N	%
4.2.1 Did the patient suffer from any of these complications following their surgery?				
a) Wound Infection	1/23	4%	1/12	8%
b) Rectal stump complications	0/23	0%	0/12	0%
c) Intra-abdominal bleeding	0/23	0%	0/12	0%
d) Intra-abdominal sepsis	1/23	4%	1/12	8%
e) Anastomotic leakage	0/23	0%	1/12	8%
f) Stoma complications	0/23	0%	0/12	0%
g) Deep vein thrombosis	0/23	0%	0/12	0%

h) Pulmonary embolus	0/23	0%	0/12	0%
i) Ileus requiring TPN	1/23	4%	0/12	0%
j) Small bowel obstruction	2/23	9%	1/12	8%
k) Cardiac	0/23	0%	0/12	0%
l) Respiratory	0/23	0%	0/12	0%
m) Clostridium difficile-associated diarrhoea	0/23	0%	0/12	0%
n) No Complications	16/23	70%	9/12	75%
o) Other	6/23	26%	2/12	17%

SECTION 5: DISCHARGE ARRANGEMENTS

Section 5 excludes any deceased patients and those recorded as transferred to another site for surgery or further medical management in Q1.3.1

5.1	DISCHARGE ARRANGEMENTS (n=173)	National results 2010		YOUR SITE 2010
		N	%	
5.1.1	Was the patient taking oral steroids on discharge?	123/173	71%	
5.1.2	Was a steroid reduction programme stated on discharge? In patients discharged on steroids	105/123	85%	
5.1.3	Were bone protection agents prescribed? In patients discharged on steroids	33/123	27%	
5.1.4	Was patient on immunosuppressives on discharge?	75/173	43%	
5.1.5	Was there a plan for maintenance Anti TNF on discharge?	11/173	6%	

Clinical audit Crohn's disease

2010 In total data were collected for **342** Crohn's disease patients (from 23 sites) median (IQR) of 16 (11-20) per site, range 1-25.

PRE-SECTION PATIENT DEMOGRAPHICS (n=342)	National results 2010		YOUR SITE 2010
Auditor discipline	N	%	
Consultant	26/342	8%	
Other medical staff	201/342	59%	
Nurse	92/342	27%	
Manager	0/342	0%	
Clinical audit	20/342	6%	
Other	21/342	6%	
What was the patient's age at admission?	Median	IQR	
	13	12 - 15	
Gender	N	%	
Female	125/342	37%	
Male	217/342	63%	

SECTION 1: ADMISSION / MORTALITY

1.1 ADMISSION	National results 2010		YOUR SITE 2010
1.1.2 What was the primary reason for admission?	N	%	
a) Emergency admission for active Crohn's disease	92/342	27%	
b) Planned admission for active Crohn's disease	72/342	21%	
c) Elective admission for surgery	51/342	15%	
d) New diagnosis of Crohn's disease	107/342	31%	
e) Transferred from another site for surgery	3/342	0.9%	
f) Transferred from another site for further medical management	17/342	5%	
The rest of this table excludes elective admissions ie those where options c) or e) were chosen in Q1.1.2 n=288			
1.1.3 Which specialty was responsible for the patient's care 24 hours after admission?	N	%	
a) Acute Medicine	6/288	2%	
b) Paediatric gastroenterology	251/288	87%	
c) Paediatric Surgery	14/288	5%	
d) General paediatrics within a paediatric GI network	5/288	2%	
e) Adult gastroenterology	2/288	0.7%	
f) Colorectal Surgery	1/288	0.4%	
g) General paediatrics	9/288	3%	
h) Other	0/288	0%	
1.1.4 What date was the patient first seen by a consultant paediatric gastroenterologist?	N	%	
Number of patients seen	279/288	97%	
Days from admission (if seen)	Median	IQR	
	1	0 - 1	
Not seen	N	%	
	5/288	2%	
Not required	4/288	1%	

1.1.5	What date was the patient first seen by a consultant paediatric surgeon?	N	%	
	Number of patients seen	48/288	17%	
	Days from admission (if seen)	Median 1	IQR 0 - 5	
	Not seen	N 78/288	% 27%	
	Not required	162/288	56%	
	Not seen by either consultant gastroenterologist or consultant colorectal surgeon (patients noted as 'not required' have been removed from this calculation)	5/286	2%	
1.1.6	Was the patient seen by a paediatric IBD nurse specialist during the admission?	207/288	72%	
1.1.7	Was the patient transferred to a specialist paediatric gastroenterology ward?	100/288	35%	
1.1.7i	If yes, which type of ward?			
	a) Medical	41/100	41%	
	b) Joint Medical/Surgical	58/100	58%	
	c) Surgical	1/100	1%	

1.2	COMORBIDITY (n=342)	National results 2010		YOUR SITE 2010
1.2.1	Did the patient have any significant co-morbid diseases?	N	%	
	a) Respiratory	12/342	3.5%	
	b) Stroke	0/342	0%	
	c) Liver Disease	1/342	0.3%	
	d) None	311/342	90.9%	
	e) Other	18/342	5.3%	

Other included: ADHD / Arthritis x2 / Autism x2 / Brancho-oto-renal syndrome / Cerebral Palsy / Coeliac disease / Eczema / Epilepsy x2 / Growth hormone deficiency / Hereditary sensory motor neuropath / Juvenile idiopathic arthritis x2 / Langerhan's cell histiocytosis / Pancreatitis / Peanut allergy / Previous Non-hodgkins Lymphoma / Sjorgen's syndrome / SVT / Turner syndrome

1.3	DISCHARGE / MORTALITY (n=342)	National results 2010		YOUR SITE 2010
1.3.1	Did the patient die during admission?	N	%	
	1.3.1i Days from admission (if died)	0/342	0%	
	1.3.1iii Length of stay (if discharged)	NA	NA	
	1.3.1iv Discharge destination	Median 5	IQR 3 - 5	
	a) Discharged home	340/342	99%	
	b) Transferred to another site for surgery	1/342	0.3%	
	c) Transferred to another site for further medical management	1/342	0.3%	

