UK Paediatric IBD Audit (2008) Report

National Results for the Organisation & Process of Paediatric IBD Care in the UK

Generic Hospital Report

Prepared by the
UK IBD Audit Steering Group
on behalf of

- Association of Coloproctology of Great Britain and Ireland
- British Society of Gastroenterology
- British Society of Paediatric Gastroenterology, Hepatology and Nutrition
- Clinical Effectiveness & Evaluation Unit, Royal College of Physicians of London
- National Association of Colitis and Crohn's Disease

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- The National Association for Colitis and Crohn's Disease (NACC)
- All hospital staff who contributed towards organising the collection, retrieval and inputting of data including Clinical Audit, IT and coding staff in addition to the members of the multidisciplinary clinical teams working in support of paediatric IBD patients.

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***Note on the term "site" used throughout this report**

Lead clinicians (in almost every instance a Consultant Paediatric Gastroenterologist) were initially contacted within each Trust/Health Board with a view to taking part in the UK Paediatric IBD Audit (2008). They were asked to register an interest to participate and collect data on the basis of having a unified specialist paediatric gastroenterology unit within their hospital. BSPGHAN (The British Society of Paediatric Gastroenterology, Hepatology and Nutrition) representatives on the UK IBD Audit Steering Group identified 25 such units as being eligible to participate in the audit.

In order to maintain consistency with the terminology used in the UK IBD Audit (Adult) 2nd Round National Report published in March 2009 the specialist paediatric gastroenterology units that participated in this audit will be referred to throughout this report as "Specialist sites"

UK Paediatric IBD Audit (2008) Report

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 patients[1]. 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. The 1st Round of the audit was widely supported by clinicians with 75% of applicable UK hospitals participating. Following dissemination of results, change implementation was supported by a series of regional meetings, a web based document repository and selected hospital visits.

Following the 1st audit round, members of the UK IBD Audit Steering Group met with representatives of the British Society of Paediatric Gastroenterology, Hepatology and Nutrition and agreed to include Paediatric Gastroenterology (<16 years of age at the date of admission to hospital) in the 2nd audit round so that the UK IBD Audit could become a truly comprehensive audit encompassing IBD patients of all ages

Although IBD was not part of the National Service Framework program, 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 NACC, 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. The UK IBD Audit Steering Group strongly endorses the new standards and whilst the UK Paediatric and Adult IBD Audits (2008) did not directly measure against these new standards we anticipate that further rounds of the UK IBD Audits will do so.

It is recommended that IBD Services should meet the National Service Standards for the healthcare of people who have Inflammatory Bowel Disease (IBD) by September 2010.

Overall Summary

The participation of paediatric sites in the UK Paediatric IBD Audit (2008) is 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 this "paediatric" audit further cements 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. Patients under the age of 16 were not included in the UK IBD Audit 1st Round in 2006, so no "benchmark" data exist against which to compare the current results. With this in mind, as well as comparing specific "Key Indicator" data from each specialist paediatric site with the national data, the equivalent results from the adult UK IBD Audit (2008) 2nd Round have also been included for reference.

The design of the audit was shaped to audit mainly inpatient activity. In paediatrics especially the vast majority of IBD care is, however, delivered in the outpatient setting. This, coupled with the relative rarity of severe UC in childhood, reflects that even using data going back over 2 years, most sites did not enter data for 20 UC inpatient admissions.

This report highlights that in 2008, paediatric IBD services in the UK are consultant led and supported in many sites by IBD clinical nurse specialists, dieticians and psychologists. However, there are still sites where this additional multidisciplinary support does not exist or where it remains inadequate. These issues can be improved by increased recruitment in the short term but specific issues highlighted by this audit, such as the lack of both adequate toilet facilities and dedicated ward areas, will take longer to address. The audit highlights disappointing deficiencies in stool culture rates and a low number of inpatients participating in clinical research. Following the launch of the Inflammatory Bowel Disease Transition to Adult Health Care Guidance for Health Professionals in 2008, it is encouraging to note that transitional care is in place for patients in most specialist sites.

This audit has provided a large amount of useful contemporary data for each participating paediatric IBD site to compare with other UK sites. The audit results will, in conjunction with the recently published National IBD Service Standards, allow all local IBD Services to address issues now so they can work towards meeting the standards by September 2010. The key action points are as follows:

- Health departments in England, Northern Ireland, Scotland and Wales must support future rounds of the UK IBD Audit to ensure that quality improvement in IBD care is sustained.
- All NHS Trusts/Health Boards should review their local audit results in relation to the new National IBD Service Standards and take any necessary action to improve their IBD Services.

Key Findings and Recommendations for action

It should be noted that the UK IBD Audit was established and the 2008 paediatric datasets agreed, before the National IBD Service Standards were published. Therefore, we did not specifically audit against them for either the 2008 Paediatric or Adult IBD Audits.

In order to reflect support for this landmark document the UK IBD Audit Steering Group has decided to group the following Key Findings and Recommendations from the UK IBD Audit (2008) Paediatric Report against the 6 core areas (A to F) of the new standards.

Results quoted in the Key Findings and Recommendations are from the national statistics for specialist paediatric gastroenterology sites stated in sections 4 -7 of this report.

Standard A – High Quality Clinical Care
High quality, safe and integrated clinical care for IBD patients, based on multi-disciplinary team working and effective collaboration across NHS organisational structures and boundaries.

Key findings:
Organisation of IBD Services

- There were IBD Clinical Nurse Specialists in 61% of paediatric sites leaving over one third of sites (39%) still without this essential specialist support.
- Designated specialist ward areas are uncommon, present in only 26% of sites.
- Transition clinics are taking place in most paediatric sites (87%).
- Inpatient stays, especially for patients with Ulcerative Colitis, are infrequent in individual paediatric sites with a median of 8 patients per unit (Crohn's Disease median of 23).
- Timetabled meetings between paediatric gastroenterologists and paediatric surgeons took place in only 48% of sites.
- Toilet facilities on designated specialist ward areas are below the required standard of a minimum of 1 easily accessible toilet per 3 beds. All such areas included mixed-sex toilets.

Quality of Care

- There was no inpatient mortality recorded for the audit patients.
- Stool cultures were collected in only 42% of admitted UC patients and 35% of admitted CD patients with diarrhoea. Less than 5% of cultures were positive. Stool specimens for C. Diff toxin were collected in only 26% of admitted UC patients and 22% of admitted CD patients with diarrhoea. 5% were positive.
- There was a median of 5 sessions of dietetic care dedicated to gastroenterology (not just IBD). 97% of Crohn's Disease patients were weighed and 72% visited by a dietician during their admission
- 20% of operations were performed laparoscopically for CD patients, 27% for UC patients.
- Acute severe UC is rare, with only 8 cases in the audit (43% of sites have local management guidelines in place for acute severe UC).
- 65% of sites perform pouch operations although 60% of these sites did not perform any pouch operations during the audit.
- Prophylactic heparin is rarely used in paediatric sites (2% of UC and 2% of CD patients)
- Whilst most paediatric patients did not smoke, smoking status was only recorded in less than half of all CD cases (47%)

Key recommendations:

- *There should be a continued focus on multidisciplinary working with sites moving towards the development of the IBD team as outlined in the National IBD Service Standards.*
- *Improvement in the provision of IBD Clinical Nurse Specialists is required to reach the minimum level of 1.5 WTE per IBD Team as recommended in the National IBD Service Standards.*
- *Trusts/Health Boards should provide appropriate levels of toilet facilities and make sure that they are suitable for paediatric patients of all ages.*
- *Immediate efforts should be made to improve stool culture and CDT collection rates for all new and relapsing IBD patients.*
- *The adoption of national guidelines, such as the Guidelines for the Management of Inflammatory Bowel Disease (IBD) in Children in the United Kingdom produced by BSPGHAN in October 2008, rather than local guidelines, may help local paediatric units with their care of UC inpatients e.g. for pouch surgery, acute severe UC and heparin use.*
- *The volume of pouch surgery is very low. Consideration for either regionalisation of pouch surgery and/or liaison with a high volume adult centre may be appropriate.*

Standard B – Local delivery of care
Care for IBD patients that is delivered as locally as possible, but with rapid access to more specialised services when needed.

Key findings:

- WBC monitoring of immunosuppressive therapy is usually done well (at least 3 monthly for 91% of CD patients on Azathioprine, Mercaptopurine or Methotrexate) and almost always takes place in a combination of primary and secondary care.

Key recommendations:

- *A system for sharing of information about test results or treatment changes should be developed through the use of IT, written communication or a patient held record.*
- *IBD Services must continue to develop shared care between specialist paediatric gastroenterology sites, district general hospitals and primary care.*

Standard C – Maintaining a patient-centred service
Care for IBD patients that is patient-centred, responsive to individual needs and offers choice of clinical care and management where possible and appropriate.

Key findings:

- 87% of sites expect to see relapsing patients within 7 days.
- Written information on who to contact in event of relapse is available in 78% of units.
- Patient panel or other patient meetings remain uncommon (26%).
- Direct telephone contact with an IBD Specialist is available in 100% of sites with many offering contact via email (52%), or less often, drop-in clinics (9%).

Key recommendations:

- *IBD Services should aim to see all relapsing patients within 7 days.*
- *Patient involvement in local IBD services should increase.*

Standard D – Patient education and support
Care for IBD patients that assists patients and their families in understanding Inflammatory Bowel Disease and how it is managed and that supports them in achieving the best quality of life possible within the constraints of the illness.

Key findings:

- Written information about IBD is available for patients in all of the paediatric units that took part in the audit. The most common literature is that developed by CICRA (96%) and NACC (74%).

Key recommendations:

- *Paediatric Sites already meet the standard of providing written information however patient education and support should continue to be developed*

Standard E – Information technology and audit
An IBD Service that uses IT effectively to support patient care and to optimise clinical management through data collection and audit.

Key findings:

- A searchable IBD database is available in 48% of sites.
- 21% of CD patients with outpatient visits in the 12 months before the audited admission had received anti-TNF therapy in this 12 month period.
- 92% of specialist paediatric gastroenterology sites participated in the audit.

Key recommendations:

- *Every IBD Service should develop a searchable IBD database.*
- *A national biologicals database should be developed.*
- *Participation in national audit is a requirement for all IBD Services.*

Standard F – Evidence-based practice and research
A service that is knowledge-based and actively supports service improvement and clinical research

Key findings:

- Only 9 patients from those audited were entered into clinical trials, all of whom were admitted with CD.

Key recommendations:

- *Participation of paediatric IBD patients in clinical research must increase substantially.*
- *The development of the UK Medicines for Children Research Network may facilitate wider participation of IBD patients in clinical trials*

1. Luces C, Bodger K. Economic burden of inflammatory bowel disease: a UK perspective. Expert Review of Pharmacoeconomics & Outcomes Research 2006; 6(4):471-482.

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 Round (Adult) Report this UK Paediatric IBD Audit (2008) Report enables each participating site to compare or benchmark their performance against national statistics. Following the 1st Round of the adult 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 1st Round (Adult) National Report was 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 8 well-attended regional meetings throughout the UK between June and October 2007 to discuss the audit results. Data from the 1st round 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 The National Association for Colitis and Crohn's Disease.

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. We also piloted site visits to 23 of the hospitals that participated in the 1st round of the IBD Audit 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.

Audit Governance

The UK Paediatric IBD Audit (2008) Report is a collaborative partnership between Gastroenterologists (the British Society of Gastroenterology), Colorectal Surgeons (the Association of Coloproctology of Great Britain and Ireland), Patients (the National Association for Colitis and Crohn's Disease), Physicians (the Royal College of Physicians of London) together with Paediatric Gastroenterologists (The British Society of Paediatric Gastroenterology, Hepatology and Nutrition).

Following the 1st Round of the UK IBD Audit, members of the UK IBD Audit Steering Group met with representatives of the British Society of Paediatric Gastroenterology, Hepatology and Nutrition and agreed to include Paediatric Gastroenterology (<16 years of age at the date of admission to hospital) in the 2nd round so that the UK IBD Audit could become truly comprehensive, encompassing IBD patients of all ages. As a consequence this separate report for the Organisation & Process of Paediatric IBD Care in the UK has been published by the UK IBD Audit Steering Group in April 2009 alongside the "adult" report published in March 2009.

The audit is funded by a grant from the Health Foundation as part of their *Engaging with Quality Initiative* which aims to improve the quality of clinical care by engaging clinicians in quality improvement. The audit is a four-year, UK-wide, full cycle comparative audit with initial audit, dissemination, change implementation and re-audit.

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 who 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 a multidisciplinary UK IBD Audit Steering Group (Appendix 1) 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

Who participated in the UK Paediatric IBD Audit (2008)?

Representatives of BSPGHAN (The British Society of Paediatric Gastroenterology, Hepatology and Nutrition) on the UK IBD Audit Steering Group identified 25 specialist paediatric gastroenterology sites across the UK as being eligible for participation as they had an IBD Service in place to routinely admit 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.

The audit of the organisation of IBD paediatric services was intended to be 'as at the 1st September 2008' (together with activity data for all admissions for IBD, including multiple admissions for IBD for the same patient) from 1st September 2007 through to 31st August 2008) and 23 specialist paediatric gastroenterology sites submitted data.

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 admitted on 31st August 2008 and then working backwards as far as 1st September 2006 as it was apparent that most paediatric units would not admit 20 paediatric UC patients per year. For both Ulcerative Colitis (UC) and Crohn's Disease (CD), inpatient details were audited and for CD the last outpatient visit prior to admission was audited (so long as that visit did not directly prompt an acute admission to hospital and that it was not the only outpatient visit during the specified 12 month period).

In total, paediatric data were collected for 248 Ulcerative Colitis patients (from 20 sites), median IQR of 15 (7-20) per site, and for 353 Crohn's Disease patients (from 22 sites), median IQR of 20 (14-20) per site.

In addition, the UK IBD Audit Steering Group was interested in collecting data on paediatric IBD patients admitted via adult gastroenterology services. As part of their submission to the 2nd round of the adult UK IBD Audit participating adult sites were asked to audit up to 5 paediatric IBD admissions in addition to their 40 adult cases. Adult sites entered a combined total of 48 UC and 87 CD patients. Combined national statistics for those patients appear in sections 5 to 7 as detailed below. Whilst their results are included for completeness it is recognised that there is a limit to any generalisations that can reasonably be made from these limited data.

Presentation of Results

The Key Indicator data below emphasise the Key Findings and Recommendations identified in the Executive Summary of Results.

For individual participating specialist paediatric gastroenterology sites these Key Indicators would 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 therefore 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.

Key Indicator results are given for the Organisation & Structure of IBD Services, Ulcerative Colitis inpatient care and Crohn's Disease inpatient and outpatient care. A small number of indicators are presented as combined results for Ulcerative Colitis and Crohn's Disease inpatients.

Key Indicator data from the corresponding UK IBD Audit (adult) 2nd Round Report is also shown in italics for reference.

Section 4: shows the combined results for the Organisation & Structure of Paediatric IBD services (as at 1st September 2008) and represents the best cross-sectional estimates available regarding the organisation and process of IBD care at that time for the 23 specialist paediatric gastroenterology sites that submitted data.

Sections 5 to 7 present the complete clinical results of the UK Paediatric IBD Audit (2008) Report, showing combined clinical data for the specialist paediatric gastroenterology sites alongside the combined data for paediatric IBD patients admitted via adult services which appear under the heading "Other hospitals".

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

Key indicator results with YOUR SITE data

23 specialist paediatric gastroenterology sites contributed organisational data to the audit.
Your site

20 specialist paediatric gastroenterology sites submitted 248 Ulcerative Colitis cases to the audit, median 15
Your site submitted xx case(s).

22 specialist paediatric gastroenterology sites submitted 353 Crohn's Disease cases to the audit, median 20
Your site submitted xx case(s).

Organisational / Structure

1. Timetabled meetings between Gastroenterologists and Colorectal Surgeons

	National 2008 (23 sites)	YOUR SITE 2008
5.2 Timetabled meetings (where IBD patients are discussed) take place between Paediatric Gastroenterologists and Paediatric Surgeons	48% (11)	
5.2 Timetabled meetings (where IBD patients are discussed) take place between Paediatric Gastroenterologists and Colorectal Surgeons	22% (5)	

Adult audit: 66% between Gastroenterologists and Colorectal surgeons

2. Gastro wards: dedicated gastroenterology ward (medical or surgical)

	National 2008 (23 sites)	YOUR SITE
3.1 Is there a dedicated Gastroenterology ward?	26% (6)	

Adult audit: 75% of sites

3. Toilets on dedicated gastroenterology ward

	National 2008 (6/23 sites)	YOUR SITE
Beds per lavatory on the gastroenterology ward	Median: 4.0 Range: 3.0-8.0 N=6	

Adult audit: median 4.3, IQR 3.2-6.0

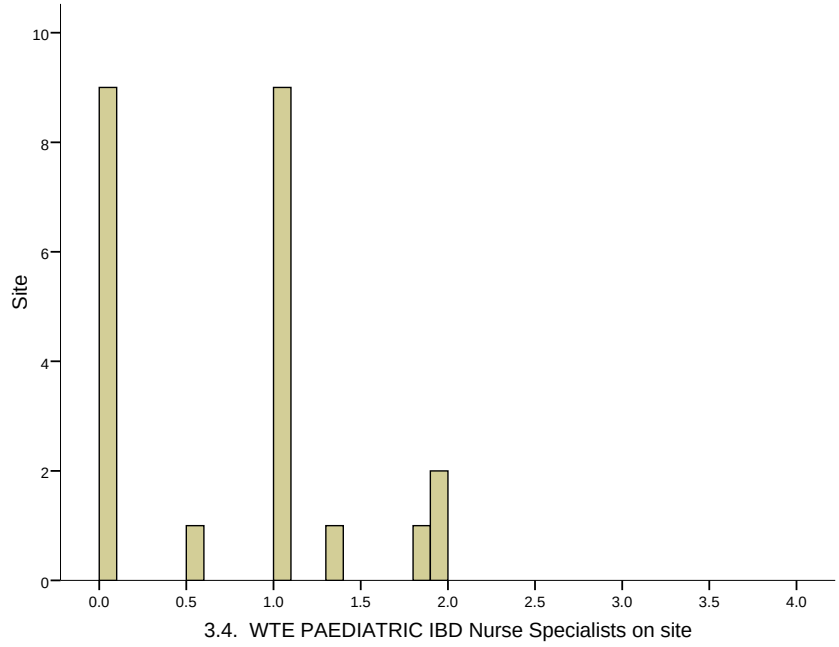
4. Yearly activity (Period 1/9/07 to 31/8/08)

	National 2008 (23 sites)		YOUR SITE 2008
	Median	IQR	
Patients <16 yrs discharged with primary diagnosis of **Ulcerative Colitis**	8	3-19	
Patients <16 yrs discharged with primary diagnosis of **Crohn's Disease**	23	14-33	
Patients <16 yrs discharged having operation, primary indication **Ulcerative Colitis**	3	0-4	
Patients <16 yrs discharged having operation, primary indication **Crohn's Disease**	4	1-6	

Adult audit: medians of 47, 57, 10 & 14 respectively

5. IBD Clinical Nurse Specialists

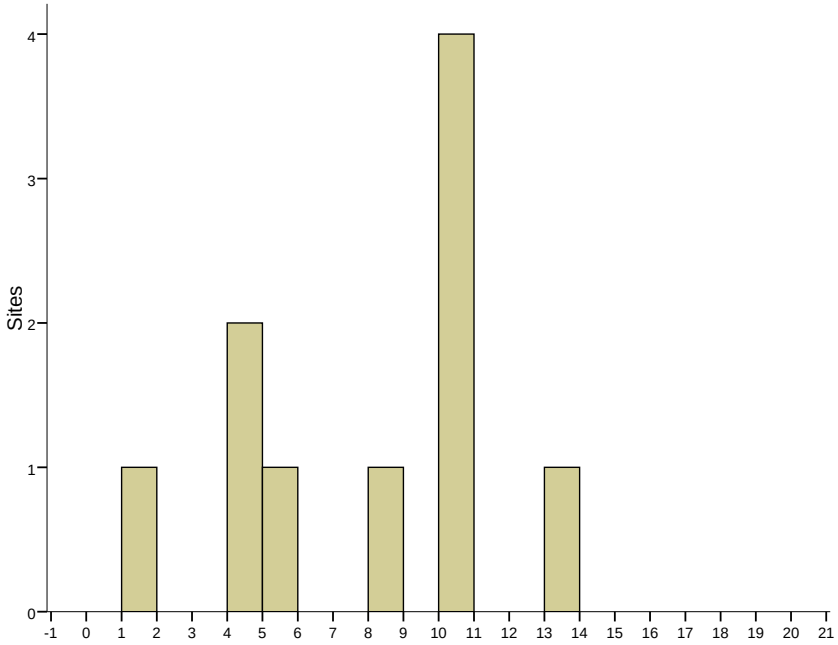
Paediatric IBD Clinical Nurse Specialists (WTE) on site