1.4 MEDICATION ON ADMISSION (n=342)		National results 2010		YOUR SITE 2010
1.4.1	What treatment was the patient taking for Crohn's disease on admission?	N	%	
	a) 5-ASA	99/342	29%	
	b) Azathioprine	112/342	33%	
	c) Mercaptopurine	5/342	1%	
	d) Methotrexate	30/342	9%	
	e) Antibiotics	26/342	8%	
	f) Corticosteroids	69/342	20%	
	g) Dietary Therapy-Exclusive enteral liquid therapy	31/342	9%	
	h) Dietary Therapy-Supplemental enteral liquid therapy	22/342	6%	
	i) anti-TNF- α	37/342	11%	
	j) None	96/342	28%	
	k) Other	23/342	7%	
1.4.2	In the 12 months prior to admission was the patient taking steroids (at any time) for >3 months?	N	%	
1.4.2i	If yes, was an appropriate dose reduction planned?	51/54	94%	
1.4.2ii	If yes, was bone protection used?	15/51	28%	
1.4.2iii	Was a DEXA scan done?	4/54	7%	
1.4.2iv	Was a course of exclusive enteral nutrition administered in the past 12 months?	21/54	39%	

1.5 SMOKING STATUS (n=259) Only eligible for patients aged 12 and over		National results 2010		YOUR SITE 2010
1.5.1	What was the smoking status of the patient?	N	%	
	a) Current smoker	4/259	2%	
	b) Lifelong non-smoker/ ex-smoker	119/259	46%	
	c) Not documented	136/259	53%	

1.6 PATIENT HISTORY (n=342)		National results 2010		YOUR SITE 2010
1.6.1	Did the patient have a pre-admission diagnosis of Crohn's disease?	N	%	
		238/342	70%	
1.6.2	What was the extent of the disease?	N	%	
	a) Terminal ileum (L1)	64/238	27%	
	b) Colonic (L2)	81/238	34%	
	c) Ileo-colonic (L3)	115/238	48%	
	d) Perianal	60/238	25%	
	e) Oral	18/238	8%	
	f) Upper GI (L4)	85/238	36%	
	g) Not known	4/238	2%	
1.6.3	Has the patient had previous admissions to your hospital with Crohn's disease in the two years prior to this admission?	N	%	
		124/238	52%	
1.6.3i	Number of admissions in the two years prior to this admission?	Median	IQR	
		2	1 - 3	

SECTION 2: ASSESSING THE SEVERITY OF CROHN'S DISEASE

Elective cases [where in Q1.1.2 c) or e)] were chosen] are excluded from all of section 2

2.1 INITIAL ASSESSMENT DURING FIRST FULL DAY FOLLOWING ADMISSION (n=288)		National results 2010		YOUR SITE 2010
2.1.1	Number of liquid stools per day	N	%	
	No liquid stools	22/288	8%	
	≥1 liquid stools	214/288	74%	
		Median	IQR	
		4	2 - 6	
	Not documented	37/288	13%	
	Not required	15/288	5%	
2.1.2	General well being	N	%	
	Well	20/288	7%	
	Mild symptoms	50/288	17%	
	Moderate symptoms	157/288	55%	
	Severe symptoms	54/288	19%	
	Not documented	7/288	2%	
2.1.3	Abdominal pain	N	%	
	None	52/288	18%	
	Present	230/288	80%	
	Not documented	6/288	2%	
2.1.4	Abdominal mass	N	%	
	None	259/288	90%	
	Present	17/288	6%	
	Not documented	12/288	4%	
2.1.5	Did the patient report any of the following complications?	N	%	
	Mouth ulcers	43/288	15%	
	Arthralgia	37/288	13%	
	Pyoderma Gangrenosum	2/288	1%	
	Anal fissure	25/288	9%	
	Fistula	14/288	5%	
	Erythema Nodosum	14/288	5%	
	Abscess	12/288	4%	
	Iritis	0/288	0%	
Other	33/288	11%		
2.1.6	Admission results for	Median	IQR	
	2.1.6i CRP	38	12 - 78	
	Recorded	263/288	91%	
	Not documented	25	9%	
2.1.6ii	Hb	Median	IQR	
		10.9	9.7 - 12.3	
	Recorded	269/288	93%	
	Not documented	19	7%	
2.1.6iii	Albumin	Median	IQR	
		34	30 - 40	
	Recorded	259/288	90%	
	Not documented	29	10%	

2.2 EXCLUSION OF INFECTION (n=214) Section 2.2 includes only patients with 1 or more loose or bloody stools (Q2.1.1)		National results 2010		YOUR SITE 2010
2.2.1 Was a stool sample sent for Standard Stool Culture?		N	%	
Yes		88/214	41%	
No		110/214	51%	
NA		16/214	7%	
		Median	IQR	
2.2.1i Days from admission until sample sent		0	0 - 1	
		N	%	
2.2.1ii Was it positive?		2	2%	
		Median	IQR	
2.2.1iii Days between sample sent and reported positive		0	0 - 3	
2.2.2 Was a stool sample sent for CDT?		N	%	
Yes		60/214	28%	
No		133/214	62%	
NA		21/214	10%	
		Median	IQR	
2.2.2i Days from admission until sample sent		0	0 - 1	
		N	%	
2.2.2ii Was it positive?		2/60	3%	
		Median	IQR	
2.2.2iii Days between sample sent and reported positive		92	2 - 182	

2.3 WEIGHT ASSESSMENT AND DIETETIC SUPPORT DURING ADMISSION (n=288)		National results 2010		YOUR SITE 2010
		N	%	
2.3.1 Was the patient's weight measured during admission		286/288	99%	
2.3.1i Was BMI measured		47/286	16%	
2.3.1i Was height measured		171/288	60%	
2.3.2 Did a dietician see the patient?		232/288	81%	
2.3.3 Was dietary treatment initiated?		205/288	71%	
2.3.3i Was exclusive liquid enteral nutrition therapy prescribed?		153/205	75%	
2.3.3ii Was supplemental liquid enteral nutrition therapy prescribed?		64/205	31%	
2.3.4 Was parenteral nutrition given?		21/288	7%	

SECTION 3: MEDICAL INTERVENTIONS

3.1 USE OF ANTITHROMBOTIC THERAPY (n=342)		National results 2010		YOUR SITE 2010
3.1.1 Did the patient have a thrombotic episode during this admission?		N	%	
		1/342	0.3%	
3.1.2 Was the patient given prophylactic heparin?		24/342	7%	

Section 3.2 excludes elective cases [Where in Q1.1.2 option c) or e) were chosen]

3.2 STEROID THERAPY (n=288)		National results 2010		YOUR SITE 2010
3.2.1	Were corticosteroids administered during this admission?	N	%	
		103/288	36%	
	a) iv corticosteroids initially prescribed	67/103	65%	
	b) oral corticosteroids initially prescribed	36/103	35%	
3.2.2	Which of the following steroids were prescribed?	N	%	
	a) Prednisolone	33/103	32%	
	b) Methylprednisolone	4/103	4%	
	c) Budesonide	30/103	29%	
	d) Hydrocortisone	36/103	35%	
		Median	IQR	
3.2.2i	Initial dose (Mg/day)	50	30 - 100	
3.2.2ii	Days between admission and initiation	0	0 - 2	
		N	%	
3.2.2iii	Was therapy increased during this admission?	7/103	7%	
		Median	IQR	
3.2.2iv	Days between initiation and increase	3	0 - 12	

3.3 WHICH OTHER THERAPIES DID THE PATIENT RECEIVE (n=288)		National results 2010		YOUR SITE 2010
3.3.1	Received Anti TNF therapy	N	%	
		25/288	9%	
3.3.1ii	Did the patient respond?	24/25	96%	
		Median	IQR	
3.3.1i	Days between admission and starting treatment	5	3 - 16	
3.3.2	Received therapy as part of a clinical trial	1/288	0.4%	
3.3.2iii	Did the patient respond?	1	100%	
		Median	IQR	
3.3.2ii	Days between admission and starting treatment	0	0 - 0	
3.3.3	Received other significant therapy	82	28%	
3.3.3ii	Did the patient respond?	70	85%	
		Median	IQR	
3.3.3i	Days between admission and starting treatment	1	0 - 5	

SECTION 4: SURGICAL INTERVENTIONS

Section 4 excludes those cases recorded as transferred to another site for surgery in Q1.3.1

4.1 SURGICAL THERAPY (n=341)		ELECTIVE ADMISSIONS		Non-ELECTIVE ADMISSIONS	
4.1.1	Did the patient have surgery on this admission?	N	%	N	%
		51/53	94%	28/288	10%
4.1.2	Days between admission and surgical decision	Median	IQR	Median	IQR
		-22	-39, - 5	1	0 - 7
4.1.3	Days between admission and surgery	1	0 - 1	3	1 - 12
4.1.4	Was there a delay of more than 24 hours between decision to operate and surgery for non-elective patients?	N	%	N	%
		3/51	6%	6/28	21%
4.1.4i	Reason for delay	N	%	N	%
	a) Improvement in severity of Crohn's	0/3	0%	0/6	0%
	b) Cancelled due to lack of theatre time	0/3	0%	1/6	17%
	c) Cancelled for other clinical reasons	0/3	0%	1/6	17%

	d) Patient declined surgery or needed time to consider	0/3	0%	0/6	0%
	e) Other	3/3	100%	4/6	67%
4.1.5	Was the patient seen by a stoma nurse during this admission?	N	%	N	%
		10	20%	8	29%
4.1.5i	Days between admission and seeing stoma nurse	Median	IQR	Median	IQR
		0	0 – 1	13	9 - 23
4.1.6	What was the grade of the senior surgeon present during surgery?	N	%	N	%
	a) Consultant paediatric surgeon	36/51	71%	22/28	79%
	b) Consultant colorectal surgeon	13/51	25%	3/28	11%
	c) Consultant GI surgeon (non-colorectal)	0/51	0%	0/28	0%
	d) Consultant General surgeon	0/51	0%	0/28	0%
	e) Other consultant surgeon	0/51	0%	0/28	0%
	f) Specialist registrar	0/51	0%	2/28	7%
	g) Other	2/51	4%	1/28	4%
4.1.7	What were the indications for surgery?	N	%	N	%
	a) Failure of Medical Therapy	31/51	61%	9/28	32%
	b) Toxic megacolon	0/51	0%	0/28	0%
	c) Bleeding	1/51	2%	0/28	0%
	d, j or k) Obstruction, perforation or abscess	7/51	13.7%	16/28	57.1%
	e) Completion Proctectomy	0/51	0%	0/28	0%
	f) High Grade Dysplasia	0/51	0%	0/28	0%
	g) Low Grade Dysplasia	0/51	0%	0/28	0%
	h) Ungraded Dysplasia	0/51	0%	0/28	0%
	i) Cancer	0/51	0%	0/28	0%
	l) Formation of Ileostomy	5/51	10%	4/28	14%
	m) Closure of stoma	3/51	6%	0/28	0%
	n) Other indication	21/51	41%	10/28	36%
4.1.8	Type of intervention	N	%	N	%
	a) Segmental/Extended Colectomy	5/51	10%	2/28	7%
	b) Subtotal Colectomy	6/51	12%	4/28	14%
	c) Proctocolectomy	0/51	0%	0/28	0%
	d) Strictureplasty	3/51	6%	2/28	7%
	e) Ileal/Jejunal Resection	5/51	10%	2/28	7%
	f) Resection of Intra-abdominal fistula	1/51	2%	1/28	4%
	g) Proctectomy	0/51	0%	0/28	0%
	h) Completion Proctectomy	0/51	0%	0/28	0%
	i) Ileocolonic Resection	13/51	25%	2/28	7%
	j) Drainage of abscess	2/51	4%	5/28	18%
	k) Formation of Ileostomy or colostomy	7/51	14%	7/28	25%
	l) Revision of Stoma	0/51	0%	0/28	0%
	m) Perineal procedure	0/51	0%	1/28	4%
	n) Closure of Stoma	3/51	6%	0/28	0%
	o) Division of adhesions	3/51	6%	1/28	4%
	p) Other intervention	19/51	37%	10/28	36%
4.1.8i	Was the surgery done laparoscopically/laparoscopically-assisted?	14/51	27%	10/28	36%
4.1.9	Was the ASA status recorded pre-operatively?				
	Yes	22/51	43%	12/28	43%
	1	1/22	5%	0/12	0%
	2	13/22	59%	6/12	50%
	3	8/22	36%	6/12	50%
	4	0/22	0%	0/12	0%
	5	0/22	0%	0/12	0%
	NA	0/22	0%	0/12	0%