	National 2008 (23 sites)	YOUR SITE 2008
Median: 1.0		
IQR: 0.0-1.0		
39% (9) NONE		

Adult audit: median 0.6, IQR 0.0-1.0

Sessions of Paediatric IBD Clinical Nurse Specialist time dedicated to IBD care per week



3.5. Sessions of Paediatric IBD Specialist Nurse time dedicated to IBD care

National 2008 (23 sites)

Median: 9

IQR: 4-10

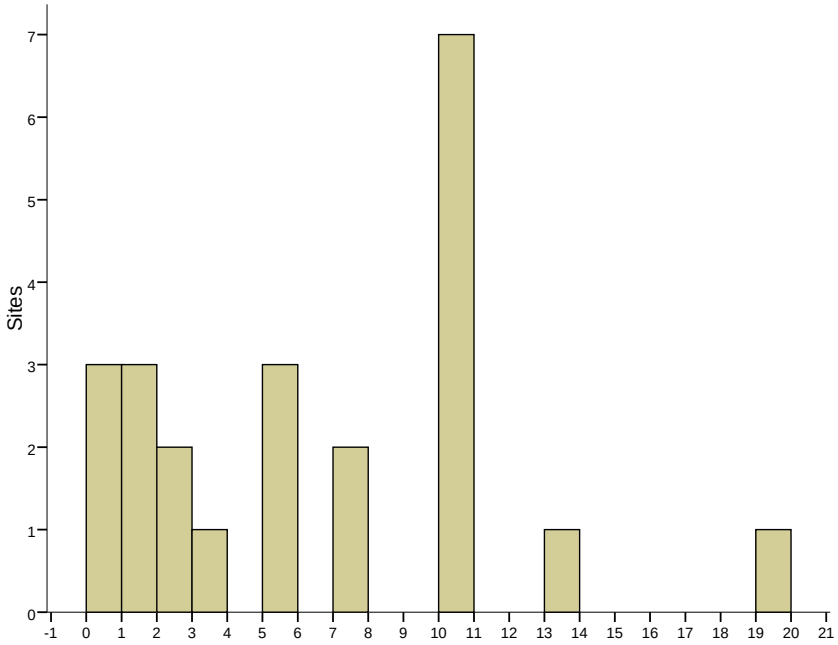
N=10 of 14 with nurse

YOUR SITE 2008

Adult audit: median 8, IQR 4-10

6. Dietetics

Paediatric dietetic sessions per week dedicated to GI disorders (not just IBD)



6.3. Paediatric dietetic sessions per week dedicated to GI disorders

National 2008

Median: 5

IQR: 2-10

N=23

YOUR SITE 2008

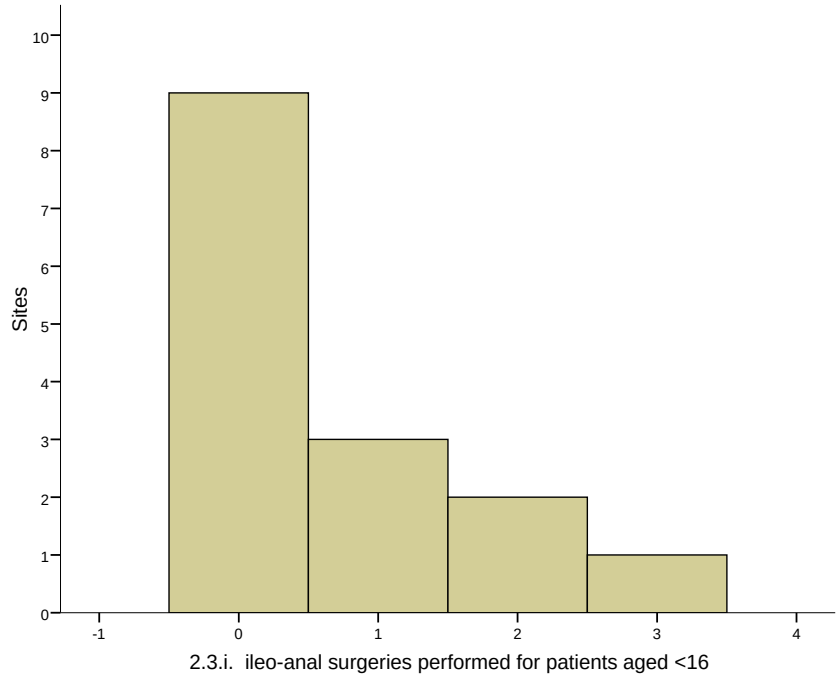
Adult audit: median 2, IQR 0-6

Pouch surgery on-site

	National 2008 (23 sites)	YOUR SITE 2008
Surgeons perform ileo-anal pouch surgery on site for patients <16 yrs	65% (15)	

Adult audit: 77%

Ileo-anal pouch operations performed (1/9/07-31/8/08):



National 2008

Median: 0

IQR: 0-1

N=15

60% (9/15)
NONE

YOUR SITE 2008

Adult audit: median 3, IQR 1-7

7. Searchable database of IBD patients on site

	National 2008 (23 sites)	YOUR SITE
5.1 Searchable database of Paediatric IBD patients on site	48% (11)	

Adult audit: 39%

8. Patient meetings

	National 2008 (23 sites)	YOUR SITE
12.1 Hospital offers open forums or meetings for paediatric patients with IBD	26% (6)	
i. If yes, how often do these take place?		
a) Less than 4 monthly	17% (1)	
b) Every 4-8 months	- (0)	
c) Every 8-12 months	67% (4)	

Adult audit: 28% (forums/meetings). 17% (<4 monthly), 43% (every 4-8 months), 33% (every 8-12 months)

9. Psychological support

	National 2008 (23 sites)	YOUR SITE
10.3 Psychologists are attached to the paediatric Gastroenterology service	43% (10)	
10.4 Pathways exist for direct access to psychological support	43% (10)	

Adult audit: 6% (psychologists), 21% (pathways for direct access).

10. Joint or parallel clinics run on site

	National 2008 (23 sites)	YOUR SITE
7.4 Joint and/or parallel clinics run between Paediatric Gastroenterologists and Surgeons	70% (16)	

Adult audit: 49%

11. Paediatric to adult handover clinic for young patients with IBD

	National 2008 (23 sites)	YOUR SITE
10.1 Paediatric to adult handover clinic for young patients with IBD	87% (20)	

Adult audit: 26%

12. Stoma care

	National 2008 Site variation WTE				YOUR SITE 2008
	Median	IQR	N	Sites with NONE	
4.3 Paediatric Stoma Nurses on site	1	0-1	23	35% (8)	

Adult audit: median 2, IQR 1-3. 4% with NONE

13. Written guidelines for acute or severe UC

	National 2008 (23 sites)	YOUR SITE
11.1 Written Trust guidelines exist for the management of acute or severe Colitis	43% (10)	

Adult audit: 69%

14. Access to care

	National 2008 (23 sites)	Your site
7.1 There is written information for patients with IBD on whom to contact in the event of a relapse	78% (18)	
7.2 In general, how soon could a relapsed patient expect to be seen in clinic?		
a) Less than 7 days	87% (20)	
b) Between 7-14 days	4% (1)	
c) Other (please specify)*	9% (2)	
7.3 Do patients have access to an IBD specialist by any of the following methods (tick all that apply)		
a) Telephone	100% (23)	
b) Drop-in clinic	9% (2)	
c) Email	52% (12)	
d) None of these	- (0)	

***** Other comprised 1 as indicated, 1 same day A&E/outpatient ward review

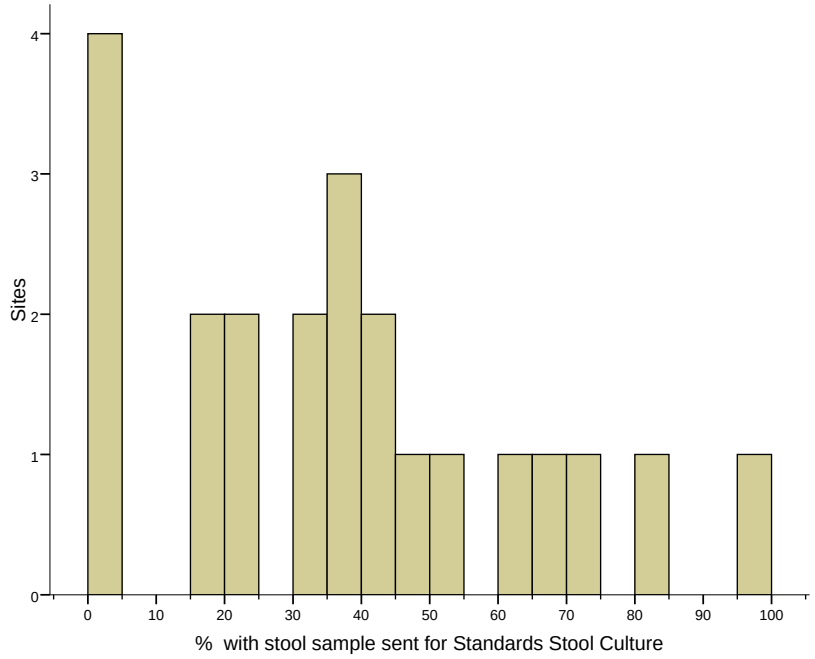
Adult audit: 68% (written information)- 67% (less than 7 days), 30% (7-14 days).
Adult audit: Access - 85% Telephone, 13% Drop-in clinic, 41% Email, 13% None of these.

Results combined for Ulcerative Colitis & Crohn's Disease patients

1. Stool samples

Site variation results are given for Ulcerative Colitis (non-elective) patients and Crohn's Disease (non-elective, with diagnosis of diarrhoea) patients combined.

Site variation in % of stool sample sent for standards stool culture :



National 2008 Site variation

Median: 36%
IQR: 19-53%
N=22

YOUR SITE 2008

Overall non-elective patient results:

Ulcerative Colitis: 42% (90/215)

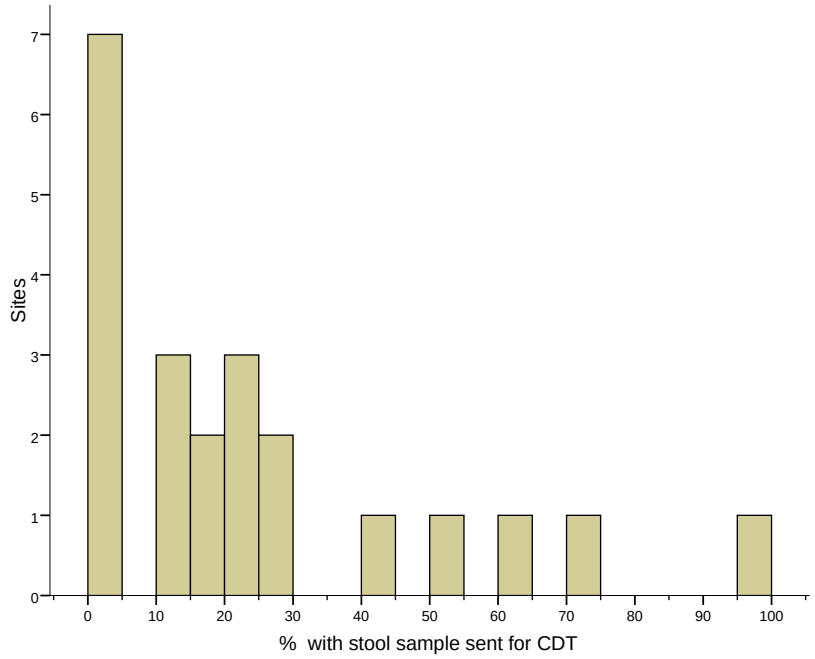
Crohn's Disease: 35% (64/182 with diarrhoea)

Adult audit: site median 62%, IQR 50-74%. Overall 67% Ulcerative Colitis & 53% Crohn's Disease patients

	National 2008 (23 sites)	YOUR SITE
Variation in % of standards stool culture samples that were positive	Only 3 sites had positive samples (one each) Overall non-elective results: Ulcerative Colitis: 3.3 % (3/90) positive Crohn's Disease: 0% (0/64) positive	

Adult audit: 2.1% Ulcerative Colitis samples and 1.7% of Crohn's Disease patients were positive.

Site variation in % of stool sample sent for CDT :



National 2008 Site variation

Median: 17%
IQR: 3-32%
N=22

YOUR SITE 2008

Overall non-elective patient results:

Ulcerative Colitis: 26% (55/215)

Crohn's Disease: 22% (40/182 with diarrhoea)

Adult audit: median 57%, IQR 42-69%. Overall 59% Ulcerative Colitis & 47% Crohn's Disease patients

	National 2008 (22 sites)	YOUR SITE
Variation in % of CDT samples that were positive	Only 5 sites had positive samples (one each) Overall non-elective results: Ulcerative Colitis: 5.5 % (3/55) positive Crohn's Disease: 5.0% (2/40) positive	

Adult audit: 3.5% Ulcerative Colitis samples and 2.6% of Crohn's Disease patients were positive.

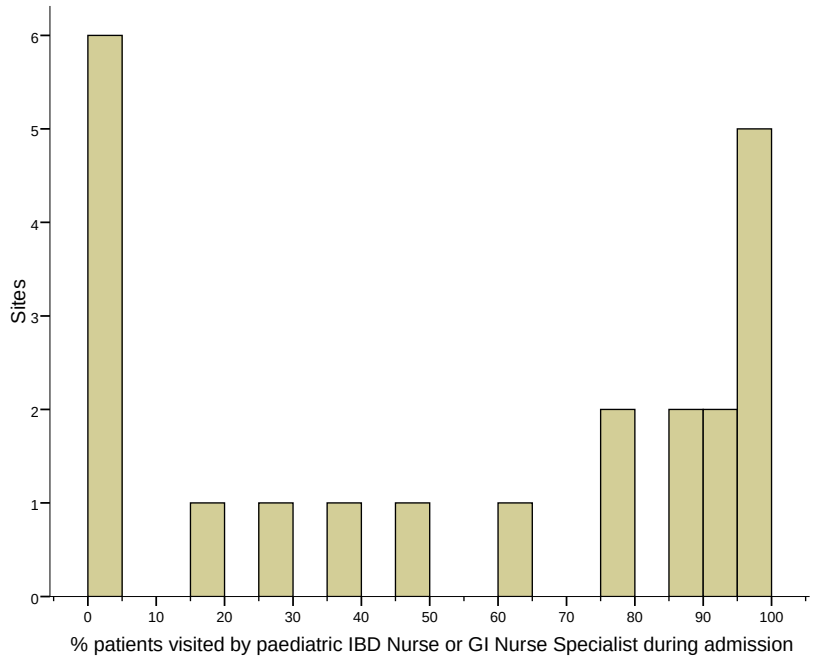
2. Prophylactic heparin (non-elective patients)

	National 2008 (22 sites)	**YOUR SITE**
Site variation in % of patients that received prophylactic heparin	Median 0% IQR (0-3%) Only 8 sites used prophylactic heparin for a total of 11 children. Overall non-elective results: Ulcerative Colitis: 2% (5/215) heparin Crohn's Disease: 2% (6/298) heparin	

Adult audit: median 73%, IQR 61-86%. Overall 73% Ulcerative Colitis & 71% Crohn's Disease patients

3. Patient seen by an IBD/GI Clinical Nurse Specialist during stay?

Site variation in % of patients (UC/CD) seen by a paediatric IBD Nurse/GI Clinical Nurse Specialist during admission:



National 2008 Site variation

Median: 71%
IQR: 3-92%
N=22

For 5/22 sites no audit patient was seen

Overall non-elective patient results:

Ulcerative Colitis: 62% (133/215)

Crohn's Disease: 58% (173/298)

YOUR SITE 2008

Adult audit: median 13%, IQR 0-44% . Overall 27% Ulcerative Colitis & 21% Crohn's Disease patients

Results for Ulcerative Colitis

Results are for non-elective patients, apart from mortality and length of stay which refer to all patients.

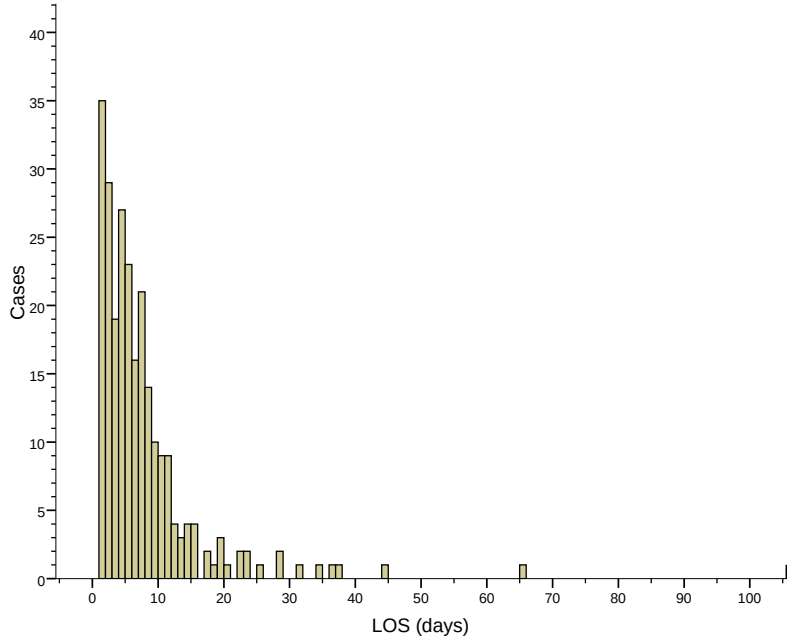
1. Mortality

There were no inpatient deaths reported for any of the audited cases.

Adult audit: 1.5% patient mortality

2. Length of stay (LOS)

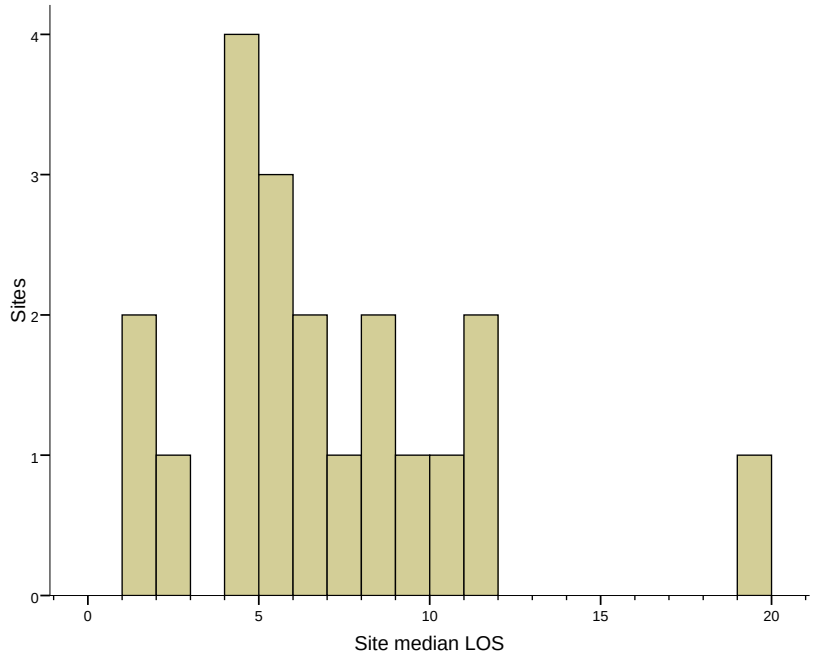
Discharged patient variation in LOS:



	National 2008	YOUR SITE 2008
	Overall median (IQR) was 5 (2-9) days, N=248 cases.	
	40% (98/248) had LOS of 7 or more days	
	11% (28/248) had LOS of 14 or more days	

Adult audit: patient median 8 days, IQR 5-14 days. 62% for 7 or more days, 27% for 14 or more days.

Variation in site median LOS:



National 2008

The inter-quartile range (IQR) for the site median LOS was 4- 9 days.

N=20 sites

YOUR SITE 2008

Adult audit: IQR for the site median LOS was 7-9 days

3. Abdominal X-ray (non-elective)

	National 2008 Site variation			Overall non-elective patient results	YOUR SITE 2008
	Median	IQR	N		
% with plain abdominal X-Ray performed	25%	14-53%	19	25% (53/215)	
% of plain abdominal X-Ray performed on same day as admission:	50%	19-81%	18	Same day: 50% (26/52)	

Adult audit: site median 86%, IQR 71-93% performed. Site median 74% IQR 60-84% on same day as admission

4. Acute severe UC (high stool frequency and high CRP) non-electives

Overall there were 8 patients (3% of non-electives) who were known to have high CRP (>45) and high stool frequency (>8 per day). 7 sites had 1 or more acute severe case within their UC audit sample, range 1-2.

	National audit (8 with acute severe UC)	**Your site (xx case(s) with acute severe UC)**
Ciclosporin	13% (1)	
Infliximab	13% (1)	
Surgery	25% (2)	

Adult audit: 24% ciclosporin, 7% infliximab, 43% surgery, mortality 2.9%

5. Clinical trials

No Ulcerative Colitis audit patients were entered into a clinical trial.

Adult audit: no audit patients were entered into a clinical trial

Results for Crohn's Disease

Inpatient results are for all patients, apart from weight and dietetics which refer to non-elective patients. Outpatient results are for all patients having an outpatient visit in the 12 months prior to the audit admission that did not directly initiate the audit admission.

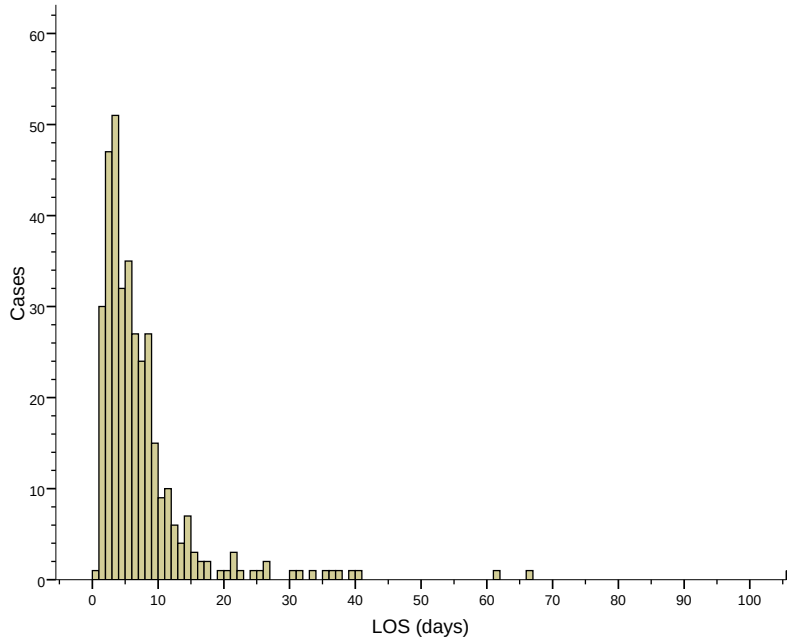
1. Mortality

There were no inpatient deaths reported for any of the audited cases.

Adult audit: 1.1% mortality

2. Length of stay (LOS)

Discharged patient variation in LOS:



National 2008

Overall median (IQR) was 5 (3-8) days, N=353 cases.

37% (132/353) had LOS of 7 or more days

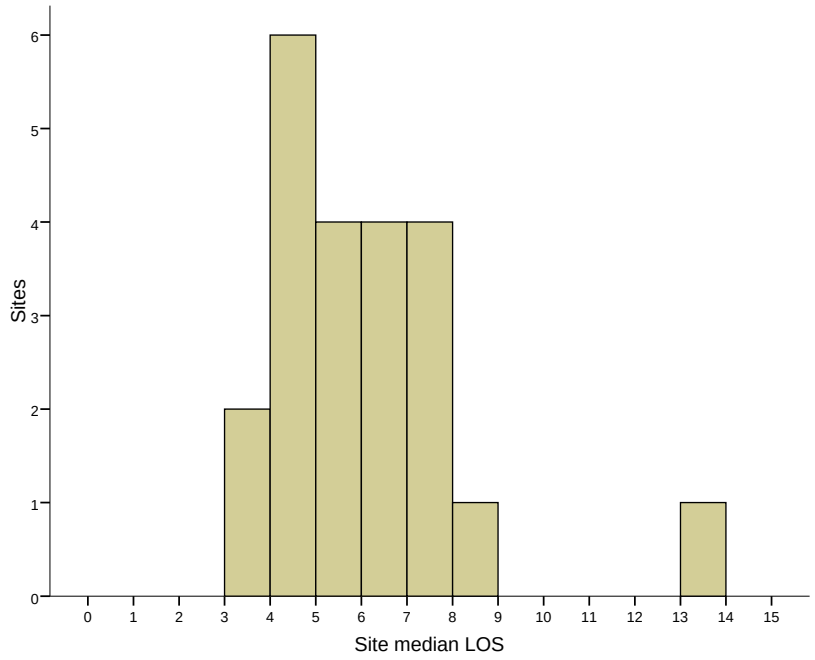
11% (38/353) had LOS of 14 or more days

Note that 1 outlier of >100 days was excluded from the histogram

YOUR SITE 2008

Adult audit: patient median 7 days, IQR 4-11 days. 52% for 7 or more days, 20% for 14 or more days.

Variation in site median LOS:



National 2008

The inter-quartile range (IQR) for the site median LOS was 4-7 days.

N=22 sites

YOUR SITE 2008

Adult audit: IQR for the site median LOS was 6-8 days

3. Smoking status documented (all patients)

	National 2008 Site variation			Overall patient results	YOUR SITE 2008
	Median	IQR	N		
% with smoking status documented	17%	4-100%	22	47% (167/353)	

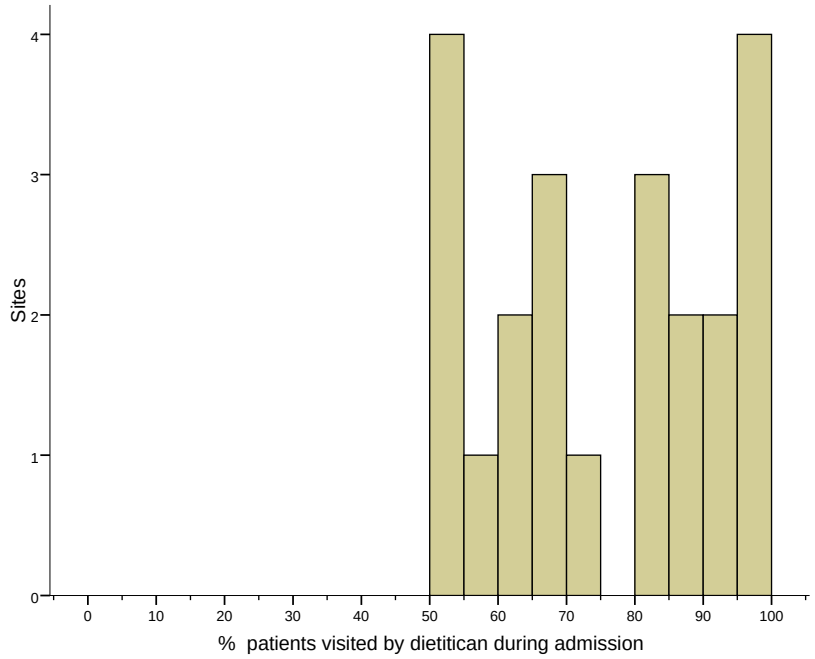
Adult audit: site median 90%, IQR 80-100%. Overall patient result 86% documented

4. Weight and dietetics (non-electives)

	National 2008 Site variation		Overall non-elective patient results	YOUR SITE 2008
	Median	N		
Site variation for % of patients having their weight measured during admission	100%	**17 of the 22 sites measured weight for all their audit patients** 22	Weighed: 97% (289/298)	

Adult audit: site median 56%, IQR 40-80%. Overall patient result = 57% weighed

Site variation for % of patients visited by a dietician during the visit:



National 2008 Site variation

Median: 76%
IQR: 62-94%
N=22

YOUR SITE 2008

Overall non-elective patient results:

Visited: 72% (214/298)

Adult audit: site median 32%, IQR 18-45%. Overall patient result 33% visited.

	National 2008 Site variation			Overall non-elective patient results	YOUR SITE 2008
	Median	IQR	N		
% of patients having dietary treatment initiated (by dietician)	62%	50-74%	22	Initiated: 63% (187/298)	
% of patients prescribed exclusive liquid enteral nutrition therapy (by dietician)	43%	25-61%	22	Therapy: 51% (151/298)	
	19/22 sites prescribed such therapy to at least 1 audit patient				

Adult audit for treatment initiated by dietician: site median 27%, IQR 11-40%. Overall patient result 28%
Adult audit for enteral nutrition therapy: site median 0%, IQR 0-13%. Overall patient result 8%

5. Laparoscopy (elective and non-elective)

	National 2008 Site variation			Overall patient results	YOUR SITE 2008
	Median	IQR	N		
% of surgical patients having surgery done laparoscopically or laparoscopically-assisted	0%	0-31% 10 sites with 0%	18	20% (18/88) of all surgical patients Elective: 28% (15/54) Non-elective: 9% (3/34)	

Adult audit: site median 13%, IQR 0-33%. Overall patient result 20% of surgical patients

6. Post operative therapy

Included in the following results are those surgical patients having segmental/extended colectomy, subtotal colectomy, ileal/jejunal resection and ileocolonic resection. 18 sites had a total of 4 such patients range 1-5.

Prophylactic therapy was taken as being any of the following drugs on discharge: Azathioprine, Mercaptopurine, Metronidazole, 5-ASA, Methotrexate.

	National 2008 Site variation			Overall patient results	YOUR SITE 2008
	Median		N		
Site variation for % of relevant surgical patients prescribed prophylactic therapy on discharge:	100%	3 sites with 0% 15 sites with 100%	18	82% (36/44) of all surgical patients Elective: 77% (24/31) Non-elective: 92% (12/13)	

Adult audit: site median 50%, IQR 25-67%. Overall patient result 46% of surgical patients

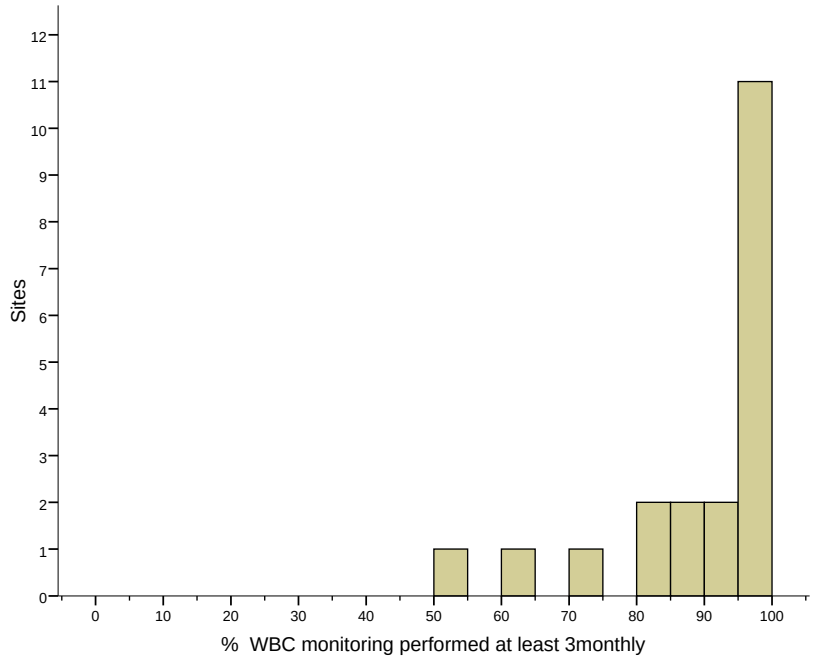
Crohn's Disease Outpatient data

56% (197/353) had previous outpatient visits for Crohn's Disease in the previous 12 months. 181 of these were visits that did not directly initiate the admission being audited, and these form the basic denominator for Crohn's Disease outpatient results.

7. Immunosuppressive monitoring (Outpatient Data)

Denominator comprises 130 patients (from 181) taking any of Azathioprine, Mercaptopurine or Methotrexate (Q6.4.1) in the 12 months prior to the start date of the audited admission.

Site variation for % of patients having WBC monitoring performed at least every 3 months:



National 2008 Site variation

Median: 100%
IQR: 84-100%
N=22

YOUR SITE 2008

Overall patient results:

Monitored:
91% (116/128)

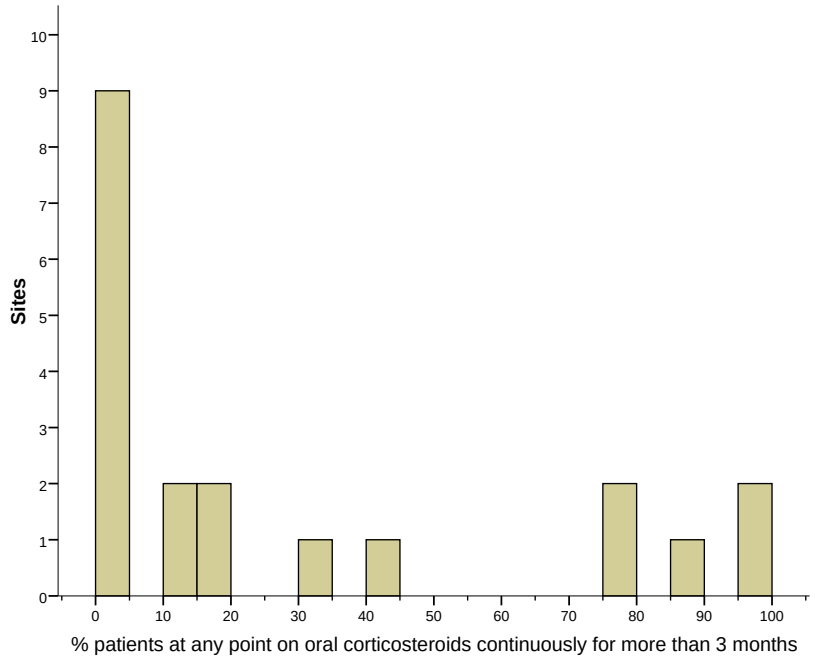
Adult audit: site median 100%, IQR 75-100%. Overall patient result 86%

8. Steroid therapy

	National 2008 Site variation			Overall patient results	YOUR SITE 2008
	Median	IQR	N		
% of patients taking corticosteroids for their Crohn's Disease in 12 months prior to admission	52%	45-66%	20	Therapy: 52% (95/181)	

Adult audit: site median 55%, IQR 38-73%. Overall patient result 55%

Site variation for % of patients at any point taking oral corticosteroids continuously for more than 3 months:



National 2008 Site variation

Median: 13%
IQR: 0-66%
N=20

YOUR SITE 2008

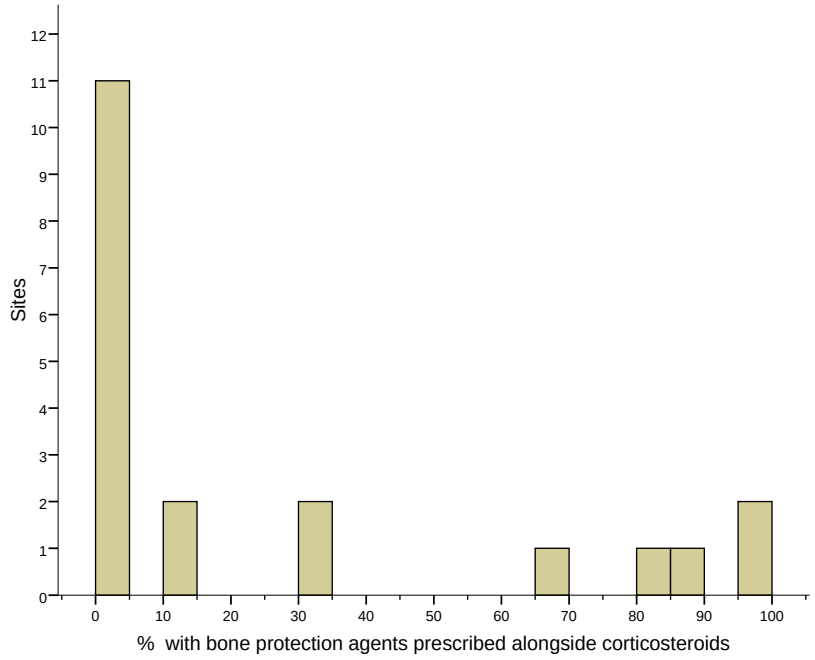
Overall patient results:

>3 months:
27% (26/95)

Adult audit: site median 33%, IQR 14-56%. Overall patient result 38%

9. Bone protection

Site variation for % of patients prescribed bone protection agents alongside corticosteroids



National 2008 Site variation

Median: 0%
IQR: 0-58%
N=20

YOUR SITE 2008

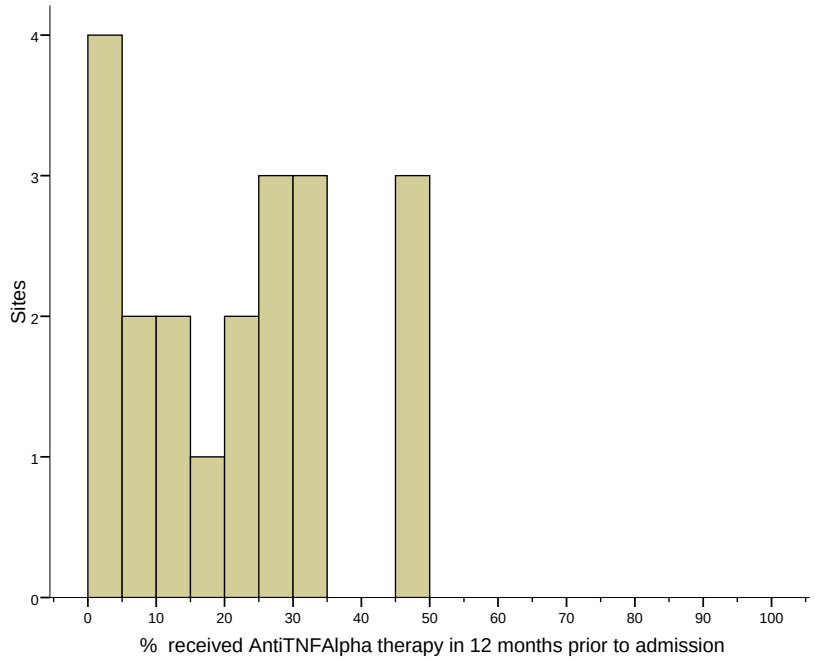
Overall patient results:

Agents:
25% (24/95)

Adult audit: site median 50%, IQR 14-83%. Overall patient result 49%

10. Anti-TNFα therapy

Site variation for % of patients receiving anti-TNF-α therapy in the 12 months prior to admission



National 2008 Site variation

Median: 22%
IQR: 8-33%
N=20

For 4/20 sites there were no audit patients receiving anti-TNF-α therapy

Overall patient results:

Therapy: 21% (38/181)

YOUR SITE 2008

Adult audit: site median 8%, IQR 0-20%. Overall patient result 12%

Overall there were 38 patients who had received anti-TNF-α therapy in the 12 months prior to admission. The number per site ranged from 1 to 9, median 2 patients. These 224 form the starting denominator for the following results:

	National audit (38 received therapy)	**Your site (xx case(s) received therapy)**
6.6.2 Anti-TNF-α therapy given for very first time at any point in 12 months before audited admission	66% (25/38)	
6.6.3 Patient had severely active Crohn's Disease at the time anti-TNF-α therapy was initiated.	95% (23/25)	
6.6.6 Fistulating disease was primary reason for decision to initiate anti-TNF-α therapy	8% (2/25)	
6.6.7 Patient had chest X-ray to exclude TB in 3 months before of initiating anti-TNF-α therapy	80% (20/25)	

Adult audit: 58% Anti-TNF, 95% severely active Crohn's, 27% fistulating disease, 89% chest X-ray.

11. Clinical Trials

Only 3% (9/298) of paediatric Crohn's Disease patients were entered into a clinical trial during their admission.

4 sites entered these 9 cases - two sites entered one case, one site entered 2 cases and one site entered 5 cases.

Your site entered xx case(s).

Adult audit: only 2 patients were entered into a clinical trial

Section 2. Introduction

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

1. Assess current structure and organisation of care for IBD
2. Assess processes and outcomes of care delivery (inpatient and outpatient) in IBD
3. Enable Trusts to compare their performance against national standards
4. Identify resource and organisational factors that may account for observed variations in care
5. Facilitate, develop and institute an intervention strategy to improve quality of care.
6. Repeat the audit to prove that change has occurred
7. Establish measures for healthcare services to use to compare quality of IBD services
8. 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.

Availability of audit results in the public domain

Individual hospital site results will not be placed in the public domain as agreed upon registration for this audit. 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.

Full and executive summary copies of the UK Paediatric IBD Audit (2008) Report will be available in the public domain via the Clinical Effectiveness & Evaluation Unit section of the Royal College of Physicians external website: www.rcplondon.ac.uk

Section 3. Methods

Datasets and Standards used in the UK Paediatric IBD Audit (2008) data collection process

The datasets for this audit of the Organisation and Processes of Care for Paediatric IBD Care were similar to those used in the UK IBD Audit (adult) 2nd Round but 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 important age-specific differences of care for paediatric IBD patients.