4.2 SURGICAL COMPLICATIONS		ELECTIVE ADMISSIONS		Non-ELECTIVE ADMISSIONS	
4.2.1	Did the patient suffer from any of these complications following their surgery?	N	%	N	%
	a) Wound Infection	3/51	6%	2/28	7%
	b) Rectal stump complications	0/51	0%	0/28	0%
	c) Intra-abdominal bleeding	0/51	0%	0/28	0%
	d) Intra-abdominal sepsis	2/51	4%	1/28	4%
	e) Anastomotic leakage	2/51	4%	0/28	0%
	f) Stoma complications	0/51	0%	1/28	4%
	g) Deep vein thrombosis	0/51	0%	0/28	0%
	h) Pulmonary embolus	0/51	0%	0/28	0%
	i) Ileus requiring TPN	5/51	10%	1/28	4%
	j) Cardiac	0/51	0%	1/28	4%
	k) Respiratory	0/51	0%	1/28	4%
	l) Clostridium difficile associated diarrhoea	0/51	0%	0/28	0%
	m) Other	4/51	8%	1/28	4%
	n) No complications	40/51	48	23/28	82

4.3 POST-OPERATIVE PROPHYLACTIC THERAPY		ELECTIVE ADMISSIONS		Non-ELECTIVE ADMISSIONS	
4.3.1	Was the patient prescribed any of the following drugs on discharge?	N	%	N (%)	
	a) Azathioprine	24/51	47%	13/28	46%
	b) Mercaptopurine	1/51	2%	0/28	0%
	c) Metronidazole	1/51	23%	3/28	11%
	d) 5-ASA	13/51	25%	5/28	18%
	e) Methotrexate	4/51	8%	1/28	4%
	f) Infliximab	2/51	4%	4/28	14%
	g) Other	12/51	24%	8/28	29%
	h) None	8/51	16%	8/28	29%

SECTION 5: DISCHARGE ARRANGEMENTS

Section 5 excludes any deceased patients and those recorded as transferred to another site for surgery or further medical management in Q1.3.1

5.1 DISCHARGE ARRANGEMENTS (n=340)		National results 2010		YOUR SITE 2010
		N	%	
5.1.1	Was the patient taking oral steroids on discharge?	113/340	33%	
5.1.1.i	Was a steroid reduction programme stated on discharge? (In patients taking steroids at discharge)	99/113	88%	
5.1.1.ii	Were bone protection agents prescribed? (In patients taking steroids on discharge)	24/113	21%	
5.1.2	Was patient on immunosuppressives on discharge?	175/340	51%	
	a) Cyclosporin	1/175	0.6%	
	b) Methotrexate	30/175	17%	
	c) 6MP	4/175	2%	
	d) Azathioprine	131/175	75%	
	e) Other	19/175	11%	
5.1.3	Was there a plan for maintenance Anti TNF on discharge?	68/340	20%	

SECTION 6: PATIENT HISTORY

6.1 PATIENT HISTORY		National results 2010		YOUR SITE 2010
6.1.1	Did the patient have previous outpatient visits for Crohn's disease at this hospital in the 12 months prior to this admission?	N	%	
		237/342	69%	
6.1.2	How many times was the patient reviewed for their Crohn's disease in an outpatient's clinic in the 12 months prior to the start date of this admission?	Median	IQR	
		4	2 - 6	
6.1.3	Approximately how many times was the patient seen by the following staff in the 12 months prior to the start date of this admission?	Median	IQR	
	a) Paediatric consultant	3	2 - 5	
	b) Paediatric IBD nurse specialist	1	0 - 3	
	c) Paediatric SpR	0	0 - 1	
	d) F2 (SHO)	0	0 - 1	
6.1.4	Days between last outpatient visit and admission	23	7 - 57	
6.1.5	Was the patient's height recorded during the outpatient visit?	N	%	
		259/342	76%	
6.1.6	If the patient was 10 years or older at the time of the last outpatient visit have they had their pubertal status recorded in the past 12 months?	59/237	25%	

Section 5: Site specific key 2010 data items

The table in this section gives named site data in alphabetical order of participating site. These data items were agreed by the UK IBD Audit Steering Group as reflecting the questions of particular importance to IBD patients. The combined UK results from all 23 participating paediatric sites are shown for comparison. These results should be interpreted within the context of the fact that many sites entered a relatively small number of cases to the audit and therefore percentages should be reviewed alongside actual numbers of cases submitted.