Furthermore, the development of the datasets for the UK Paediatric IBD Audit (2008) predated the publication in October 2008 of the BSPGHAN 'Guidelines for the Management of Inflammatory Bowel Disease (IBD) in Children in the United Kingdom' therefore 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 (British Society of Paediatric Gastroenterology, Hepatology and Nutrition) representatives on the UK IBD Audit Steering Group. Their audit data were entered onto the web tool between 1st September and 31st December 2008.

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

The audit of the site organisation of paediatric IBD services was to be "as at" the 1st September 2008. Some organisational questions related to discharges and operations during the 12 month period from 1st September 2007 through to 31st August 2008. In total, organisational audit data was received from 23 sites.

For individual patient care, the case-notes were to be audited of 40 consecutive inpatients (20 Crohn's Disease and 20 Ulcerative Colitis) admitted on or up to 31st August 2008 then working backwards as far as 1st September 2006 if necessary to identify the 40.

Adult sites that participated in the concurrent adult UK IBD (adult) Audit 2nd Round (2008) were asked to audit the case notes of up to 5 paediatric IBD patients admitted to their hospital in addition to the 40 adult admissions for IBD that they were due to enter. These 5 paediatric admissions could be any combination of UC or Crohn's Disease. Where a Trust or Health Board had both a specialist paediatric gastroenterology site and an adult site registered to participate in the audit the clinical leads for each site were advised to consult with their colleagues within that organisation to ensure that there was no duplication of data entry for the same admission for paediatric IBD.

Case identification was based on patients being aged under 16 at the date of admission with a discharge diagnosis of IBD as this defined the standards a clinical team expects to be assessed against (the list of relevant ICD-10 Codes to search against that was provided to participating sites appears on the following page).

Data were collected for 248 paediatric Ulcerative Colitis patients (from 20 specialist paediatric gastroenterology sites), median (IQR) of 15 (7-20) per site and 33 other adult sites entered data for a total of 48 paediatric UC patients.

Data were collected for 353 Crohn's Disease patients (from 22 specialist paediatric gastroenterology sites), median (IQR) of 20 (14-20) per site and 47 other adult sites entered data for a total of 87 paediatric CD patients.

Selection criteria for the patient cohorts (ICD-10 codes)

For the Crohn's Disease and Ulcerative Colitis clinical audits, case identification was based on the discharge diagnosis using the following relevant ICD codes:-

- Crohn's Disease K50.0 (small intestine), K50.1 (large intestine), K50.8 (other), K50.9 (unspecified).
- Ulcerative Colitis K51.0 (enterocolitis), K51.1 (ileocolitis), K51.2 (proctitis), K51.3 (rectosigmoiditis), K51.4 (pseudopolyposis of colon), K51.5 (mucosal proctocolitis), K51.8 (other), K51.9 (unspecified)

A patient was to be included in the clinical audit only once, this being for the most recent admission for IBD prior to 31st August 2008.

For the Organisational audit all admissions for IBD during the year prior to 31st August 2008 (medical and surgical) meeting the criteria below were to be counted and in the case of the organisational dataset multiple admissions for IBD for the same patient were to be counted.

Inclusion and Exclusion criteria

Patients were to be included in the audit if the primary reason for admission was because of IBD or symptoms that were later diagnosed as IBD and excluded if IBD was not indicated as the main reason e.g. a person with known IBD admitted because of a myocardial infarction.

Day cases were to be excluded, such as for endoscopy or drug infusions as were cases where a patient was admitted and stayed overnight but was discharged the following day within 24 hours of admission. Patients with a diagnosis of Indeterminate Colitis were also excluded.

Presentation of results

Wherever possible the 2008 audit question numbers have been added within tables of results to facilitate reference to the actual questions in the audit datasets as seen in Appendix 2.

- Section 1 provides a breakdown of Key National Results, overall, by site variation. Local 'YOUR SITE' results are shown alongside national and site variation statistics for key indicators.
- Section 4 gives the 2008 national summary results for the organisational audit for all of the 23 specialist paediatric gastroenterology sites that participated in this audit.
- Section 5 gives the national summary results for the 2008 audit of Ulcerative Colitis inpatient care for the 20 specialist paediatric gastroenterology sites submitting data and a comparison against the results from the 33 other adult sites that entered data for paediatric UC admissions
- Sections 6 & 7 give the national summary results for the 2008 audit of Crohn's Disease inpatient and outpatient care for the 22 specialist paediatric gastroenterology sites submitting data and a comparison against the results from the 47 other adult sites that entered data for paediatric CD admissions

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 and in graphical form by histogram plots.

Section 4. Organisation & Structure of Paediatric IBD services as at 1st September 2008

23 specialist paediatric gastroenterology sites submitted organisational data.

Auditor Discipline

	Specialist sites (n=23)	
Consultant	78%	(18)
Other medical staff	61%	(14)
Nurse	30%	(7)
Manager	0%	(0)
Clinical Audit staff	26%	(6)
Other *	4%	(1)

* Other: medical student

General Hospital Demographics

Standard:
Hospitals where surgery is performed for IBD should have ITU beds with 24 hr care by anaesthetists/intensivists on-site.

		Specialist sites (n=23)
1.1 How many paediatric beds does your hospital have in total?	Median (IQR)	97 (70-210)
1.2 Does your centre have a Paediatric Intensive Care Unit (ICU)/High Dependency (HDU) Unit on site?	% YES	96% (22)
If yes, is it:	a) Medical	0% (0)
	b) Surgical	0% (0)
	c) Mixed	100% (22)
If yes, how many ICU beds	Median (IQR)	8 (1-15), n=22
If yes, how many HDU beds	Median (IQR)	4 (0-8), n=22

Inpatient Activity

Standard:
2.3 Patients undergoing surgery for ulcerative colitis should have the opportunity to have ileo-anal pouch surgery either locally, if available, or at a regional centre.

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
2.1 How many patients aged under 16 years at the time of admission were discharged with a primary diagnosis of **Ulcerative Colitis**	Median (IQR) Range	8 (3-19), n=23 1-43
2.1 How many patients aged under 16 years at the time of admission were discharged with a primary diagnosis of **Crohn's Disease**	Median (IQR) Range	23 (14-33), n=23 1-79
2.2 How many patients aged under 16 years at the time of admission were discharged having had an operation where the primary indication was **Ulcerative Colitis**	Median (IQR)	3 (0-4), n=23
2.2 How many patients aged under 16 years at the time of admission were discharged having had an operation where the primary indication was **Crohn's Disease**	Median (IQR)	4 (1-6), n=23
2.3 Do surgeons perform ileo-anal pouch surgery on site for patients <16?	% YES	65% (15/23)
If yes, how many ileo-anal pouch operations were performed?	Median (IQR)	0 (0-1), n=15 60% (9/15) NONE

Gastroenterology Services

Standards:
3.1 Specialty triage of emergency admitted IBD patients to appropriate medical or surgical gastroenterology.
3.1 No more than 3 patients per lavatory.
3.3 At least 2 WTE Medical Gastroenterologists.
3.4 and 3.5 At least 1.5 WTE IBD Clinical Nurse Specialist with at least 5 sessions dedicated to IBD.

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
3.1 Is there a dedicated Paediatric Gastroenterology ward?	% YES	26% (6)
If yes, how many beds per lavatory on the ward	Median (range)	4.0 (3.0-8.0), n=6
Are any of the toilets Mixed-sex?	% YES	100% (6/6)
3.2 How many WTE Paediatric Gastroenterologists are there on site?	Median (IQR)	2 (1-3), range 0.5-5, n=23
3.3 How many Paediatric Gastroenterology staff of the following grades are there on site?		
i. Specialist Registrar (SpR)	Median (IQR)	1 (1-2), n=23, 17% (4) NONE
ii. Associate Specialist	%	87% (20) NONE 13% (3) ONE
3.4 How many WTE Paediatric IBD Nurse Specialists are there on site?	Median (IQR)	1 (0-1), n=23 39% (9) NONE
If NONE, has a business case been submitted for a Paediatric IBD Nurse Specialist post?	% YES	25% (2/8)
Was the business case successful?	% YES	0% (0/1), 1 decision pending
3.5 How many sessions of Paediatric IBD Specialist Nurse time are dedicated to IBD care per week?	Median (IQR)	9 (4-10), n=10/14 Range 1-13

NOTE: In 17% (1/6) of sites with a dedicated gastroenterology ward there were 3.0 or less beds per lavatory. In 33% (2/6) there were 6.0 or more beds per lavatory.

Colorectal Services

Standards:
4.1 At least 2 FTE Colorectal surgeons.
4.3 and 4.4 At least 1 stoma-care nurse specialist with at least 5 sessions dedicated to stoma care.

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
4.1 How many WTE Consultant Paediatric Surgeons are there on site?	Median (IQR)	5 (3-6), n=23 9% (2) NONE
4.2 How many Paediatric surgery staff of the following grades are there on site?		
i. Specialist Registrar (SpR)	Median (IQR)	4 (2-6), n=23 9% (2) NONE
ii. Associate Specialist	Median (IQR)	0 (0-1), n=23 65% (15) NONE
4.3 How many WTE Paediatric Stoma Nurses are there on site?	Median (IQR)	1 (0-1), n=23 35% (8) NONE
4.4 How many sessions of Paediatric Stoma Nurse time are dedicated to stoma care per week?	Median (range)	2 (1-10), n=8/15

Multi-Disciplinary Working

Standards:
5.1 Sites should have a searchable data-base to allow adequate audit.
5.2 A weekly multi-disciplinary meeting should take place between gastroenterologists, colorectal surgeons and radiologists. There should be regular histopathology conferences (at least 1 per month).
5.3 and 5.4 Each hospital should have a radiologist and pathologist with a special interest in gastroenterology.

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
5.1 Is there a searchable database of Paediatric IBD patients on site?	% YES	48% (11)
5.2 Do timetabled meetings where IBD patients are discussed take place between the following specialties:		
i. Paediatric Gastroenterologists and Paediatric Surgeons	% YES	48% (11)
ii. Paediatric Gastroenterologists and colorectal surgeons	% YES	22% (5)
iii. Paediatric Gastroenterologists and Pathologists	% YES	87% (20)
iv. Paediatric Gastroenterologists and Radiologists	% YES	87% (20)
v. Surgeons (Colorectal or Paediatric) and Pathologists	% YES	70% (16)
vi. Surgeons (Colorectal or Paediatric) and Radiologists	% YES	83% (19)
5.3 Is there a specialist GI Pathologist?	% YES	65% (15)
5.4 Is there a specialist GI Radiologist?	% YES	43% (10)

Dietetics and Nutritional Services

Standards:
6.1-6.2 Each site should have a multidisciplinary nutrition team. This team should conduct ward rounds at least twice a week.
6.3 At least 5 dietetic sessions per week should be dedicated to gastroenterological diseases (includes inpatients and outpatients).

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
6.1 Is there a hospital paediatric nutrition team?	% YES	91% (21)
6.2 Does the team go on ward rounds?	% YES	100% (21/21)
If yes, how frequently?	%Daily	24% (5/21)
6.3 How many paediatric dietetic sessions per week are dedicated to GI disorders (not just IBD)?	Median (IQR)	5 (2-10), n=23

Outpatient Services

Standards:
7.1-7.3 A clear process for telephone access for ill patients should be established that allows review within one week. Written information for patients with IBD should be readily available in clinic areas (BSG guidelines).
7.4 Joint or parallel clinics should exist to discuss and refer patients between medical and surgical teams

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
7.1 Is there written information for paediatric patients with IBD on whom to contact in the event of a relapse?	% YES	78% (18)
7.2 In general, how soon could a relapsed patient expect to be seen in clinic?		
a) Less than 7 days	% YES	87% (20)
b) Between 7-14 days	% YES	4% (1)
c) Other (please specify)*	% YES	9% (2)
7.3 Do patients have access to a Paediatric IBD specialist by any of the following methods (tick all that apply)		
a) Telephone	% YES	100% (23)
b) Drop-in clinic	% YES	9% (2)
c) Email	% YES	52% (12)
d) None of these	% YES	0% (0)
7.4 Are there any joint or parallel clinics run between Paediatric Gastroenterologists and Surgeons?		
a) Joint	% YES	57% (13)
b) Parallel	% YES	26% (6)
c) Neither	% YES	30% (7)

* Other comprised: 1 as indicated, 1 same day A&E/outpatient ward review

Patient Information

Standard:
8.1 Written information on IBD should be provided to each patient with IBD. (BSG Guidelines)

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
8.1 Are patients provided with written information about IBD?	% YES	100% (23)
i. If yes, is the information produced by (select all that apply):		
a) NACC	% YES	74% (17)
b)CICRA	% YES	96% (22)
c) Pharmaceutical	% YES	17% (4)
d) Locally written	% YES	57% (13)
e) Drug specific	% YES	65% (15)
f) Other (please specify)*	% YES	17% (4)

* Other comprised: 1 website contact, 1 endoscopy & colonoscopy, 1 leaflets about procedures, 1 all patients get a 1:1 powerpoint presentation from specialist nurse

Monitoring of established immunosuppressive therapy

Standard:
9.1 Should be a written policy for mechanism of monitoring immunosuppressive therapy (National Patient Safety Agency)

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
9.1 How is established immunosuppressive therapy monitored? (Please tick all that apply)		
a) By the GP	% YES	22% (5)
b) A dedicated monitoring service	% YES	0% (0)
c) During clinic visits	% YES	43% (10)
d) A combination of primary and secondary care monitoring	% YES	91% (21)

IBD Support Services

Standard:
10.1 There should be regular (usually 1 or 2 per year) transition clinics involving paediatricians and adult gastroenterologists for hand over of patients to adult services. These can be done on a regional basis.

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
10.1 Is there a paediatric to adult handover clinic for young patients with IBD?	% YES	87% (20)
10.2 Is a registered counsellor available to patients as part of your paediatric IBD Service?	% YES	17% (4)
10.3 Are there any psychologists attached to the paediatric Gastroenterology service?	% YES	43% (10)
If yes, how many sessions per month are dedicated to the paediatric Gastroenterology service?	Median (RANGE)	2, (1-16), n=10
10.4 Do pathways exist for direct access to psychological support?	% YES	43% (10)
10.5 Is there an acute pain management team on site?	% YES	100% (23)

Management of Ulcerative Colitis

Standard:
Written trust guidelines should exist for the management of acute or severe colitis.

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
11.1 Do written trust guidelines exist for the management of acute or severe colitis?	% YES	43% (10)

Interactions between hospitals, patients and patient groups

Standard:
12.1 There should be regular meetings (at least once a year and usually on a regional basis) between groups of patients with IBD (and their relatives or carers) and hospital staff, this should involve medical, surgical and nursing staff.

		Specialist sites (Period 1/9/07 to 31/8/08) (n=23)
12.1 Does your hospital offer open forums or meetings for paediatric patients with IBD?	% YES	26% (6)
i. If yes, how often do these take place?		
a) Less than 4 monthly	% YES	17% (1)
b) Every 4-8 months	% YES	0% (0)
c) Every 8-12 months	% YES	67% (4)
d) Other (please specify)*	% YES	17% (1)
ii. If yes, which staff attend these meetings? (select all that apply)		
a) Medical	% YES	100% (6)
b) Surgical	% YES	33% (2)
c) Nursing	% YES	100% (6)
d) Other**	% YES	50% (3)
12.2 Are any of the following activities or systems in place to involve patients in giving their views on the development of your paediatric IBD services? (Please tick all that apply)		
a) Regular patient surveys	% YES	13% (3)
b) Individual patient representatives	% YES	0% (0)
c) Patient panel meetings	% YES	9% (2)
d) None	% YES	61% (14)
e) Other	% YES	17% (4)

* Other comprised: 12-18 months

** Other comprised: 1 dieticians, 1 allied health professionals, 1 clinical psychologist

Section 5. Clinical Audit Ulcerative Colitis (inpatient)

20 specialist paediatric gastroenterology sites submitted 248 cases, median IQR of 15 (7-20) per centre.
33 other (adult) hospital sites submitted 48 cases for children (<16 years).

Auditor Discipline:

	Specialist sites (n=248)		Other hospitals (n=48)	
	%	N	%	N
Consultant	23	58	42	20
Other medical staff	52	130	31	15
Nurse	19	46	27	13
Manager	-	0	-	0
Clinical Audit	8	20	-	0
Other (please specify)*	6	16	-	0

* Other (Specialist sites) comprised medical student (16).

Patient Demographics

	Specialist sites (n=248)		Other hospitals (n=48)	
	Median	IQR	Median	IQR
Patient age* (years)	12	10-14	13	11-14

Derived from year of birth and year of admission

	Specialist sites (n=248)		Other hospitals (n=48)	
Gender	%	N	%	N
Male	56	138	52	25
Female	44	110	48	23

When were patients admitted?

Specialist sites: 44% (108/248) of cases audited were admitted in the 6 month period prior to 1st September 2008. 75% (185/248) of cases audited were admitted in the 12 month period prior to 1st September 2008.

Other sites: 65% (31/48) of cases audited were admitted in the 6 month period prior to 1st September 2008.

	Specialist sites			Other sites	
Admission	2006	2007	2008	2007	2008
January	-	6	16	1	1
February	-	5	13	1	3
March	-	8	14	-	5
April	-	7	19	-	6
May	-	5	26	1	10
June	-	3	17	-	6
July	-	4	16	-	3
August	1	2	16	-	1
September	4	14	-	5	-
October	6	16	-	1	-
November	7	12	-	2	-
December	5	6	-	2	-

Admission details

Standards:

1.1.5 Patients should be transferred to the care of a medical gastroenterologist or colorectal surgeon within 24 hours of admission.

1.1.6 Patients should be seen by a consultant gastroenterologist or colorectal surgeon within 3 days of admission.

1.1.8 Patients should be seen by an IBD Clinical Nurse Specialist during admission.

1.1.9 Patients should be transferred to a specialist gastroenterology ward.

	Specialist sites (n=248)		Other hospitals (n=48)	
	%	N	%	N
1.1.2 What was the primary reason for admission?				
a) Emergency admission for active Ulcerative Colitis	36%	90	58%	28
b) Planned admission for active Ulcerative Colitis	19%	48	19%	9
c) Elective admission for surgery	13%	33	-	0
d) New diagnosis of Ulcerative Colitis	31%	77	23%	11
The rest of this table excludes Elective admissions: Remaining total cases		**215**		**48**
1.1.3 What was the source of admission to hospital?				
a) General Practitioner (GP)	7%	15	33%	16
b) Accident and Emergency (A&E)	20%	42	15%	7
c) Outpatients Department (OPD)	45%	96	33%	16
d) Other hospital	27%	57	4%	2
e) Not documented	2%	5	15%	7
1.1.4 What was the duration of active colitis (new or relapse) precipitating this admission?				
a) Less than two weeks	22%	48	27%	13
b) Two to three weeks	16%	35	19%	9
c) Four to eight weeks	32%	68	21%	10
d) More than eight weeks	27%	58	33%	16
e) Not documented	3%	6	-	0
1.1.5 Which specialty was responsible for the patient's initial care 24 hours after admission?				
a) Acute Medicine	2%	5	2%	1
b) Paediatric Gastroenterology	81%	175	21%	10
c) Paediatric Surgery	4%	8	-	0
d) General Paediatrics within a paediatric GI network	7%	15	38%	18
e) Adult Gastroenterology	-	0	-	0
f) Colorectal surgery	1%	2	-	0
g) General Adult Medicine	-	0	2%	1
h) General Adult Surgery	0.5%	1	2%	1
i) General Paediatrics	3%	7	33%	16
j) Other	1%	2	2%	1
1.1.6 What date was the person first seen by an adult Consultant Gastroenterologist?				
Not Seen	99.5%	214	75%	36
Not required	85%	181/214	50%	18/36
		N	Median (IQR)	N
If seen (days from admission)	2 days	1	1 (1-3)	12
1.1.6 What date was the person first seen by a Consultant Paediatrician with an interest in Gastroenterology?				
Not Seen	98%	210	73%	35
Not required	86%	180/210	34%	12/35
	Median	N	Median (IQR)	N
If seen (days from admission)	(range)			
	1 (0-6)	5	1 (0-1)	13
1.1.6 What date was the person first seen by a Consultant Paediatric Gastroenterologist?				
Not Seen	4%	9	65%	31
Not required	67%	6/9	16%	5/31
	Median (IQR)	N	Median (IQR)	N
If seen (days from admission)	1 (0-1)	206	0 (0-3)	17
1.1.7 What date was the person first seen by a Consultant Colorectal Surgeon?				
Not Seen	99.5%	214	90%	43
Not required	84%	179/214	47%	20/43
		N	Median	N
If seen (days from admission)			(range)	
	1 day	1	1 (1-4)	5