Key Indicators	How many cases were entered to the UK IBD audit?		Was the patient seen by a paediatric gastroenterologist during their admission? (this does not apply to patients who were admitted for either elective surgery or who were under the direct care of a surgeon)		In patients with diarrhoea, was a stool sample sent for Standard Stool Culture (SSC)? <i>(SSC is a test to identify bacteria or viruses that may be causing an infection)</i>		Was pubertal status recorded in the 12 months prior to admission? (In patients aged 10 at the time of their last outpatient appointment)	What was the smoking status of the patient NOT recorded during the admission (only asked for patients aged 12 and over at the date of admission)	Was the patient weighed during admission? (Crohn's disease only)	Was the patient seen by a dietician during their admission? (Crohn's disease only)
	Ulcerative colitis	Crohn's Disease	Ulcerative colitis	Crohn's Disease	Ulcerative colitis	Crohn's Disease	Crohn's disease	Crohn's disease	CD Only	CD Only
UK results 2010	Median = 8 cases	Median = 16 cases	Yes = 147/153 (96%)	Yes = 279/288 (97%)	Yes = 88/126 (70%)	Yes = 88/214 (41%)	Yes = 59/237 (25%)	Yes = 136/259 (53%)	Yes = 286/288 (99%)	Yes = 232/288 (81%)
Addenbrooke's Hospital (Paediatric Gastro unit)	4	14	4 (100%)	9 (100%)	0 (0%)	1 (20%)	0 (0%)	7 (54%)	9 (100%)	9 (100%)
Alder Hey Children's Hospital	16	20	12 (86%)	14 (88%)	9 (75%)	5 (38%)	5 (33%)	11 (73%)	14 (88%)	14 (88%)
Barts and The London Children's Hospital	9	20	6 (86%)	15 (88%)	5 (71%)	4 (31%)	1 (8%)	18 (95%)	17 (100%)	12 (71%)
Birmingham Children's Hospital	16	25	16 (100%)	23 (100%)	14 (88%)	12 (60%)	0 (0%)	0 (0%)	23 (100%)	22 (96%)
Bristol Royal Hospital for Sick Children	9	15	8 (100%)	9 (100%)	3 (43%)	2 (25%)	1 (9%)	9 (75%)	9 (100%)	5 (56%)

Key Indicators	How many cases were entered to the UK IBD audit?		Was the patient seen by a paediatric gastroenterologist during their admission? (this does not apply to patients who were admitted for either elective surgery or who were under the direct care of a surgeon)		In patients with diarrhoea, was a stool sample sent for Standard Stool Culture (SSC)? (SSC is a test to identify bacteria or viruses that may be causing an infection)		Was pubertal status recorded in the 12 months prior to admission? (In patients aged 10 at the time of their last outpatient appointment)	What was the smoking status of the patient NOT recorded during the admission (only asked for patients aged 12 and over at the date of admission)	Was the patient weighed during admission? (Crohn's disease only)	Was the patient seen by a dietician during their admission? (Crohn's disease only)
	Ulcerative colitis	Crohn's Disease	Ulcerative colitis	Crohn's Disease	Ulcerative colitis	Crohn's Disease	Crohn's disease	Crohn's disease	CD Only	CD Only
UK results 2010	Median = 8 cases	Median = 16 cases	Yes = 147/153 (96%)	Yes = 279/288 (97%)	Yes = 88/126 (70%)	Yes = 88/214 (41%)	Yes = 59/237 (25%)	Yes = 136/259 (53%)	Yes = 286/288 (99%)	Yes = 232/288 (81%)
Children's Services, Chelsea and Westminster Hospital	15	13	14 (100%)	11 (100%)	14 (100%)	10 (91%)	5 (100%)	0 (0%)	11 (100%)	11 (100%)
Department of Child Health, University Hospital of Wales	9	14	8 (100%)	6 (86%)	3 (43%)	2 (50%)	7 (88%)	0 (0%)	7 (100%)	3 (43%)
Great Ormond Street Hospital, London	3	3	3 (100%)	3 (100%)	2 (100%)	0 (0%)	0 (0%)	2 (100%)	3 (100%)	3 (100%)
Leeds General Infirmary (Paediatric Gastroenterology)	3	16	1 (100%)	13 (100%)	1 (100%)	5 (42%)	1 (10%)	9 (90%)	13 (100%)	8 (62%)
Leicester Royal Infirmary Children's Hospital	2	8	2 (100%)	6 (86%)	0 (0%)	1 (20%)	0 (0%)	5 (71%)	7 (100%)	2 (29%)
Morrison Children's Hospital	4	1	4 (100%)	1 (100%)	2 (100%)	0 (0%)	0 (0%)	0 (0%)	1 (100%)	1 (100%)
North-East Scotland Paediatric Gastroenterology Network (Royal Aberdeen Hospital, Ninewells Hospital and Raigmore Hospital combined)	11	10	8 (89%)	8 (100%)	7 (88%)	2 (40%)	3 (43%)	4 (50%)	8 (100%)	7 (88%)
Nottingham Children's Hospital	12	23	10 (100%)	22 (100%)	4 (67%)	6 (46%)	2 (20%)	17 (100%)	22 (100%)	16 (73%)
Oxford Children's Hospital	3	11	1 (100%)	8 (100%)	1 (100%)	5 (71%)	7 (70%)	4 (40%)	8 (100%)	7 (88%)

Key Indicators	How many cases were entered to the UK IBD audit?		Was the patient seen by a paediatric gastroenterologist during their admission? (this does not apply to patients who were admitted for either elective surgery or who were under the direct care of a surgeon)		In patients with diarrhoea, was a stool sample sent for Standard Stool Culture (SSC)? (SSC is a test to identify bacteria or viruses that may be causing an infection)		Was pubertal status recorded in the 12 months prior to admission? (In patients aged 10 at the time of their last outpatient appointment)	What was the smoking status of the patient NOT recorded during the admission (only asked for patients aged 12 and over at the date of admission)	Was the patient weighed during admission? (Crohn's disease only)	Was the patient seen by a dietician during their admission? (Crohn's disease only)
	Ulcerative colitis	Crohn's Disease	Ulcerative colitis	Crohn's Disease	Ulcerative colitis	Crohn's Disease	Crohn's disease	Crohn's disease	CD Only	CD Only
UK results 2010	Median = 8 cases	Median = 16 cases	Yes = 147/153 (96%)	Yes = 279/288 (97%)	Yes = 88/126 (70%)	Yes = 88/214 (41%)	Yes = 59/237 (25%)	Yes = 136/259 (53%)	Yes = 286/288 (99%)	Yes = 232/288 (81%)
Royal Belfast Hospital for Sick Children	3	2	3 (100%)	2 (100%)	3 (100%)	2 (100%)	0 (NA%)	0 (NA%)	2 (100%)	2 (100%)
Royal Free Hospital (Paediatric Gastroenterology Network)	5	14	4 (80%)	13 (100%)	1 (33%)	0 (0%)	0 (0%)	0 (0%)	13 (100%)	11 (85%)
Royal Hospital for Sick Children, Edinburgh	8	17	8 (100%)	16 (100%)	6 (100%)	9 (90%)	9 (90%)	0 (0%)	16 (100%)	14 (88%)
Royal Manchester Children's Hospital	2	20	2 (100%)	19 (95%)	0 (0%)	2 (12%)	2 (14%)	14 (100%)	20 (100%)	19 (95%)
Royal Victoria Infirmary Children's Services	10	20	9 (90%)	19 (95%)	2 (40%)	2 (20%)	1 (17%)	11 (79%)	20 (100%)	13 (65%)
Sheffield Children's Hospital	8	19	4 (100%)	18 (100%)	2 (50%)	3 (20%)	1 (8%)	14 (100%)	18 (100%)	15 (83%)
Southampton Children's Hospital	9	20	7 (100%)	14 (100%)	2 (40%)	2 (33%)	6 (60%)	1 (6%)	14 (100%)	13 (93%)
St George's Hospital (Paediatric Gastroenterology)	5	20	4 (100%)	17 (94%)	1 (25%)	8 (47%)	2 (20%)	6 (50%)	18 (100%)	14 (78%)
Yorkhill Children's Hospital, Glasgow	10	17	9 (100%)	13 (100%)	6 (75%)	5 (56%)	6 (50%)	4 (29%)	13 (100%)	11 (85%)

Appendix 1: Methodology and sample

Methods

The participation of paediatric sites in the UK paediatric IBD audits (2008 and 2010) has been a major step forward in helping to ensure that the desired consistent, high quality care is available for all IBD patients, independent of age. The publication of these 'paediatric' audits further cement the increasingly strong professional relationship between paediatric and adult gastroenterologists as well as their respective professional bodies. Whilst there are clearly some important age-specific aspects of care that apply to the management of IBD in children, there is a much larger body of generic aspects of IBD care that apply to patients of all ages. As this is now the second time that paediatric data has been collected it has been possible to compare findings in 2008 with those published here for 2010.

The design of the audit was shaped to mainly investigate inpatient activity; it is worth noting however that in paediatrics especially the majority of care is known to be delivered in the outpatient setting. This coupled with the relative rarity of severe UC in childhood, means that most sites did not enter data for 20 UC admissions.

Datasets and standards used in the UK paediatric IBD audit (2010) data collection process

The datasets for this round of the paediatric UK IBD audit are almost identical to those used in the 2nd Round but were slightly adapted, by consensus through the UK IBD Audit Steering Group that includes representatives from The British Society of Paediatric Gastroenterology, Hepatology and Nutrition, to reflect the IBD Standards following their publication in 2010. Furthermore the datasets were developed to also reflect the BSPGHAN '[Guidelines for the Management of Inflammatory Bowel Disease \(IBD\) in Children in the United Kingdom](#)', in areas where there was an absence of paediatric guidance, data were audited against adult standards produced and published by the British Society of Gastroenterology in the document '[Guidelines for the management of inflammatory bowel disease in adults](#)'.

Data collection tool

The web tool included context specific online help including definitions and clarifications, internal logical data checks and feedback to enable more complete and accurate data. Security and confidentiality were maintained through the use of site specific codes. Sites accessed the datasets by using unique identifiers and passwords and data could be saved during, as well as at the end of, an input session

Recruitment

Three individuals from each hospital were approached: a lead Clinician, lead surgeon and a lead from within their Clinical Audit Department. An overall 'audit lead' (usually a consultant paediatric gastroenterologist) from each site was then identified following local discussion. This 'audit lead' was responsible for ensuring the quality of data collection and entry for their particular site. Trust/Health Board Chief Executives were alerted to the study.

Hospitals were eligible to participate in this audit if they had a unified specialist paediatric gastroenterology site within their hospital that routinely admits paediatric IBD patients acutely. 25 such sites were invited to participate in the audit as identified by the BSPGHAN representatives on the UK IBD Audit Steering Group. Their audit data were entered onto the web tool between 1st September 2010 and 31st August 2011.

Each participating site was provided with an appropriate unique login and password and help booklets. A telephone and email helpdesk was provided by the Clinical Effectiveness & Evaluation Unit at the Royal College of Physicians in order to answer any individual queries about the audit.

Data required

For individual patient care, the case-notes were to be audited of 40 consecutive inpatients (20 Crohn's disease and 20 ulcerative colitis) beginning with those patients discharged from 1st September 2010 and continuing until 31st August 2011, or until the full cohort of patients had been entered.

Case identification was based on patients being aged 17 years or under at the date of admission with a discharge diagnosis of IBD as this defined the standards a clinical team expects to be assessed against, a list of relevant ICD10 and OPCS codes was provided to aid patient identification (the list of the relevant codes can be found at: <https://audit.rcplondon.ac.uk/IBD>)

Inclusion and exclusion criteria

Patients with were to be included in the audit if the primary reason for their admission was because of IBD or symptoms that were later diagnosed with IBD and excluded if IBD was not the main reason for admission eg an IBD patient admitted for an exacerbation of asthma. Patients with indeterminate colitis were excluded as were those aged over 17 years of age at admission, a separate adult UK IBD audit report has been produced relating to patients admitted to the care of adult hospital services. Only those patients with a length of stay of greater than 24 hours were audited, excluding day cases for endoscopy/infusion. Patients admitted more than once during the time period, were only audited once; the case for inclusion was that which occurred first chronologically.

Presentation of results

Wherever possible the 2010 audit question numbers have been added within tables of results to facilitate reference to the actual questions in the audit dataset.

- Table 1 gives the 2010 key national results compared against 2008 results for appropriate questions (using only sites that participated in both rounds)
- Table 2 provides a breakdown of key national results. Local 'YOUR SITE' results are shown alongside national and site variation statistics for key indicators.

National results are presented as percentages for categorical data and as median and inter-quartile range (IQR) for numerical data. Site variation is also summarised by the median and IQR.