1.1.7	What date was the person first seen by a Consultant Paediatric Surgeon?				
	Not Seen	86%	185	92%	44
	Not required	84%	155/185	41%	18
	If seen (days from admission)	Median (IQR)	N	Median (range)	N
		1 (0-3)	30	0 (0-10)	4
1.1.8	Was patient visited by a Paediatric IBD Nurse/GI Nurse specialist during admission?				
	YES	62%	133	25%	12
1.1.9	Was the patient transferred to a specialist gastroenterology ward?				
	a) Medical	39%	84	25%	12
	b) Joint	19%	40	-	0
	c) Surgical	7%	16	2%	1
	d) Not transferred	35%	75	73%	35
1.1.10	Was the patient's weight measured during the admission?				
	YES	97%	208	85%	41
		Median (IQR)	N	Median (IQR)	N
1.1.10	What was the weight on admission?	40 (29-52)	208	46 (34-54)	41
1.1.11	Was the patient's height measured during the admission?				
	YES	29%	62	29%	14
		Median (IQR)	N	Median (IQR)	N
1.1.11	What was the height on admission?	151 (126-159)	62	157 (150-167)	14

Comorbidity

		Specialist sites (n=248)		Other hospitals (n=48)	
		%	N	%	N
1.2.1	Does the patient have any significant co-morbid diseases? (please tick all that apply)				
	a) Heart Disease	-	0	-	0
	b) Peripheral Vascular Disease	-	0	-	0
	c) Respiratory	2	4	-	0
	d) Renal Failure	-	0	-	0
	e) Diabetes	-	0	-	0
	f) Stroke	1	3	-	0
	g) Liver Disease	3	8	-	0
	h) Active cancer	-	0	-	0
	i) None	94	234	100%	48

Inpatient Mortality

1.3.1 There were no deaths reported for any of the audited cases.

Length of stay

		Specialist sites (n=248)		Other hospitals (n=48)	
		Median (IQR)	N	Median (IQR)	N
1.3.2	Length of stay (days)	5 (2-9)	248	5 (2-13)	48
	Length of stay:	%	N	%	N
	0-1 days	14	35	21	10
	2 days	12	29	13	6
	3-6 days	34	85	29	14
	7-13 days	28	70	17	8
	14-27 days	8	20	8	4
	>=28 days	3	8	13	6

Assessment: Patient History

		Specialist sites (n=248)		Other hospitals (n=48)	
		%	N	%	N
2.1.1	Did the patient have a pre-admission diagnosis of Ulcerative Colitis?				
	YES	63%	156	69%	33
2.1.2	Has the patient had previous admissions with Ulcerative Colitis in the two years prior to this admission?				
	YES	71%	111/156	67%	22/33
	If yes, how many times in the two years prior to this admission?	Median (IQR)	N	Median (IQR)	N
		1 (1-2)	111	2 (1-3)	22

Assessment: Severity of Disease (Table excludes Elective admissions)

Standards:
2.2.1 Patients should have stool frequency documented in first 24 hours of admission. (BSG guidelines)
2.2.2 & 2.2.3 Pulse rate and temperature to be taken at least 4 times in first 24 hours of admission. (BSG guidelines)
2.2.4 Patients should have haemoglobin, albumin and CRP (or ESR) performed (BSG guidelines)
2.2.5 & 2.2.6 Patients with diarrhoea should have a standard stool culture and CDT performed (BSG guidelines) **within 48 hours of admission.**

		Specialist sites (n=215)		Other hospitals (n=48)	
		%	N	%	N
2.2.1	How many stools were passed in the first full day following admission?				
	Not applicable, patient had stoma	2%	4	-	0
	Not documented	28%	60	35%	17
	If yes, how many times?	Median (IQR)	N	Median (IQR)	N
		5 (3-7)	151	6 (3-8)	31
2.2.2	What was the highest recorded pulse rate (bpm) during the first full day following admission?				
	Not documented	7%	15	4%	2
		Median (IQR)	N	Median (IQR)	N
	If documented	105 (95-116)	200	101 (91-114)	46
2.2.3	What was the highest temperature (^{o}C) during the first full day following admission?				
	Not documented	9%	19	6%	3
		Median (IQR)	N	Median (IQR)	N
	If documented	37.1 (36.9-37.5)	196	37.0 (36.5-37.5)	45
2.2.4	At this admission, what was the initial result for **CRP** (mg/L)				
	Not documented	13%	28	13%	6
	Less than 5 mg/L	33%	70	38%	18
		Median (IQR)	N	Median (IQR)	N
	If documented and >5 mg/L	34 (15-63)	117	32 (9-68)	24
2.2.4	At this admission, what was the initial result for **Albumin** (g/L)				
	Not documented	13%	27	15%	7
		Median (IQR)	N	Median (IQR)	N
	If documented	37 (32-42)	188	38 (34-41)	41
2.2.4	At this admission, what was the initial result for **Hb** (g/dL)				
	Not documented	10%	22	8%	4
		Median (IQR)	N	Median (IQR)	N
	If documented	10.8 (9.2-12.1)	193	11.9 (10.3-13.1)	44
2.2.4	At this admission, what was the initial result for **ESR** (mmh^{-1})				
	Not documented	42%	90	46%	22
		Median (IQR)	N	Median (IQR)	N
	If documented	26 (10-49)	125	24 (11-41)	26
2.2.5	Was a stool sample sent for Standard Stool Culture*				
	YES	42%	90	56%	27
		Median (IQR)	N	Median (IQR)	N
	Date sent: Days from admission	1 (0-1)	90	0 (0-1)	27
2.2.5	Was it positive?				
	YES	3%	3/90	-	0/27
	Date sent: Days from admission of positive sample	0, 3, 14 days	N 3		
2.2.6	Was a stool sample sent for CDT*				
	YES	26%	55	38%	18
		Median (IQR)	N	Median (IQR)	N
	Date sent: Days from admission	1 (0-1)	55	1 (0-1)	18
2.2.6	Was it positive?				
	YES	5%	3/55	-	0/18
	Date sent: Days from admission of positive sample	0, 1, 4 days	N 3		

*Specialist sites : Stool sample was sent for both in 25% (53/215)
*Other sites : Stool sample was sent for both in 38% (18/48)

Assessment: Endoscopic Assessment (Table excludes Elective admissions)

Standards:

2.3.1 New cases of suspected ulcerative colitis admitted to hospital should have endoscopic confirmation within 3 days of admission.

2.3.2 Endoscopy report should contain an assessment of severity.

New cases of ulcerative colitis admitted to hospital should have biopsies taken for histology and these should be reported within 5 days.

		Specialist sites (n=215)		Other hospitals (n=48)	
		%	N	%	N
2.3.1	On this admission, did patient have any of the following procedures? (Please tick all that apply)				
	a) Rigid sigmoidoscopy	-	0	-	0
	b) Flexible sigmoidoscopy	1%	2	17%	8
	c) Colonoscopy	53%	115	27%	13
	d) None of the above	46%	99	58%	28
	Date of first procedure : days after admission	Median (IQR)	N	Median (IQR)	N
		1 (1-3)	116	3 (0-5)	20
2.3.2	Were biopsies taken for histology?	54%	116	38%	18
		Median (IQR)	N	Median (IQR)	N
	Days from admission to histology reported by histopathology:	7 (5-11)	116	10 (6-16)	18

Specifically for the non-electives with no pre-admission diagnosis of Ulcerative Colitis:

		Specialist sites (n=92)		Other hospitals (n=15)	
2.3.1	On this admission, did patient have any of the following procedures? (Please tick all that apply)	%	N	%	N
	a) Rigid sigmoidoscopy	-	0	-	0
	b) Flexible sigmoidoscopy	1%	1	13%	2
	c) Colonoscopy	89%	82	53%	8
	d) None of the above	11%	10	33%	5
	Date of first procedure : days after admission	Median (IQR)	N	Median (IQR)	N
		1 (1-3)	82	3 (0-6)	10

Monitoring of Colitis – Post-Admission: General information

Standards:
3.1.1 and 3.1.2 Pulse rate and temperature to be monitored at least 4 times a day (BSG guidelines).
3.1.3 Stool frequency should be monitored daily (BSG guidelines).
3.1.4 and 3.15 ESR, or CRP should be monitored every 24–48 hours in severely active ulcerative colitis (BSG guidelines).

This table excludes Elective admission

		Specialist sites (n=215)		Other hospitals (n=48)	
3.1.1	In the first 7 days following admission did the patient have a persistent Tachycardia* *Defined as the patient having the following bpm **on more than one occasion in 24 hours** in relation to their age on admission: - Patients aged 4 years and under = pulse rate over 140bpm - Patients aged between 5 and 7 years = pulse rate over 130bpm - Patients aged between 8 and 11 years = pulse rate over 120bpm - Patients aged between 12 and 15 years = pulse rate over 100bpm				
	YES	18%	38	15%	7
	Days after admission	Median (IQR)	N	Median (IQR)	N
		1 (0-1)	38	0 (0-0)	7
3.1.2	In the first 7 days following admission did the patient have a Fever (Temperature >37.5°C on more than one occasion in 24 hours)				
	YES	15%	32	19%	9
	Days after admission	Median (IQR)	N	Median (IQR)	N
		1 (0-2)	32	0 (0-1)	9
3.1.3	In the first seven days following admission, how often was stool frequency monitored?				
	a) Daily	76%	164	60%	29
	b) Every 2-3 days	2%	4	4%	2
	c) Every 4-6 days	0.5%	1	-	0
	d) Once a week	1%	3	6%	3
	e) Not applicable, stoma present	2%	4	-	0
	f) Not documented	18%	39	29%	14
3.1.4	In the first seven days following admission, how often was CRP monitored?				
	a) Daily	8%	17	13%	6
	b) Every 2-3 days	30%	65	31%	15
	c) Every 4-6 days	6%	12	10%	5
	d) Once	41%	88	23%	11
	e) Not documented	15%	33	23%	11
3.1.5	At any point following the first 72-hours of steroid therapy was the patient's CRP level reported to be greater than >45mg/L (N with CRP monitoring known)				
	YES	14%	25	5%	2
	No	79%	144	78%	29
	Not documented	7%	13	16%	6

The table below is for Specialist sites, split by differing lengths of time in hospital (0-2 days, 3-6 days and 7 or more days):

		LOS (discharges/deaths)		
		0-2 days N=63	3-6 days N=76	7+days N=76
3.1.1	In the first 7 days following admission did the patient have a persistent Tachycardia on more than one occasion in 24 hours)			
	YES	8%	16%	28%
3.1.2	In the first 7 days following admission did the patient have a Fever (Temperature >37.5°C on more than one occasion in 24 hours)			
	YES	8%	17%	18%

3.1.3	In the first seven days following admission, how often was stool frequency monitored?			
	a) Daily	46%	88%	89%
	b) Every 2-3 days	2%	1%	3%
	c) Every 4-6 days	-	-	1%
	d) Once a week	3%	1%	-
	e) Not applicable, stoma present	-	3%	3%
	f) Not documented	49%	7%	4%
3.1.4	In the first seven days following admission, how often was CRP monitored?			
	a) Daily	6%	8%	9%
	b) Every 2-3 days	2%	28%	57%
	c) Every 4-6 days	2%	7%	8%
	d) Once	67%	41%	20%
	e) Not documented	24%	17%	7%
3.1.5	At any point following the first 72-hours of steroid therapy was the patient's CRP level reported to be greater than >45mg/L (N with CRP monitoring known)			
	YES	2%	6%	28%
	No	92%	86%	65%
	Not documented	6%	8%	7%

Monitoring of Colitis – Post-Admission: Radiology (Table excludes Elective admissions)

Standards:
3.2.1 Patients should have a plain abdominal X-ray (BSG guidelines) **within 24 hours of admission.**
3.2.2 If toxic megacolon is present the abdominal X-ray should be repeated the next day if emergency surgery is not undertaken. (BSG guidelines)

		Specialist sites (n=215)		Other hospitals (n=48)	
		%	N	%	N
3.2.1	Plain abdominal X-Ray performed	25%	53	31%	15
	Date requested:				
	Same day as admission	55%	29	53%	8
	Next day after admission	21%	11	27%	4
	Later	25%	13	20%	3
	Date performed:				
	Same day as request	87%	46	87%	13
	Next day after request	6%	3	-	0
	Later	8%	4	13%	2
	Date reported by Radiologist:				
	Same day as X-Ray performed or next day	65%	33	60%	6
	2-3 days after X-Ray performed	18%	9	10%	1
	More than 3 days after X-Ray performed	18%	9	30%	3
3.2.2	Was toxic megacolon present in the x-ray?				
	NA	6%	3		0
	YES	6%	3/50	-	0
	If yes, was a repeat x-ray or CT scan performed?	100%	3/3		
	Days after abdominal Xray (3.2.1) performed	1,1,2 days	N 3		

Medical Intervention:

Standards:

4.1.1 Patients should have prophylactic heparin (BSG guidelines).

4.2.1 and 4.2.2 Appropriate intravenous steroid therapy (400 mg hydrocortisone or 60mg methylprednisolone) (BSG Guidelines) **should be initiated within 24 hours of admission in a suspected severe attack of ulcerative colitis.**

4.2.4 (together with 3.1.5) If the attack of colitis is not settling within 72 hours of appropriate steroid therapy the risk of colectomy is high. If there is no response to appropriate corticosteroids within 3 days, rescue therapeutic options need to be discussed with the patient (BSG guidelines) **(either surgery, ciclosporin or anti-TNFα therapy). A consultant colorectal surgeon should discuss the surgical option with the patient.** (BSG guidelines).

	Steroid therapy (Table excludes Elective admissions)	Specialist sites (n=215)		Other hospitals (n=48)	
		%	N	%	N
4.1.1	Patient given Prophylactic heparin	2%	5	10%	5
4.2.1	Were IV corticosteroids prescribed during this admission?				
	i. Yes	53%	114	40%	19
	ii. No, but oral corticosteroids were prescribed	26%	55	29%	14
	iii. No, neither IV or Oral corticosteroids were prescribed during this admission	21%	46	31%	15
	Rest of the table is for those prescribed steroids				
4.2.2	Which of the following steroids were initially prescribed?		**N=169**		**N=33**
	Prednisolone	70%	119	67%	22
	Budesonide	-	0	-	0
	Hydrocortisone	30%	50	33%	11
	Initial dose (Mg per day)	Median (IQR)	N	Median (IQR)	N
	Prednisolone	40 (35-40)	119	40(40-60)	22
	Budesonide	-	0	-	0
	Hydrocortisone	200 (200-400)	48	400 (300-400)	11
4.2.3	Date therapy initiated or increased:				
	Same day as admission	44%	74	55%	18
	Next day after admission	26%	44	18%	6
	2-7 days after admission	25%	43	24%	8
	Later	5%	8	3%	1
4.2.4	At any point following the first 72-hours of steroid therapy did the patient produce stools at a frequency greater than 8 per day?				
	YES	8%	14	12%	4
	No	74%	125	73%	24
	Not documented	18%	30	15%	5
4.2.5	Did the patient respond to corticosteroids and not require any other significant therapy for Ulcerative Colitis?				
	YES	78%	131	73%	24

Medical Intervention: Other Therapies (Table excludes Elective admissions)

		Specialist sites (n=215)		Other hospitals (n=48)	
		%	N	%	N
4.3.1	Ciclosporin	5%	11	2%	1
	Start date: Days after admission	Median (IQR) 1 (0-9)	N 11	7 days	N 1
	Patient achieved remission on ciclosporin therapy	91%	10/11	100%	1/1
4.3.2	Anti-TNF	1%	2	2%	1
	Start date: Days after admission	3, 9 days	N 2	9 days	N 1
	Patient achieved remission on TNF therapy	100%	2/2		
4.3.3	Clinical Trial (please specify)	-	0	-	0
	Start date: Days after admission				
	Patient achieved remission from clinical trial				

4.3.4	Significant Other therapies (please specify)**	7%	15	6%	3
	Start date: Days after admission	Median (IQR)	N		N
		1 (1-4)	15	0,0,9,17 days	4
	Patient achieved remission from other therapy	53%	8/15	100%	4/4
4.3.5	Surgical therapy				
	YES	5%	11	4%	2

** Specialist sites: antibiotics (3), azathioprine (3), balsalazide (1), azathioprine & balsalazide (1), mesalazine (2), asacol (1), neocate advance liquid diet (1), olsalasine (1), sulphasalazine (1), tacrolimus (1). Other hospitals: azathioprine (1), blood transfusion (1), enteral nutrition (1)

Medical Intervention: Initiating Ciclosporin Therapy (N=150)
(Table excludes elective admissions)

Standards:
4.4.1 Creatinine should be measured (BSG guidelines) **within the 48 hours prior to initiation of ciclosporin.**
4.4.2 and 4.4.3 Magnesium and cholesterol should be measured (BSG guidelines) **within the 48 hours prior to initiation of intravenous ciclosporin.**

		Specialist sites (n=11)		**Other hospitals (n=1)**	
		%	N	**N**	
4.4.1	Pre-treatment results for Creatinine (µmol/L)				
	Not documented	-	0	-	0
	Results	Median (IQR)	N		N
		56 (48-62)	11	39 µmol/L	1
	Date of sample:				
	3 days or more before ciclosporin started	-	0	-	0
	2 days before ciclosporin started	9%	1	-	0
	1 day before ciclosporin started	36%	4	-	0
	Same day as ciclosporin started	55%	6	100%	1
4.4.2	Pre-treatment results for Magnesium (mEq/L)				
	Not documented	27%	3	-	0
	Results	Median (IQR)	N		N
		0.8 (0.8-0.9)	8	1.0 mEq/L	1
	Date of sample for intravenous ciclosporin :				
	3 days or more before ciclosporin started	29%	2	-	0
	2 days before ciclosporin started	-	0	-	0
	1 day before ciclosporin started	29%	2	-	0
	Same day as ciclosporin started	42%	3	100%	1
4.4.3	Pre-treatment results for Cholesterol (mmol/L)				
	Not documented	91%	10	-	0
	Results		N		N
		5.5 mmol/L	1	3.0 mmol/L	1
	Date of sample for intravenous ciclosporin :				
	3 days or more before ciclosporin started	-	0	-	0
	2 days before ciclosporin started	-	0	-	0
	1 day before ciclosporin started	100%	1	100%	1
	Same day as ciclosporin started	-	0	-	0
4.4.4	How was the ciclosporin initially administered?				
	Oral	18%	2	100%	1
	IV	82%	9	-	0
	Initial daily dose (Mg/Kg)	Median (IQR)	N		N
		2 (2-2)	11	5 Mg/Kg	1

Medical Intervention: Monitoring Ciclosporin Therapy (N=150)
(Table excludes Elective admissions)

Standards:
Creatinine and FBC should be monitored daily.
4.5.1 Ciclosporin levels should be checked daily after 3 days of IV therapy.

		Specialist sites (n=11)		Other hospitals (n=1)	
		%	N	%	N
4.5.1	After three days of ciclosporin therapy, how often were serum ciclosporin levels checked?				
	a) Daily	27%	3	-	0
	b) Every two days	18%	2	100%	1
	c) Every three days	27%	3	-	0
	d) Once a week	27%	3	-	0
	e) Less than once a week	-	0	-	0
	f) Not documented	-	0	-	0

Surgical Interventions
Standards:

5.1.2 Consultant colorectal surgeons should be involved with the discussion with the patient regarding the decision to operate (BSG guidelines).
5.1.4 Patients having resectional surgery for Ulcerative Colitis should see a stoma nurse prior to the operation (BSG guidelines).
5.1.5 and 5.1.6 Operations should be performed or assisted by a consultant colorectal surgeon.
5.1.9 ASA status should be recorded pre-operatively.