New components for the 3rd Round

For each complete admission audited, an inpatient and GP questionnaire were generated by the UK IBD audit web tool. These questionnaires were distributed by participating sites to all relevant inpatients and General Practitioners. Use of a unique cross reference code on the questionnaires allows for anonymised linkage of questionnaire data with clinical data. The results of these questionnaires will be reported upon separately in April 2012. For the first time the UK IBD audit includes a biologics audit aspect, data collection is currently ongoing and will be reported separately in June 2012.

Audit governance

The UK paediatric IBD audit (2010) report is a collaborative partnership between gastroenterologists (the British Society of Gastroenterology), colorectal surgeons (the Association of Coloproctology of Great Britain and Ireland), Patients (Crohn's and Colitis UK), Physicians (the Royal College of Physicians of London) together with paediatric gastroenterologists (The British Society of Paediatric Gastroenterology, Hepatology and Nutrition).

This paediatric clinical report follows the publication by the UK IBD Audit Steering Group, of the National Organisational Audit of paediatric IBD Services in the UK, in May 2011. This enables sites to not only benchmark their provision of both service and care against national standards, but also to identify areas of improvement and monitor change from the previous round in 2008.

The audit is commissioned and funded by the Health Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) with additional funding from Health Improvement Scotland. The audit is co-ordinated by the Clinical Effectiveness and Evaluation unit (CEEu) of the Royal College of Physicians of London. Each hospital identified an overall clinical lead that was responsible for data collection and entry for their IBD Service. Data were collected by hospitals using a standardised method. The audit was guided by the multidisciplinary UK IBD Audit Steering Group which oversaw the preparation, conduct, analysis and reporting of the audit. Any enquiries in relation to the work of the UK IBD audit can be directed to: ibd.audit@rcplondon.ac.uk

Representatives of BSPGHAN on the UK IBD Audit Steering Group identified 25 specialist paediatric gastroenterology sites across the UK as being eligible for participation; eligible services were those with an IBD Service in place that routinely admits paediatric IBD patients acutely. All 25 units registered to participate with 23 sites actually submitting data. This encouraging rate of participation was achieved through the hard work and time-commitment of local clinical teams involved in the management of paediatric patients with IBD and in most cases with considerable assistance from their colleagues in clinical audit departments.

For individual patient care, 40 consecutive inpatient case notes were to be audited (20 Crohn's disease and 20 ulcerative colitis) beginning with those patients discharged from 1st September 2010 and continuing until 31st August 2011, or until the full cohort of patients had been entered. For both ulcerative colitis (UC) and Crohn's disease (CD), inpatient details were audited and for CD the some brief outpatient data was included.

In total, paediatric data were collected for 176 ulcerative colitis patients (from 23 sites), median (IQR) of 8 (3-10) per site, and for 342 Crohn's disease patients (from 23 sites), median IQR of 16 (11-20) per site.

Appendix 2: Glossary / abbreviations

Abbreviation	Full title
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5ASA	5-Aminosalicylic acid
ACPGBI	Association of Coloproctology of Great Britain and Ireland
Anti TNF α	Anti-Tumour Necrosis Factor Alpha
ASA Status	American Society of Anesthesiologists Status
BPM	Beat Per Minute
BSG	British Society for Gastroenterology
BSPGHAN	British Society for Paediatric Gastroenterology Hepatology and Nutrition
CD	Crohn's disease
CDT	Clostridium Difficile Toxin
CEEu	Clinical Effectiveness and Evaluation Unit
CQC	Care Quality Commission
CRP	C-Reactive Protein
$^{\circ}$ C	Degrees Celsius
F2	Foundation Doctor-Year 2
HQIP	Health Quality Improvement Partnership
IBD	Inflammatory Bowel Disease
IBDQIP	Inflammatory Bowel Disease-Quality Improvement Project
IQR	Inter-Quartile Range
MG/DAY	Milligrams per Day
NCAPOP	National Clinical Audit and Patient Outcomes Programme
NICE	National Institute for Health and Clinical Excellence
NSF	National Service Framework
RCN	Royal College of Nursing
RCP	Royal College of Physicians
SG	Steering Group
SHO	Senior House Officer
SSC	Standard Stool Culture
UC	Ulcerative colitis
UK	United Kingdom

Appendix 3: Members of the UK IBD Audit Steering Group

Chair

Dr Ian Arnott, consultant gastroenterologist, Western General Hospital, Edinburgh
Association of Coloproctology of Great Britain and Ireland
Mr Bruce George, consultant colorectal surgeon, John Radcliffe Hospital
Association of Coloproctology of Great Britain and Ireland
Mr Graeme Wilson, consultant colorectal surgeon, Western General Hospital, Edinburgh
British Dietetic Association
Ms Miranda Lomer, consultant dietician, Guy's and St Thomas' NHS Foundation Trust
British Society of Gastroenterology
Dr Stuart Bloom, consultant gastroenterologist, University College Hospital
British Society of Gastroenterology
Dr Keith Bodger, consultant physician & gastroenterologist, University Hospital Aintree
British Society of Gastroenterology
Dr Barney Hawthorne, consultant gastroenterologist, University Hospital of Wales
British Society of Gastroenterology
Dr Keith Leiper, consultant gastroenterologist, Royal Liverpool University Hospital
British Society of Gastroenterology
Professor Chris Probert, consultant gastroenterologist, Bristol Royal Infirmary
British Society of Gastroenterology
Professor Jonathan Rhodes, professor of medicine, University of Liverpool
British Society of Gastroenterology
Mrs Chris Romaya, executive secretary
British Society of Gastroenterology
Dr Ian Shaw, consultant gastroenterologist, Gloucestershire Royal Hospital
British Society of Gastroenterology
Dr Abraham Varghese, consultant gastroenterologist, Causeway Hospital
British Society of Paediatric Gastroenterology, Hepatology and Nutrition
Dr Sally Mitton, consultant paediatric gastroenterologist, St George's Hospital
British Society of Paediatric Gastroenterology, Hepatology and Nutrition
Dr Richard Russell, consultant paediatric gastroenterologist, Yorkhill Hospital, Glasgow
Health Services Modernisation
Mr John Frankish, Aneurin Bevan Health Board
Crohn's and Colitis UK (NACC)
Mr Richard Driscoll, chief executive
Crohn's and Colitis UK (NACC)
Ms Elaine Steven, vice-president
Primary Care Society for Gastroenterology
Dr John O'Malley, clinical director, All Day Health Centre, Arrowe Park Hospital
Royal College of Nursing Crohn's and Colitis Special Interest Group
Ms Karen Kemp, IBD clinical nurse specialist, Manchester Royal Infirmary
Royal College of Nursing Crohn's and Colitis Special Interest Group
Ms Allison Nightingale, IBD clinical nurse specialist, Addenbrooke's Hospital
Royal College of Physicians
Ms Rhona Buckingham, manager, Clinical Effectiveness and Evaluation Unit
Royal College of Physicians
Mr Calvin Down, project manager, UK IBD audit
Royal College of Physicians
Ms Jane Ingham, director of Clinical Standards
Royal College of Physicians
Miss Aimee Protheroe, project coordinator, UK IBD audit
Royal College of Physicians

Dr Jonathan Potter, clinical director, Clinical Effectiveness and Evaluation Unit (*Retired May 2011*)

Royal College of Physicians

Dr Kevin Stewart, clinical director, Clinical Effectiveness and Evaluation Unit (*August 2011*)

Royal College of Physicians

Professor John Williams, consultant gastroenterologist, Abertawe Bro Morgannwg University NHS Trust & Director of Health Informatics Unit, RCP

Royal Pharmaceutical Society of Great Britain

Ms Anja St. Clair-Jones, lead pharmacist-surgery and digestive diseases, Royal Sussex County Hospital

Appendix 4: Participating sites 2010

Each of the sites listed below contributed to the 2010 round of the paediatric audit, submitting one or more cases for inclusion:

Addenbrooke's Hospital (Paediatric Gastroenterology unit)

Alder Hey Children's Hospital

Barts and The London Children's Hospital

Birmingham Children's Hospital

Bristol Royal Hospital for Sick Children

Children's Services, Chelsea and Westminster Hospital

Department of Child Health, University Hospital of Wales

Great Ormond St Hospital, London

Leeds General Infirmary (Paediatric Gastroenterology Unit)

Leicester Royal Infirmary Children's Hospital

Morrison Hospital (Paediatric Gastroenterology)

North-East Scotland Paediatric Gastroenterology Network
(Royal Aberdeen Children's Hospital, Ninewells Hospital and Raigmore Hospital combined)

Nottingham Children's Hospital

Oxford Children's Hospital

Royal Belfast Hospital for Sick Children

Royal Free Hospital (Paediatric Gastroenterology Unit)

Royal Hospital for Sick Children, Edinburgh

Royal Manchester Children's Hospital

Royal Victoria Infirmary Children's Services

Sheffield Children's Hospital

Southampton Children's Hospital

St George's Hospital (Paediatric Gastroenterology unit)

Yorkhill Children's Hospital, Glasgow

Appendix 5: Action plan

This action plan has been produced to enable you to take forward the recommendations of this national audit and allows for localisation in the addition of further actions as you feel appropriate for your own service. We would recommend the use of the IBDQIP Shared Document Store (SDS) www.ibdqip.co.uk as a particularly useful resource when considering the actions required below, here you can freely access guidelines, business cases and examples of best practice from around the UK.

National recommendation	Action required	Staff responsible	Progress at your site
1. Every paediatric site should have a dedicated IBD/gastroenterology nurse	Where there is no IBD nurse provision at a site, business cases should be submitted examples of which are available through the IBD Quality Improvement Project Shared Document Store	Consultant paediatric gastroenterologists / Hospital staffing and business and development departments	
2. Every paediatric patient (aged ≥ 10 years, or showing signs of early puberty) with IBD should have pubertal status recorded every 12 months	Standardised medical assessment or self-estimation form to be used for all relevant patients	Medical and nursing staff working with paediatric IBD patients	
3. Local anti-thrombotic policy in paediatric patients with IBD should be reviewed and updated. Where no anti-thrombotic policy for paediatric patients exists, one should be developed	In sites where there is a paediatric anti-thrombotic policy, this should be reviewed taking into account the most recent evidence base. Likewise in sites without one, a policy should be drafted	Consultant paediatric gastroenterologists / Hospital Policy Departments	
4. Every paediatric patient admitted with severe colitis should have a PUCAI score recorded on admission and daily thereafter. In line with ESPGHAN/ECCO recommendations	PUCAI index scoring charts have been distributed to all registered UK IBD audit paediatric site leads. Medical staff should be calculating and documenting this score in the patient medical records as a matter of course	Medical and nursing staff working with paediatric IBD patients. BSPGHAN should also promote its use in conjunction with ESPGHAN/ECCO acute severe colitis guideline	
5. Local hospitals should develop a practice where testing for Clostridium difficile toxin is routinely carried out alongside tests for Standard Stool Culture in all stool samples sent for IBD patients admitted with diarrhoea	Discussion should be undertaken with local laboratory managers to outline explain the importance of ruling out any form of infection in IBD patients	Consultant paediatric gastroenterologists / Hospital Laboratory Management Staff	

5. Instigation of and enrolment into paediatric IBD RCTs	<p>- The IBD audit will produce a list of proposed research topics for the paediatric IBD community to undertake. Alongside this the community needs to recognise the importance of RCTs in furthering the knowledge base for most effective treatment of these patients</p> <p>- Members of the IBD team should be encouraging their patients to enrol onto appropriate RCTs whenever reasonable to do so</p>	<p>UK IBD Audit Steering Group / MCRN / BSPGHAN / All members of the local IBD Team</p> <p>All members of the local IBD Team</p>	
ENTER THE LOCAL ACTIONS YOU HAVE IDENTIFIED HERE			
ENTER THE LOCAL ACTIONS YOU HAVE IDENTIFIED HERE			

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