		Specialist sites				Other hospitals			
		Electives (33)		Non-elective (11)		Electives (0)		Non-elective (2)	
		%	N	%	N	%	N	%	N
5.1.1	What date was the decision to operate made?								
	Not known		6		0				0
	Date of decision: days from admission	Median (IQR)	N	Median (IQR)	N	Median (IQR)	N		N
		-42 (-70 to -21)	27	2 (1-5)	11			2, 3 days	2
5.1.2	Who made the decision to operate?								
	a) Consultant Paediatric Surgeon	76%	25	82%	9			-	0
	b) Consultant Colorectal Surgeon	21%	7	9%	1			50%	1
	c) Consultant GI Surgeon (non-colorectal)	-	0	-	0			-	0
	d) Consultant General Surgeon	-	0	-	0			-	0
	e) Other Consultant Surgeon	-	0	-	0			-	0
	f) Specialist Registrar	-	0	-	0			-	0
	g) *Other (please specify)	3%	1	9%	1			50%	1
	Not documented	-	0	-	0			-	0
5.1.3	Date of Surgery: days from admission	Median (IQR)	N	Median (IQR)	N	Median (IQR)	N		N
		1 (0-1)	33	3 (2-8)	11			4, 7 days	2
5.1.4	Patient seen by stoma nurse during admission	64%	21	100%	11			100%	2
	If yes, date first seen : days from admission	Median (IQR)	N	Median (IQR)	N	Median (IQR)	N		N
		1 (0-5)	21	4 (2-8)	11			0, 8 days	2
5.1.5	What was the grade of the operating surgeon?								
	a) Consultant Paediatric Surgeon	64%	21	91%	10			50%	1
	b) Consultant Colorectal Surgeon	21%	7	9%	1			50%	1
	c) Consultant GI Surgeon (non-colorectal)	-	0	-	0			-	0
	d) Consultant General Surgeon	-	0	-	0			-	0
	e) Other Consultant Surgeon	-	0	-	0			-	0
	f) Specialist Registrar	15%	5	-	0			-	0
	g) Associate specialist	-	0	-	0			-	0
	h) **Other (please specify)	-	0	-	0			-	0

5.1.6	What was the grade of the assisting surgeon?						
	a) Consultant Paediatric Surgeon	15%	5	-	0	-	0
	b) Consultant Colorectal Surgeon	3%	1	-	0	-	0
	c) Consultant GI Surgeon (non-colorectal)	-	0	-	0	-	0
	d) Consultant General Surgeon	3%	1	-	0	-	0
	e) Other Consultant Surgeon	-	0	-	0	-	0
	f) Specialist Registrar	73%	24	100%	11	100%	2
	g) Associate specialist	-	0	-	0	-	0
	h) ***Other (please specify)	6%	2	-	0	-	0

		Specialist sites				Other hospitals			
		Electives (33)		Non-elective (11)		Electives (0)		Non-elective (2)	
		%	N	%	N	%	N	%	N
5.1.7	What were the indications for surgery?(select all that apply)								
	a) Failure of Medical Therapy	52%	17	82%	9			100%	2
	b) Toxic megacolon	-	0	9%	1			-	0
	c) Bleeding	9%	3	-	0			-	0
	d) Obstruction	3%	1	9%	1			-	0
	e) High Grade Dysplasia	-	0	-	0			-	0
	f) Low Grade Dysplasia	-	0	-	0			-	0
	g) Ungraded Dysplasia	-	0	-	0			-	0
	h) Cancer	-	0	-	0			-	0
	i) Perforation	-	0	9%	1			-	0
	j) Abscess	-	0	-	0			-	0
	k) Formation of ileostomy	15%	5	9%	1			-	0
	M Ileoanal pouch	21%	7	-	0			-	0
	l) Other indication (please specify)*	12%	4	-	0			-	0
5.1.8	Type of intervention:								
	a) Subtotal colectomy	42%	14	45%	5			100%	2
	b) Proctocolectomy	12%	4	36%	4			-	0
	c) Proctectomy	3%	1	-	0			-	0
	d) Ileoanal pouch with stoma	12%	4	-	0			-	0
	e) Ileoanal pouch without stoma	6%	2	-	0			-	0
	f) Formation of ileostomy	33%	11	18%	2			50%	1
	g) Other (please specify)**	45%	15	36%	4			-	0
5.1.8i	Was the surgery done laparoscopically/ laparoscopically-assisted?								
	YES	27%	9	27%	3			50%	1
5.1.9	ASA status recorded pre-operatively	39%	13	55%	6			100%	2
	If yes, what was the status?								
	1	8%	1	17%	1			50%	1
	2	46%	6	17%	1			-	0
	3	31%	4	50%	3			50%	1
	4	8%	1	-	0			-	0
	5	-	0	-	0			-	0
	N/A	8%	1	17%	1			-	0

*closure of stoma (4)

** Specialist sites: adhesionolysis (1), appendicectomy (1), closure of ileostomy (6), Ileo-anal pull through & loop (1), ligation rectal stump & appendicectomy (1), refashioning of stoma (1), reversal of ileostomy (1), total colectomy & ileostomy (3). Other hospitals: total colectomy (2), total colectomy & ileostomy form (1), adhesionolysis/laparotomy (1).

Surgical Complications

		Specialist sites				Other hospitals			
		Electives (33)		Non-elective (11)		Electives (0)		Non-elective (2)	
		%	N	%	N	%	N	%	N
5.2.1	Did the patient suffer from any of these complications with their surgery?								
	a) Wound Infection	3%	1	-	0			-	0
	b) Rectal stump complications	3%	1	-	0			50%	1
	c) Intra-abdominal bleeding	-	0	-	0			-	0
	d) Intra-abdominal sepsis	-	0	9%	1			50%	1
	e) Anastomotic leakage	-	0	-	0			50%	1
	f) Stoma complications	9%	3	-	0			-	0
	g) Deep vein thrombosis (DVT)	-	0	-	0			-	0
	h) Pulmonary embolus (PE)	-	0	-	0			-	0
	i) Small bowel obstruction	18%	6	9%	1			-	0
	j) Ileus requiring parenteral nutrition	-	0	-	0			-	0
	k) Cardiac	-	0	-	0			-	0
	l) Respiratory	-	0	-	0			-	0
	m) clostridium difficile-associated diarrhoea (CDAD)	-	0	-	0			-	0
	n) Other (please specify)*	3%	1	-	0			50%	1
	0) No Complications	79%	26	82%	9			50%	1

* pouchitis (specialist site), Addisonian crisis (other hospital)

Discharge Arrangements

Standards:

6.1.1 Patients should be followed up by a gastroenterologist or colorectal surgeon.

6.1.2 Patients discharged on oral steroids should have a steroid reduction programme stated on discharge.

6.1.3 Patients on oral steroids should be co-prescribed bone protection agents (such as calcium and vitamin D or bisphosphonates (BSG guidelines).

			Specialist sites (248)		Other hospitals (48)	
			%	N	%	N
6.1.1	Was the patient taking oral steroids on discharge?					
		YES	71%	177	71%	34
		No	29%	71	27%	13
		N/A	-	0	2%	1
6.1.2	Was a steroid reduction programme stated on discharge			N=177		N=34
		YES	79%	140	82%	28
		No	19%	34	15%	5
		N/A	2%	3	3%	1
6.1.3	Were bone protection agents prescribed?					
		YES	27%	47	24%	8
		No	72%	127	67%	23
		N/A	2%	3	9%	3

Section 6. Clinical Audit: Crohn's Disease (Inpatient)

22 specialist paediatric gastroenterology sites submitted 353 cases, median IQR of 20 (14-20) per centre.
47 other (adult) hospital sites submitted 87 cases for children (<16 years).

Auditor Discipline:

	Specialist sites (n=353)		Other hospitals (n=87)	
	%	N	%	N
Consultant	23%	81	29%	25
Other medical staff	50%	178	30%	26
Nurse	26%	92	37%	32
Manager	-	0	-	0
Clinical Audit	6%	22	8%	7
Other (please specify)*	5%	19	2%	2

* Other (Specialist sites) comprised: medical student (19)
* Other (other hospitals) comprised: medical student (1), secretary (1)

Patient Demographics

	Specialist sites (n=353)		Other hospitals (n=87)	
	Median	IQR	Median	IQR
Patient age* (years)	13	11-14	14	12-15

Derived from year of birth and year of admission

	Specialist sites (n=353)		Other hospitals (n=87)	
Gender	%	N	%	N
Male	62%	220	54%	47
Female	38%	133	46%	40

When were patients admitted?

Specialist sites: 47% (166/353) of cases audited were admitted in the 6 month period prior to 1st September 2008. 84% (297/353) of cases audited were admitted in the 12 month period prior to 1st September 2008.

Other sites: 63% (55/87) of cases audited were admitted in the 6 month period prior to 1st September 2008.

	Specialist sites (n=353)			Other hospitals (n=87)		
Admission	2006	2007	2008	2006	2007	2008
January	-	6	25	-	-	3
February	-	7	26	-	-	4
March	-	3	26	-	-	4
April	-	5	36	-	-	6
May	-	3	26	-	2	12
June	-	4	33	-	1	14
July	-	9	27	-	2	15
August	-	5	18	-	1	4
September	3	21	-	1	2	-
October	3	19	-	1	6	-
November	3	19	-	1	5	-
December	5	21	-	-	3	-

Admission details

		Specialist sites (n=353)		Other hospitals (n=87)	
		%	N	%	N
1.1.2	What was the primary reason for admission to this hospital?				
	a) Emergency admission for active Crohn's Disease	35%	123	44%	38
	b) Planned admission for active Crohn's Disease	21%	74	20%	17
	c) Elective admission for surgery	16%	55	9%	8
	d) New diagnosis of Crohn's Disease	29%	101	28%	24
	Rest of table excludes Elective admissions				
1.1.3	What was the source of admission?	N=298		N=79	
	a) General Practitioner (GP)	5%	16	25%	20
	b) Accident and Emergency (A&E)	22%	66	16%	13
	c) Outpatients Department (OPD)	44%	131	41%	32
	d) Other hospital	23%	70	11%	9
	e) Not Documented	5%	15	6%	5
1.1.4	What duration of new or relapse symptoms did the patient report prior to their admission?				
	a) Less than two weeks	23%	68	35%	28
	b) Two to three weeks	11%	34	11%	9
	c) Four to eight weeks	18%	53	16%	13
	d) More than eight weeks	46%	136	33%	26
	e) Not Documented	2%	7	4%	3

Admitting Specialty (Table excludes elective admissions)

Standards:

1.2.1 Patients admitted with Crohn's Disease should be under the care of medical gastroenterologists or colorectal surgeon within 24 hours of admission.

1.2.2 Patients should be transferred to a specialist gastroenterology ward.

1.2.3 and 1.2.4. All patients should be seen by a consultant gastroenterologist or colorectal surgeon within 3 days of admission.

1.2.5 All patients should be seen by an IBD specialist nurse during admission.

		Specialist sites (n=298)		Other hospitals (n=79)	
		%	N	%	N
1.2.1	Which specialty was responsible for the patient's care 24 hours after admission?				
	a) Acute Medicine	0.3%	1	3%	2
	b) Paediatric Gastroenterology	83%	247	10%	8
	c) Paediatric Surgery	5%	15	3%	2
	d) General Paediatrics within a paediatric GI network	9%	26	20%	16
	e) Adult Gastroenterology	-	0	1%	1
	f) Colorectal surgery	0.3%	1	1%	1
	g) General Adult Medicine	-	0	1%	1
	h) General Adult Surgery	-	0	5%	4
	i) General Paediatrics	3%	8	56%	44
1.2.2	Was the patient transferred to a specialist gastroenterology ward?				
	a) Medical	46%	138	6%	5
	b) Joint	13%	40	3%	2
	c) Surgical	5%	14	4%	3
	d) Not transferred	36%	106	87%	69
1.2.3	What date was the person first seen by an adult Consultant Gastroenterologist?				
	Not Seen	99%	295	78%	62
	Not required	82%	243/295	37%	23/62
			N	Median (IQR)	N
	Date seen: days from admission	3, 26 days	2	2 (1-6)	17
1.2.3	What date was the person first seen by a Consultant Paediatrician with an interest in Gastroenterology?				
	Not Seen	97%	288	58%	46
	Not required	82%	236/288	33%	15/46
		Median (range)	N	Median (IQR)	N
	Date seen: days from admission	1 (0-5)	9	0 (0-1)	33

1.2.3 What date was the person first seen by a Consultant Paediatric Gastroenterologist?				
Not Seen	5%	15	77%	61
Not required	20%	3/15	26%	16/61
	Median (IQR)	N	Median (IQR)	N
Date seen: days from admission	1 (0-1)	283	1 (0-5)	17
1.2.4 What date was the person first seen by an adult Consultant Colorectal Surgeon?				
Not Seen	96%	286	89%	70
Not required	81%	233/286	44%	31/70
	Median (IQR)	N	Median (range)	N
Date seen: days from admission	2 (1-6)	10	0 (0-3)	9
1.2.4 What date was the person first seen by a Consultant Paediatric Surgeon?				
Not Seen	83%	248	97%	77
Not required	81%	200/248	40%	31/77
	Median (IQR)	N		N
Date seen: days from admission	1 (0-2)	49	1, 7 days	2
1.2.5 Was the patient visited by a Paediatric IBD Nurse/GI Nurse specialist during admission?				
YES	58%	173	27%	21

Comorbidity

	Specialist sites (n=353)		Other hospitals (n=87)	
	%	N	%	N
1.4.1 Does the patient have any important co-morbid diseases? (please tick all that apply)				
a) Heart Disease	0.3	1	-	0
b) Renal Failure	-	0	-	0
c) Respiratory	4	15	3	3
d) Diabetes	-	0	-	0
e) Liver Disease	0.3	1	-	0
f) Stroke	-	0	-	0
g) Liver Disease	0.3	1	-	0
h) Active cancer	-	0	-	0
i) None of the above	95	336	97	84

Inpatient Mortality

1.3.1 There were no deaths reported for any of the audited cases.

Length of stay (Discharged)

	Specialist sites (353 discharged)		Other hospitals (87 discharged)	
1.3.2 Date of discharge				
	Median (IQR)	N	Median (IQR)	N
Length of stay (days)	5 (3-8)	353	4 (2-7)	86
Length of stay:	%	N	%	N
0-1 days	9	31	14	12
2 days	13	47	14	12
3-6 days	41	143	42	36
7-13 days	27	94	16	14
14-27 days	7	24	10	9
>=28 days	4	14	3	3

Medication on Admission

	Specialist sites (n=353)		Other hospitals (n=87)	
	%	N	%	N
1.5.1 What treatment was the patient taking for Crohn's Disease on admission? (select all that apply)				
a) 5-ASA	32	113	30	26
b) Azathioprine	33	115	32	28
c) Mercaptopurine	4	13	-	0
d) Methotrexate	7	23	1	1
e) Antibiotics	9	31	2	2
f) Corticosteroids	17	61	20	17
g) Dietary Therapy	11	40	13	11
h) Anti-TNF-α	5	19	3	3
i) None of the above	35	125	45	39
j) Other (e.g. trial medicine please specify)*	2	8	7	6

*Specialist sites: budesonide (1), calcium sandoz (1), cinnamon&benzoate free diet (1), hydrocorticosone lozenges (1), modulin (1), ranitidine & domperidone (1), thalasaemia trait (1), thalidomide (1) Other hospitals: hydrocorticosone cream (1), mesalamine (2), pentasa&domperidone (1), sulpasalazine (2).

Smoking Status

Standard:

1.6.1 Smoking status should be documented (BSG guidelines**) and smoking cessation support should be offered.**

	Specialist sites (n=353)		Other hospitals (n=87)	
	%	N	%	N
1.6.1 **What is the smoking status of the patient?**				
a) Current smoker	0.8	3	2	2
b) Lifelong non-smoker/ ex-smoker	46	164	69	60
c) Not documented	53	186	29	25

Patient History

		Specialist sites (n=353)		Other hospitals (n=87)	
		%	N	%	N
1.7.1	Did the patient have a pre-admission diagnosis of Crohn's Disease?				
	YES	70	246	67	58
1.7.2	What is the extent of the disease? (if 1.7.1=Yes)				
	a) Small bowel	23	57	26	15
	b) Colonic	40	99	36	21
	c) Ileo-colonic	46	113	36	21
	d) Perianal	20	50	12	7
	e) Panenteric	14	35	9	5
	f) Not known	0.4	1	14	8
	g) Other (including combinations of above options)	6	29	5	3
1.7.3	Has patient had previous admissions to your hospital with Crohn's Disease in the last 2 years?				
	YES	66	162/246	55	32/58
	If yes, how many times in the two years prior to this admission?				
	Once	52	85	59	19
	Twice	23	37	16	5
	More than twice	25	40	25	8

Assessment: Severity of Disease (excludes elective admissions)

Standards:
2.1.2 Patients should have stool frequency documented in the first 24 hours following admission.
2.1.5 Patients should have haemoglobin, albumin and CRP (or ESR) performed in the first 24 hours following admission.

		Specialist sites (n=298)		Other hospitals (n=79)	
		%	N	%	N
2.1.1	Was diarrhoea recorded as a symptom upon admission?				
	YES	61%	182	58%	45
	No	37%	109	40%	31
	Patient has Stoma	2%	7	1%	1
2.1.2	How many stools were passed in the first full day following admission?				
	Not documented	29%	52/182	42%	19/45
	If documented	Median (IQR)	N	Median (IQR)	N
		4 (2-6)	130	3 (2-6)	26
2.1.3	What was the highest recorded pulse rate (bpm) during the first full day following admission?				
	Not documented	5%	16	13%	10
	If documented	Median (IQR)	N	Median (IQR)	N
		100 (90-113)	282	102 (88-120)	69
2.1.4	What was the highest recorded temperature (^{o}C) during the first full day following admission?				
	Not documented	6%	19	14%	11
	If documented	Median (IQR)	N	Median (IQR)	N
		37.2 (36.8-37.6)	279	37.0 (36.8-37.7)	68
	Did the patient have a fever (temperature >37.5°C on more than one occasion in 24 hours) within the first 7 days of admission?				
	YES	15%	44	24%	19
	No	79%	236	59%	47
	Not documented	6%	18	16%	13
2.1.5	At this admission, what was the initial result for **CRP** (mg/L)				
	Not documented	19%	56	18%	14
	Less than 5 mg/L	12%	37	10%	8
	If documented and >5 mg/L	Median (IQR)	N	Median (IQR)	N
		38 (19-90)	205	53 (33-86)	57
2.1.5	At this admission, what was the initial result for **Albumin** (g/L)				
	Not documented	16%	47	24%	19
	If documented	Median (IQR)	N	Median (IQR)	N
		35 (30-39)	251	34 (29-38)	60
2.1.5	At this admission, what was the initial result for **Hb** (g/dL)				
	Not documented	14%	41	16%	13
	If documented	Median (IQR)	N	Median (IQR)	N
		11.3 (10.2-12.4)	257	10.5 (9.4-11.6)	66
2.1.5	At this admission, what was the initial result for **ESR** (mmh^{-1})				
	Not documented	38%	114	63%	50
	If documented	Median (IQR)	N	Median (IQR)	N
		35 (16-52)	184	36 (17-56)	29

Assessment: Exclusion of Infection (excludes elective admissions)

Standards:
2.2.1 & 2.2.2 Patients with diarrhoea should have a standard stool culture and CDT performed within 48 hours of admission.

			Specialist sites (n=182 with diarrhoea)		Other hospitals (n=45 with diarrhoea)	
			%	N	%	N
2.2.1	Was a stool sample sent for Standard Stool Culture*					
		YES	35%	64/182	31%	14/45
	Date sent: Days from admission		Median (IQR)	N	Median (IQR)	N
			0 (0-1)	64	1 (1-4)	14
2.2.1	Was it positive					
		YES	-	0/64	-	0/14
	Date of positive sample: Days from admission		Median (IQR)	N	Median (IQR)	N
2.2.2	Was a stool sample sent for CDT*					
		YES	22%	40/182	20%	9/45
	Date sent: Days from admission		Median (IQR)	N	Median (IQR)	N
			1 (0-1)	40	2 (1-8)	9
2.2.2	Was it positive					
		YES	5%	2/40	-	0/9
	Date of positive sample: Days from admission		0, 157 days	N 2	Median (IQR)	N

Assessment: Documentation of Sepsis (excludes elective admissions)

Standards:
2.3.2 Patients with fever (>37.5° C on two occasions) should have blood cultures performed.

		Specialist sites (n=44 with fever)		Other hospitals (n=19 with fever)	
		%	N	%	N
2.3.1	Were antibiotics given? N with fever (2.1.4)				
	YES	64	28	26	5
	No	34	15	74	14
	Not documented	2	1	-	0
2.3.2	Were blood cultures taken? N with fever				
	YES	52	23	16	3
	If yes, were the cultures Positive	4	1	0	0
	If yes, were the cultures Negative	96	22	100	3

Assessment: Imaging

Standards:
2.4 For suspected abdominal sepsis, imaging should be performed within 48 hours of request and reported within 24 hours of being done.

			Specialist sites (n=353)		Other hospitals (n=87)	
			%	N		
2.4.1	Ultrasound Scan performed		15%	52	16%	14
	Date requested:					
		Same day as admission	21%	11/52	36%	5/14
			Median (IQR)	N	Median (IQR)	N
			1 (1-4)	52	1 (0-1)	14

	Date performed:				
	Performed same day as request	65%	34	71%	10
	1-2 days after request	27%	14	29%	4
	3-5 days after request	6%	3	-	0
	6 or more days after request	2%	1	-	0
2.4.2	CT Scan of the abdomen performed	3%	10	5%	4
	Date requested:				
	Same day as admission	30%	3	25%	1
		Median (IQR)	N	Median (IQR)	N
		3 (0-8)	10	1,4,5,7 days	4
	Date performed:				
	Performed same day as request	80%	8	75%	3
	1-2 days after request	10%	1	25%	1
	3-5 days after request	10%	1	-	0
	6 or more days after request	-	0	-	0
2.4.3	MRI performed	3%	12	8%	7
	Date requested:				
	Same day as admission	-	0	14%	1
		Median (IQR)	N	Median (IQR)	N
		3 (1-5)	12	0,2,3,3,9,10,19	7
	Date performed:				
	Performed same day as request	17%	2	43%	3
	1-2 days after request	50%	6	29%	2
	3-5 days after request	17%	2	14%	1
	6 or more days after request	17%	2	14%	1
2.4.4	Abscess found during imaging YES	8%	5	-	0
	No	92%	58	100%	22
	If drainage was undertaken , was it:		N=5		N=0
	a) Surgical	20%	1		
	b) Radiological	-	0		
	Not documented	80%	4		

Assessment: Weight Assessment and Dietetic Support (excludes elective admissions)

Standards:
2.5.1 Patients should be weighed (BSG guidelines) **and BMI calculated.**
2.5.3 Non-elective admissions should be seen by a dietician.
2.5.4-2.5.5 Nutritional support should be provided for malnourished patients (BSG guidelines).

		Specialist sites (n=298)		**Other hospitals (n=79)**	
		%	N	%	N
2.5.1	Was the patient's weight measured during the admission?				
	YES	97%	289	90%	71
		Median (IQR)	N	Median (IQR)	N
	What was the weight on admission?	38 (30-45)	289	41 (33-50)	70
2.5.2	Was the patient's height measured during the admission?				
	YES	30%	88	41%	32
		Median (IQR)	N	Median (IQR)	N
	What was the height on admission?	149 (136-156)	88	156 (144-163)	32
2.5.3	Did a dietician visit the patient?				
	YES	72%	214	51%	40
2.5.4	Was dietary treatment initiated?				
	YES	63%	187	52%	41
	Exclusive liquid enteral nutrition therapy prescribed	81%	151/187	66%	27/41
2.5.5	Was parenteral nutrition given?				
	YES	5%	15	5%	4

Medical Intervention:

Standard:
3.1.1 Patients should have prophylactic heparin (BSG guidelines**).**

	(excludes elective admissions)	Specialist sites (n=298)		Other hospitals (n=79)	
		%	N	%	N
3.1.1	Was the patient given:				
	Prophylactic heparin	2%	6	10%	8
3.2.1	Were IV corticosteroids prescribed during this admission?				
	i. Yes	22%	67	21%	16/77
	ii. No, but oral corticosteroids were administered	13%	39	23%	18/77
	iii. No, neither IV or Oral corticosteroids were administered	64%	192	56%	43/77
3.2.2	Which of the following steroids were prescribed?		(N on steroids)		
	Prednisolone	61%	65	59%	20
	Budesonide	1%	1	6%	2
	Hydrocortisone	38%	40	35%	12
	Initial dose (Mg per day)	Median (IQR)	N	Median (IQR)	N
	Prednisolone	40 (35-60)	65	30 (25-40)	19
	Budesonide	9	1	9, 9	2
	Hydrocortisone	200 (170-400)	40	400 (320-400)	12
3.2.3	Date therapy initiated or increased: (N on steroids)				
	Same day as admission	40%	42	56%	19
	Next day after admission	20%	21	9%	3
	2-7 days	30%	32	18%	6
	Later	10%	11	18%	6

Medical Intervention: Initiation of Treatment with anti-TNF-α During Admission

Standard:
3.3.2 All patients given anti-TNF-α for the first time should have a chest X-ray within the previous 3 months (Joint Tuberculosis Committee of the BTS in conjunction with the BSG and British Society of Rheumatology).

		Specialist sites (n=298)		Other hospitals (n=79)	
		%	N	%	N
3.3.1	Anti-TNF-α therapy given during this admission				
	YES	4%	12	4%	3
	Start date: Days after admission	Median (IQR)	N		N
		4 (1-6)	12	1,3, 11 days	3
3.3.2	Is there evidence of a chest x-ray performed in the three months prior to the initiation of anti-TNF-α therapy?				
	YES	50%	6/12	67%	2/3
	Date of chest x-ray : Days after admission	Median=1	N=6	3, 10 days	N=2

		Specialist sites (n=298)		Other hospitals (n=79)	
		%	N	%	N
3.4.1	Was the patient entered into a Clinical Trial on this admission?				
	Clinical Trial (please specify)*	3%	9*	-	0
	Start date: Days after admission	Median= 1 Range 0-11	N=9		

*entered by auditors as: Adverse Effects of Glucocorticoid Therapy on Bone in Childhood Crohn's Disease (7), randomised steroids (1), not stated (1)

Surgical Interventions

Standards:
4.1.3 Consultant colorectal surgeons should be involved with the discussion with the patient regarding the decision to operation (BSG guidelines).
4.1.4 Patients having resectional surgery for Crohn's Disease should see a stoma nurse prior to operation (BSG guidelines).
4.1.6 & 4.1.7 Operation should be performed or assisted by a consultant colorectal surgeon.
4.1.10 Patients should have ASA status documented prior to surgery.

		Specialist sites				Other hospitals			
4.1.1	Did the patient have surgery on this admission?	Electives 98% (54/55)		Non-Electives 11% (34/298)		Electives 88% (7/8)		Non-Electives 5% (4/79)	
	WITH SURGERY	Electives (54)		Non-electives (34)		Electives (7)		Non-electives (4)	
		%	N	%	N	%	N	%	N
4.1.2	What date was the decision to operate made?								
	Not known	-	0	-	0	29%	2	-	0
	Date of decision: days from admission	Median (IQR)	N	Median (IQR)	N		N		N
		-21 (-59 to -10)	54	1 (0-4)	34	-61,-51,-12,-9, 1	5	0,0,1,6 days	4
4.1.3	Which Surgeon made the decision to operate?								
	a) Consultant Paediatric Surgeon	65%	35	74%	25	43%	3	-	0
	b) Consultant Colorectal Surgeon	31%	17	15%	5	57%	4	75%	3
	c) Consultant GI Surgeon (non-colorectal)	-	0	3%	1	-	0	25%	1
	d) Consultant General Surgeon	-	0	-	0	-	0	-	0
	e) Other Consultant Surgeon	-	0	-	0	-	0	-	0
	f) Specialist Registrar	-	0	9%	3	-	0	-	0
	g) *Other (please specify)	4%	2	-	0	-	0	-	0
	Not documented	-	0	-	0	-	0	-	0

4.1.4	Patient seen by a stoma nurse during this admission	22%	12	24%	8	14%	1	-	0
	If yes, date first seen : days from admission	Median (IQR) 1 (0-2)	N 12	Median =8 Range 2-33	N=8	2 days	N 1		
4.1.5	Date of Surgery: days from admission	Median (IQR) 1 (0-1)	N 54	Median (IQR) 2 (1-9)	N 34	0,0,0,0,1,1,31	N 7	0,1,1,6 days	N 4
4.1.6	What was the grade of the operating surgeon?								
	a) Consultant Paediatric Surgeon	61%	33	68%	23	29%	2	-	0
	b) Consultant Colorectal Surgeon	30%	16	18%	6	71%	5	50%	2
	c) Consultant GI Surgeon (non-colorectal)	-	0	3%	1	-	0	25%	1
	d) Consultant General Surgeon	-	0	-	0	-	0	-	0
	e) Other Consultant Surgeon	-	0	-	0	-	0	-	0
	f) Specialist Registrar	6%	3	12%	4	-	0	25%	1
	g) Associate specialist	-	0	-	0	-	0	-	0
	h) **Other (please specify)	4%	2	-	0	-	0	-	0
4.1.7	What was the grade of the assisting surgeon?								
	a) Consultant Paediatric Surgeon	6%	3	-	0	-	0	-	0
	b) Consultant Colorectal Surgeon	-	0	-	0	-	0	25%	1
	c) Consultant GI Surgeon (non-colorectal)	-	0	-	0	-	0	-	0
	d) Consultant General Surgeon	-	0	3%	1	-	0	-	0
	e) Other Consultant Surgeon	-	0	-	0	-	0	-	0
	f) Specialist Registrar	87%	47	82%	28	86%	6	50%	2
	g) Associate specialist	2%	1	-	0	14%	1	-	0
	h) **Other (please specify)	6%	3	15%	5	-	0	25%	1

* Gastroenterologist (1), consultant paediatric gastroenterologist (1)
** Consultant (1), consultant paediatric gastroenterologist (1)
*** Specialist centre Elective: SHO (1), none (1) not known (1); Specialist centre non-elective: consultant paediatric gastroenterologist (1), medical student (1), None (3). Other hospital non-elective: FY2 (1)

		Specialist sites				**Other hospitals**			
		Electives (54)		Non-electives (34)		Electives (7)		Non-electives (4)	
		%	N	%	N	%	N	%	N
4.1.8	What were the indications for surgery?								
	a) Failure of Medical Therapy	57%	31	24%	8	71%	5	-	0
	b) Obstruction	26%	14	26%	9	14%	1	-	0
	c) Intra-abdominal Abscess	-	0	3%	1	-	0	-	0
	d) Intra-abdominal fistula	4%	2	-	0	-	0	-	0
	e) Stoma complications	-	0	-	0	-	0	-	0
	f) Perineal disease	17%	9	35%	12	14%	1	50%	2
	g) Toxic megacolon	-	0	-	0	-	0	-	0
	h) Bleeding	6%	3	3%	1	-	0	-	0
	i) Dysplasia	-	0	-	0	-	0	-	0
	j) Cancer	-	0	-	0	-	0	-	0
	k) Perforation	-	0	15%	5	-	0	25%	1
	l) Other (please specify)*	4%	2	-	0	29%	2	-	0
4.1.9	Type of intervention :								
	a) Segmental/Extended Colectomy	13%	7	9%	3	29%	2	-	0
	b) Subtotal Colectomy	15%	8	9%	3	14%	1	-	0
	c) Proctocolectomy	2%	1	-	0	-	0	-	0
	d) Stricturoplasty	4%	2	3%	1	-	0	-	0
	e) Ileal/Jejunal Resection	4%	2	12%	4	-	0	-	0
	f) Resection of Intra-abdominal Fistula	2%	1	-	0	-	0	-	0
	g) Proctectomy	%	0	-	0	-	0	-	0
	h) Completion proctectomy	%	0	-	0	-	0	-	0
	i) Ileocolonic Resection	31%	17	15%	5	29%	2	25%	1
	j) Drainage of abscess	%	0	18%	6	14%	1	50%	2
	k) Formation of ileostomy or colostomy	13%	7	18%	6	-	0	-	0
	l) Revision of Stoma	2%	1	-	0	14%	1	-	0
	m) Perineal procedure	6%	3	24%	8	-	0	-	0
	n) Other intervention (please specify)**	4%	2	-	0	-	0	25%	1

4.1.9i	Was the surgery done laparoscopically/ laparoscopically-assisted?								
	YES	28%	15	9%	3	29%	2	-	0

		Specialist sites				Other hospitals			
		Electives (54)		Non-electives (34)		Electives (7)		Non-electives (4)	
		%	N	%	N	%	N	%	N
4.1.10	ASA status recorded pre-operatively	44%	24	35%	12	71%	5	25%	1
	If yes, what was the status?								
	1	13%	3	25%	3	-	0	100%	1
	2	63%	15	42%	5	100%	5	-	0
	3	8%	2	33%	4	-	0	-	0
	4	%	0	-	0	-	0	-	0
	5	%	0	-	0	-	0	-	0
	N/A	17%	4	-	0	-	0	-	0

* Stoma closure (4)

** Specialist centre: stoma closure (2). Other hospitals: diagnostic laparoscopy/laparotomy (1)

Surgical Complications

		Specialist sites				Other hospitals			
		Electives (54)		Non-electives (34)		Electives (7)		Non-electives (4)	
		%	N	**%**	N	%	N	**%**	N
4.2.1	Did the patient suffer from any of these complications following their surgery?								
	a) Wound Infection	11%	6	-	0	-	0	-	0
	b) Rectal stump complications	-	0	-	0	-	0	-	0
	c) Intra-abdominal bleeding	-	0	3%	1	-	0	-	0
	d) Intra-abdominal sepsis	-	0	3%	1	-	0	-	0
	e) Anastomotic leakage	-	0	-	0	-	0	-	0
	f) Stoma complications	-	0	-	0	-	0	-	0
	g) Deep vein thrombosis (DVT)	-	0	-	0	-	0	-	0
	h) Pulmonary embolus (PE)	-	0	-	0	-	0	-	0
	i) Ileus requiring TPN	2%	1	9%	3	-	0	-	0
	j) Cardiac	-	0	-	0	-	0	-	0
	k) Respiratory	-	0	-	0	-	0	-	0
	l) Clostridium difficile-associated diarrhoea (CDAD)	-	0	-	0	-	0	-	0
	m) Other (please specify)*	2%	1	-	0	-	0	-	0
	n) No complications	81%	44	88%	30	100%	7	100%	4

*Ileus (1)

Post-Operative Prophylactic Therapy

Standard:

4.3.1 Prophylactic therapy to try to reduce recurrence should be discussed with Crohn's Disease patients having resectional surgery with anastomosis (BSG Guidelines).

There are some types of intervention where post operative prophylactic therapy is indicated and others where it is not. The indications are for Segmental/Extended Colectomy, Subtotal Colectomy, Ileal/Jejunal Resection and Ileocolonic Resection (4.1.9). These form the denominator for the next table.

		Specialist sites				Other hospitals			
		Electives (31)		Non-electives (13)		Electives (5)		Non-electives (1)	
		%	N	%	N	%	N	%	N
4.3.1	Was patient prescribed any of the following drugs on discharge? (please select all that apply)								
	a) Azathioprine	42%	13	69%	9	100%	5	-	0
	b) Mercaptopurine	6%	2	8%	1	-	0	-	0
	c) Metronidazole	3%	1	8%	1	-	0	-	0
	d) 5-ASA	42%	13	38%	5	80%	4	-	0
	e) Methotrexate	3%	1	8%	1	-	0	-	0
	f) None	23%	7	8%	1	-	0	100%	1

Other drugs: Specialist centre (Elective) - corticosteroids weaning dose (1), sulphate/paracetamol/dicofenac (1); Specialist centre (non-elective) - Non-elective: iron (1); Other hospitals: corticosteroids weaning dose (1).

Discharge Arrangements

Standards:
Patients should be followed up by a gastroenterologist or colorectal surgeon.
5.1.2 Patients discharged on oral steroids should have a steroid reduction programme stated on discharge.
5.1.3 Patients on oral steroids should be co-prescribed bone protection agents (such as calcium and vitamin D or bisphosphonates (BSG Guidelines).

		Specialist sites (n=353)		Other hospitals (n=87)	
		%	N	%	N
5.1.1 Was the patient taking oral steroids on discharge?					
	YES	35%	122	40%	35
	No	65%	230	56%	49
	N/A	0.3%	1	3%	3
5.1.2 Was a steroid reduction programme stated on discharge? (N on steroids)					
	YES	77%	94	83%	29
	No	21%	26	17%	6
	N/A	2%	2	-	0
5.1.3 Were bone protection agents prescribed? (N on steroids)					
	YES	14%	17	29%	10

Section 7. Clinical Audit: Crohn's Disease (Outpatient)

Patient History

Standard:
6.1.3 Continuity of care in hospital outpatient visits matters to patients - patients dislike seeing different individuals at each visit (BSG guidelines**). Patients should be offered the opportunity to see an IBD specialist (nurse or doctor) at last once a year.**

		Specialist sites (n=353)		Other hospitals (n=87)	
		%	N	%	N
6.1.1	Has patient had previous outpatient visits for Crohn's Disease at this hospital in last 12 months?				
	YES	56%	197	55%	48
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)	N	Median (IQR)	N
		4 (2-6)	197	4 (2-7)	48
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? (If the patient was seen by more than one of the following staff in a single clinic visit please count each staff member individually)*				
		Median (IQR)	N	Median (IQR)	N
	Consultant	3 (2-5)	197	4 (2-7)	48
	IBD Nurse Specialist	0 (0-1)	197	0 (0-0)	48
	Specialist Registrar	0 (0-1)	197	0 (0-0)	48
	F2 (SHO)	0 (0-0)	197	0 (0-0)	48
6.1.4	What was the date of the last visit at the Outpatient Department prior to admission?				
		Median (IQR)	N	Median (IQR)	N
	Days before current admission	-41 (-82 to -15)	197	-32 (-72 to -11)	48
6.1.4	Did this visit directly initiate the admission being audited in the previous sections 1 to 5?				
	YES	8%	16	17%	8
	NO	92%	181	83%	40

*** Specialist sites:** For 97% (191/197) of cases patient was seen by a consultant, in 17% (33/197) by an IBD specialist nurse, in 44% (87/197) by a specialist registrar and in 8% (15/197) by a F2/SHO.

*** Other hospitals:** For 100% (48/48) of cases patient was seen by a consultant, in 19% (9/48) by an IBD specialist nurse, in 19% (9/48) by a specialist registrar and in 0% (0/48) by a F2/SHO.

The remaining outpatient results are for those who were said to have had a previous outpatient visit in the last 12 months but whose visit did not directly initiate the admission being audited in the previous sections (Q6.1.4).

Assessment of Crohn's Activity

Standard:

6.2.1 – 6.2.7i Patients should have general well being, stool frequency, presence and severity of abdominal pain documented. Weight should be documented (BSG guidelines)**. CRP (ESR) and albumin should be checked.**

		Specialist sites (n=181)		Other hospitals (n=40)	
		%	N	%	N
6.2.1	Number of liquid stools per day	Median (IQR)	N	Median (IQR)	N
		2 (0-4)	115	2 (0-3)	22
6.2.2	General well being:	%	N	%	N
	Well	32	58	23	9
	Mild symptoms	31	56	48	19
	Moderate symptoms	30	54	25	10
	Severe symptoms	4	7	3	1
	Not documented	3	6	3	1
6.2.3	Abdominal Pain				
	None	41	75	30	12
	Present	49	89	58	23
	Not documented	9	17	13	5
6.2.4	Abdominal Mass				
	None	69	125	68	27
	Present	3	5	3	1
	Not documented	28	51	30	12
6.2.5	Did the patient report any of the following complications at this clinical visit?				
	a)Mouth ulcers	7	12	5	2
	b)Arthralgia	7	13	8	3
	c)Pyoderma Gangrenosum	1	2	-	0
	d) Anal fissure	7	13	3	1
	e) Fistula	4	7	5	2
	f) Erythaema Nodosum	-	0	-	0
	g) Abscess	2	3	3	1
	h) Iritis	-	0	-	0
6.2.6	**CRP**	%	N	%	N
	CRP low <5	19	34	13	5
		Median (IQR)	N	Median (IQR)	N
	CRP (if 5 and above)	27 (12-49)	80	27 (18-56)	19
6.2.6	**Albumin** (g/L)				
	If documented	Median (IQR)	N	Median (IQR)	N
		38 (35-41)	122	38 (31-43)	22
6.2.6	**Hb** (g/dL)				
	If documented	Median (IQR)	N	Median (IQR)	N
		11.7 (10.7-12.5)	127	11.3 (10.3-12.2)	26
6.2.6	**ESR** (mmh^{-})				
	If documented	Median (IQR)	N	Median (IQR)	N
		30 (14-41)	96	28 (17-46)	19
6.2.7	Was the patient weighed during this clinic visit?	%	N	%	N
	YES	95	172	83	33
6.2.7i	Was there evidence of unintentional weight loss of more than 3kgs (or more than 10%) prior to this clinic visit?				
	No	88	151	85	28
	Yes	10	17	12	4
	Not documented	2	4	3	1

Monitoring of immunosuppressive therapy

Standard:

6.4.2 – 6.4.3 Full blood count should be monitored at least 3 monthly for patients on established immunosuppressive therapy (BSG guidelines).

		Specialist sites (n=181)		Other hospitals (n=40)	
		%	N	%	N
6.4.1	Was patient taking any of these drugs in the 12 months prior to the start date of this admission?				
	Azathioprine	56%	102	63%	25
	Mercaptopurine	8%	14	-	0
	Methotrexate	13%	24	5%	2
	None of these	28%	51	33%	13
6.4.2	Was the patient's white blood cell (WBC) count routinely measured? (denominator comprises those on any of the three drugs in 6.4.1)				
	YES	98%	128/130	96%	26/27
6.4.3	How often was WBC monitoring performed?		N=128		N=26
	At least once a month	34%	43	65%	17
	Every 2-3 months	57%	73	23%	6
	Other	3%	4	8%	2
	Not documented	6%	8	4%	1
6.4.4	Did patient's WBC fall below $3x10^9$ at any time during 12 months prior to the start date of this admission?				
	YES	7%	9/128	-	0/26
6.4.5	If the white blood cell count was less than $3.0x10^9$ what action was taken?				
	Reduced dose	-	0		
	Stopped drug	56%	5		
	No action taken	44%	4		
6.4.6	What was the outcome of the reduced white blood cell count?				
	No sequelae (resolved)	100%	9		
	Treatment required (e.g. prophylactic antibiotics)	-	0		
	Admission	-	0		

Use of Corticosteroids

Standards:

6.5.2 Prolonged use of steroid therapy is of no benefit in maintaining remission in Crohn's Disease, increases the risk of septic complications and is associated with an increased mortality. Prolonged use of steroids (>3 months oral prednisolone or budesonide) should be avoided.

6.5.3 Patients on oral steroids should be co-prescribed bone protection agents (BSG Guidelines).

		Specialist sites (n=181)		Other hospitals (n=40)	
		%	N	%	N
6.5.1	Was the patient taking oral corticosteroids for their Crohn's Disease in the 12 months prior to the start date of this admission?				
	YES	52%	95	53%	21
	If YES to Q6.5.1				
6.5.2	Was there any point at which the patient was taking oral corticosteroids continuously for more than three months?				
	YES	27%	26/95	52%	11/21
6.5.3	Were bone protection agents prescribed alongside corticosteroids?				
	YES	25%	24/95	14%	3/21

Specialist sites: Of those who were on corticosteroids for > 3 months 62% (16/26) were not on bone protection agents

Other hospitals : Of those who were on corticosteroids for > 3 months 100% (11/11) were not on bone protection agents

Use of anti-TNF-α therapy

Standards:
6.6.3 Patients initiated on infliximab should have severely active Crohn's Disease (NICE guidance**).**
6.6.5 All patients receiving infliximab therapy should be on concomitant immunosuppressive therapy if tolerated (BSG Guidelines).
6.6.7 Infliximab treated patients should have a documented chest X-ray within 3 months prior to first treatment (Joint Tuberculosis Committee of the BTS in conjunction with the BSG and British Society of Rheumatology).

			Specialist sites (n=181)		Other hospitals (n=40)	
			%	N	%	N
6.6.1	Did the patient receive anti-TNF-α therapy in the 12 months prior admission?					
		YES	21%	38	18%	7
6.6.2	Was anti-TNF-α therapy initiated at any point in the 12 months prior to the start date of this admission?					
		YES	66%	25/38	71%	5/7
6.6.3	Did the patient have severely active Crohn's Disease at the time anti-TNF-α therapy was initiated?					
		YES	92%	23/25	100%	5/5
6.6.4	What was the CRP prior to the first anti-TNF-α infusion on record?		Median (IQR)	N		N
			56 (14-101)	16	11,72	2
			Low <5	4		2
6.6.5	Was the patient on immunosuppressive therapy at this time?					
		YES	88%	22/25	80%	4/5
	If NO, is there any evidence that patient was intolerant of these immunosuppressive therapies?					
		YES	33%	1/3	-	0/1
6.6.6	Was fistulating disease the primary reason for the decision to initiate anti-TNF-α therapy?					
		YES	8%	2/25	-	0/5
6.6.7	Did the patient have a chest X-ray to exclude TB in the three months prior to initiation of anti-TNF-α therapy?					
		YES	80%	20/25	60%	3/5

Specialist sites: Of those who were on corticosteroids for > 3 months (Q6.5.2), 35% (9/26) received anti-TNF-α therapy in the 12 months prior admission

Other hospitals: Of those who were on corticosteroids for > 3 months (Q6.5.2), 27% (3/11) received anti-TNF-α therapy in the 12 months prior admission

Appendix 1

UK IBD Audit Steering Group – March 2009

Chair & UK IBD Audit Clinical Director
Dr Ian Arnott, Consultant Gastroenterologist, Western General Hospital, Edinburgh, NHS Lothian

Association of Coloproctology of Great Britain and Ireland
Miss Asha Senapati, Consultant Surgeon, Portsmouth Hospitals NHS Trust

British Dietetic Association
Dr Miranda Lomer, Locum Consultant Dietitian in Gastroenterology, Guy's and St Thomas' NHS Foundation Trust

British Society of Gastroenterology
Dr Stuart Bloom, Consultant Physician and London Gastroenterologist, University College London Hospitals NHS Foundation Trust.

British Society of Gastroenterology
Dr Keith Leiper, Consultant Gastroenterologist, Royal Liverpool and Broadgreen University Hospitals NHS Trust & UK IBD Audit Clinical Director

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 Simon Travis, Clinical Director of Gastroenterology & Endoscopy, Oxford Radcliffe Hospitals NHS Trust

British Society of Gastroenterology
Dr Ian Shaw, Consultant Gastroenterologist, Gloucestershire Hospitals NHS Foundation Trust

British Society of Gastroenterology
Dr Abraham Varghese, Consultant Gastroenterologist, Causeway Hospital, Northern Health and Social Care Trust

British Society of Paediatric Gastroenterology Hepatology and Nutrition
Dr Sally Mitton, Consultant / Senior Lecturer Paediatric Gastroenterology, St George's Hospital, London Paediatric Gastroenterology Unit.

British Society of Paediatric Gastroenterology Hepatology and Nutrition
Dr Richard Russell, Consultant Paediatric Gastroenterologist, Royal Hospital for Sick Children (Yorkhill), NHS Greater Glasgow & Clyde

National Association for Colitis and Crohn's Disease (NACC)
Mr Richard Driscoll, Chief Executive (NACC)

Newport Local Health Board
Mr John Frankish, Head of Service Modernisation, Newport Local Health Board

Royal College of Nursing Crohn's and Colitis Special Interest Group
Ms Lindsey Hurst, IBD Clinical Nurse Specialist, North Tees and Hartlepool NHS Foundation Trust

Royal College of Nursing Crohn's and Colitis Special Interest Group
Ms Karen Kemp, IBD Clinical Nurse Specialist, Central Manchester University Hospitals NHS Foundation Trust

Royal College of Nursing Crohn's and Colitis Special Interest Group
Ms Allison Nightingale, IBD Clinical Nurse Specialist, Cambridge University Hospitals NHS Foundation Trust

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
Dr Barney Hawthorne, Consultant Gastroenterologist, Cardiff and Vale NHS Trust

Royal College of Physicians
Ms Jane Ingham, Director of Clinical Standards

Royal College of Physicians
Ms Clare Moloney, Project Co-ordinator, UK IBD Audit

Royal College of Physicians
Dr Jonathan Potter, Clinical Director, Clinical Effectiveness and Evaluation Unit

Royal Pharmaceutical Society of Great Britain
Ms Jackie Eastwood, Senior Specialist Gastroenterology Pharmacist, St. Mark's Hospital

UK IBD Audit 2008
Paediatric Gastroenterology
Organisation & Structure Proforma

This Proforma relates to your Paediatric IBD Services as at 1st September 2008

Auditor Discipline: **Which people have been involved in the collection and input of data for this form?** (Select all that apply)

a) Consultant ☐ b) Other medical staff ☐ c) Nurse ☐ d) Manager ☐

e) Clinical Audit staff ☐ f) Other (please specify): ☐

1 General Hospital Demographics

1.1 **How many paediatric beds does your hospital have in total?** ☐☐☐☐

1.2 **Does your centre have a Paediatric Intensive Care Unit (ICU)/High Dependency Unit (HDU) on site?** Yes ☐ No ☐

i. If yes is it: a) Medical ☐ b) Surgical ☐ c) Mixed ☐

ii. If yes, how many ICU beds? ☐☐☐

iii. If yes, how many HDU beds? ☐☐☐

2 Inpatient Activity

2.1 **How many patients aged under 16 years at the time of admission were discharged between 1st September 2007 and 31st August 2008 with a primary diagnosis of:**

i. Ulcerative Colitis ☐☐☐☐

ii. Crohn's Disease ☐☐☐☐

2.2 **How many patients aged under 16 years at the time of admission were discharged between 1st September 2007 and 31st August 2008 having had an operation where the primary indication was:**

i. Ulcerative Colitis ☐☐☐☐

ii. Crohn's Disease ☐☐☐☐

2.3 **Do surgeons perform ileo-anal pouch surgery on site for patients aged <16?** Yes ☐ No ☐

i. If yes, how many ileo-anal pouch operations were performed on site for patients aged <16 between **1st September 2007 and 31st August 2008**? ☐☐☐☐

3 Gastroenterology Services

3.1 **Is there a dedicated Paediatric Gastroenterology ward?** Yes ☐ No ☐

i. If yes, how many beds per lavatory on the ward? ☐☐.☐

ii. Are any of the toilets Mixed-Sex? Yes ☐ No ☐

3.2 **How many WTE Paediatric Gastroenterologists are there on site?** ☐☐.☐

3.3 **How many Paediatric Gastroenterology staff of the following grades are there on site?**

i. Specialist Registrar (SpR) ☐☐

ii. Associate Specialist ☐☐

3.4 **How many WTE Paediatric IBD Nurse Specialists are there on site?** ☐☐.☐

3.4 **i. If 0 have you submitted a business case for a Paediatric IBD Nurse Specialist post?** Yes ☐ No ☐

ii. Was the business case successful? Yes ☐ No ☐ Decision pending ☐

3.5 **How many sessions of Paediatric IBD Specialist Nurse time are dedicated to IBD care per week?** ☐☐

4 Colorectal Services

4.1 **How many WTE Consultant Paediatric Surgeons are there on site?** ☐☐.☐

4.2 **How many Paediatric Surgery staff of the following grades are there on site?**

i. Specialist Registrar (SpR) ☐☐

ii. Associate Specialist ☐☐

4.3 **How many WTE Paediatric Stoma Nurses are there on site?** ☐☐.☐

4.4 **How many sessions of Paediatric Stoma Nurse time are dedicated to stoma care per week?** ☐☐ N/A ☐

5 Multi-Disciplinary Working

5.1 **Is there a searchable database of Paediatric IBD patients on site?** Yes ☐ No ☐

5.2 **Do timetabled meetings where IBD patients are discussed take place between the following specialties:**

i. Paediatric Gastroenterologists and Paediatric Surgeons Yes ☐ No ☐

ii. Paediatric Gastroenterologists and Colorectal Surgeons Yes ☐ No ☐

iii. Paediatric Gastroenterologists and Pathologists Yes ☐ No ☐

iv. Paediatric Gastroenterologists and Radiologists Yes ☐ No ☐

v. Surgeons (Colorectal or Paediatric) and Pathologists Yes ☐ No ☐

vi. Surgeons (Colorectal or Paediatric) and Radiologists Yes ☐ No ☐

5.3 **Is there a specialist GI Pathologist?** Yes ☐ No ☐

5.4 **Is there a specialist GI Radiologist?** Yes ☐ No ☐

6 Dietetics and Nutritional Services

6.1 **Is there a hospital paediatric nutrition team?** Yes ☐ No ☐

6.2 **Does the team go on ward rounds?** Yes ☐ No ☐

i. If yes, how frequently? Daily ☐ Weekly ☐ Other (please specify): ☐

6.3 **How many paediatric dietetic sessions per week are dedicated to GI disorders (not just IBD)?** ☐☐

7 Outpatient Services

7.1 **Is there written information for paediatric patients with IBD on whom to contact in the event of a relapse?** Yes ☐ No ☐

7.2 **In general, how soon could a relapsed patient expect to be seen in clinic?**

a) Less than 7 days ☐ b) Between 7-14 days ☐ c) Other (please specify): ☐

7.3 **Do patients have access to a Paediatric IBD specialist by any of the following methods (tick all that apply)**

a) Telephone ☐ b) Drop-in clinic ☐ c) Email ☐ d) None of these ☐

7.4 **Are there any joint or parallel clinics run between Paediatric Gastroenterologists and Surgeons?**

a) Joint ☐ b) Parallel ☐ c) Neither ☐

8 Patient Information

8.1 **Are patients provided with written information about IBD?** Yes ☐ No ☐

i. If yes, is the information produced by: (select all that apply)

a) NACC ☐ b) CICRA ☐

c) Pharmaceutical ☐ d) Locally written ☐ e) Drug specific ☐

f) Other (please specify) ☐

9 Monitoring of Established Immunosuppressive Therapy

9.1 **How is established immunosuppressive therapy monitored? *(Please tick all that apply)***

a) By the GP ☐ c) During clinic visits ☐

b) A dedicated monitoring service ☐ d) A combination of primary and secondary care monitoring ☐

10 IBD Support Services

10.1 **Is there a paediatric to adult handover clinic for young patients with IBD?** Yes ☐ No ☐

10.2 **Is a registered counsellor available to patients as part of your paediatric IBD Service?** Yes ☐ No ☐

10.3 **Are there any psychologists attached to the paediatric Gastroenterology service?** Yes ☐ No ☐

i. If yes, how many sessions per month are dedicated to the paediatric Gastroenterology service? ☐☐.☐

10.4 **Do pathways exist for direct access to psychological support?** Yes ☐ No ☐

10.5 **Is there an acute pain management team on site?** Yes ☐ No ☐

11 Management of Ulcerative Colitis

11.1 **Do written trust guidelines exist for the management of acute or severe colitis?** Yes ☐ No ☐

12 Interactions between your Hospital and it's Paediatric IBD Patients

12.1 **Does your hospital offer open forums or meetings for paediatric patients with IBD?** Yes ☐ No ☐

i. If yes, how often do these take place?

- a) Less than 4 monthly ☐
- b) Every 4-8 months ☐
- c) Every 8-12 months ☐
- d) Other (please specify) ☐

ii. Which staff attend these meetings? (select all that apply)

- a) Medical ☐
- b) Surgical ☐
- c) Nursing ☐
- d) Other (please specify) ☐

12.2 **Are any of the following activities or systems in place to involve patients in giving their views on the development of your paediatric IBD services? (Please tick all that apply)**

- a) Regular patient surveys ☐
- b) Individual patient representatives ☐
- c) Patient panel meetings ☐
- d) None ☐
- e) Other (please specify) ☐

UK IBD Audit 2008
Paediatric Ulcerative Colitis Proforma

Pre-section: Patient Demographics

A **Auditor Discipline:** a) Consultant ☐ b) Other medical staff ☐ c) Nurse ☐ d) Manager ☐
e) Clinical Audit staff ☐ f) Other (please specify): ☐

B **Patient Audit Number:** (Once you begin to enter this case onto the audit website it will be allocated a Patient ID number, record this on the paper form for reference) ☐☐☐☐

C **What was the patient's age at admission?** ☐☐

D **Gender:** Male ☐ Female ☐

E **What are the first 2 characters of the patient's postcode?** ☐☐

Section 1: Admission / Mortality

1.1 Admission

1.1.1 **What was the date of admission to this hospital?** ☐☐/☐☐/☐☐

1.1.2 **What was the primary reason for admission?**

*Please note that if option **c) Elective admission for surgery** was the primary reason for admission then you do not need to answer the following questions:

Section 1: Questions 1.1.3 through to 1.1.9
Section 2: Questions 2.2.1 through to 2.2.6 2.3.1 and 2.3.2
Section 3: None of the questions in Section 3
Section 4: None of the questions in section 4 apart from 4.1.1

a) Emergency admission for active Ulcerative Colitis ☐
b) Planned admission for active Ulcerative Colitis ☐
c) Elective admission for surgery ☐
d) New diagnosis of Ulcerative Colitis ☐

*If none of the above options a) – d) can be chosen please disregard this patient's notes and choose the next case to enter

1.1.3 **What was the source of admission to this hospital?**

a) General Practitioner (GP) ☐
b) Accident and Emergency (A&E) ☐
c) Outpatients Department (OPD) ☐
(Includes referrals from a formally booked IBD telephone clinic)
d) Other hospital ☐
e) Not documented ☐

1.1.4 **What was the duration of active colitis (new or relapse) precipitating this admission?**

a) Less than two weeks ☐
b) Two to three weeks ☐
c) Four to eight weeks ☐
d) More than eight weeks ☐
e) Not documented ☐

1.1.5 Which specialty was responsible for the patient's care 24 hours after admission?

a) Acute Medicine ☐ b) Paediatric Gastroenterology ☐ c) Paediatric Surgery ☐

d) General Paediatrics within a paediatric GI network ☐ e) Adult Gastroenterology ☐ f) Colorectal Surgery ☐

g) General Adult Medicine ☐ h) General Adult Surgery ☐ i) General Paediatrics ☐

j) Other ☐ please specify:

1.1.6 i. What date was the patient first seen by a Consultant Paediatric Gastroenterologist? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

ii. What date was the patient first seen by a Consultant Paediatrician with an interest in Gastroenterology? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

iii. What date was the patient first seen by an adult Consultant Gastroenterologist? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

1.1.7 i. What date was the patient first seen by a Consultant Paediatric Surgeon? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

ii. What date was the patient first seen by a Consultant Colorectal Surgeon? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

1.1.8 Was the patient visited by a Paediatric IBD Nurse/GI Nurse specialist during admission? Yes ☐ No ☐

1.1.9 Was the patient transferred to a specialist gastroenterology ward?

a) Medical ☐ b) Joint ☐ c) Surgical ☐ d) Not transferred ☐

1.1.10 Was the patient's weight measured during the admission? Yes ☐ No ☐

i. What was the weight on admission? ☐☐.☐ **kg** ☐

1.1.11 Was the patient's height measured during the admission? Yes ☐ No ☐

i. What was the height on admission? ☐☐☐ **cm**

1.2 Comorbidity

1.2.1 Does the patient have any significant co-morbid diseases? (please tick all that apply)

a) Heart Disease ☐ b) Renal Failure ☐

c) Respiratory ☐ d) Diabetes ☐

e) Liver Disease ☐ f) Stroke ☐

g) None of the above ☐

1.3 Mortality/Discharge

1.3.1 Did the patient die during admission? Yes ☐ No ☐

If yes

i. Date of death ☐☐/☐☐/☐☐

ii. Primary cause of death: _____

iii. Please use this space to enter any further details of death if required:
(max of 300 characters)

If no

1.3.2 Date of discharge ☐☐/☐☐/☐☐

Section 2: Assessing the extent of UC

2.1 Patient History

2.1.1 Did the patient have a pre-admission diagnosis of Ulcerative Colitis? Yes ☐ No ☐

2.1.2 Has the patient had previous admissions with Ulcerative Colitis in the two years prior to this admission? Yes ☐ No ☐

i. If yes, how many times in the two years prior to this admission? ☐☐

2.2 Severity of Disease

2.2.1 How many stools were passed in the first full day following admission? ☐☐ Not documented ☐

Not applicable, patient had stoma ☐

2.2.2 What was the highest recorded pulse rate during the first full day following admission? ☐☐☐ bpm

Not documented ☐

2.2.3 What was the highest temperature recorded during the first full day following admission? ☐☐.☐ °C

Not documented ☐

2.2.4 At this admission, what was the initial result for:

i. CRP	☐☐☐	mg/L	Less than 5 ☐	Not documented ☐
ii. Albumin	☐☐	g/L	Not documented ☐	
iii. Hb	☐☐.☐	g/dL	Not documented ☐	
iv. ESR	☐☐☐	mmh^{-1}	Not documented ☐	

2.2.5 Was a stool sample sent for Standard Stool Culture? Yes ☐ No ☐

i. Date sent: ☐☐/☐☐/☐☐

ii. Was it positive? Yes ☐ No ☐

iii. Date of positive sample ☐☐/☐☐/☐☐

2.2.6 Was a stool sample sent for CDT? Yes ☐ No ☐

i. Date sent: ☐☐/☐☐/☐☐

ii. Was it positive? Yes ☐ No ☐

iii. Date of positive sample ☐☐/☐☐/☐☐

2.3 Endoscopic Assessment

2.3.1 On this admission, did the patient have any of the following procedures? (Please tick all that apply)

a) Rigid sigmoidoscopy ☐ b) Flexible Sigmoidoscopy ☐ c) Colonoscopy ☐

d) None of the above ☐

i. Date of first procedure: ☐☐/☐☐/☐☐

2.3.2 Were biopsies taken for histology? Yes ☐ No ☐

i. Date histology reported by histopathology: ☐☐/☐☐/☐☐

Section 3: Monitoring of Colitis – Post-Admission

3.1 General information

3.1.1 In the first 7 days following admission did the patient have a persistent* Tachycardia? Yes ☐ No ☐

*Defined as the patient having the following bpm **on more than one occasion in 24 hours** in relation to their age on admission:

- Patients aged 4 years and under = pulse rate over 140bpm
- Patients aged between 5 and 7 years = pulse rate over 130bpm
- Patients aged between 8 and 11 years = pulse rate over 120bpm
- Patients aged between 12 and 15 years = pulse rate over 100bpm

i. If yes, date recorded ☐☐/☐☐/☐☐

3.1.2 In the first 7 days following admission did the patient have a Fever
(Temperature >37.5°C on more than one occasion in 24 hours) Yes ☐ No ☐

i. If yes, date recorded ☐☐/☐☐/☐☐

3.1.3 In the first seven days following admission, how often was stool frequency monitored?

a) Daily ☐ b) Every 2-3 days ☐ c) Every 4-6 days ☐

d) Once a week ☐ e) Not applicable, stoma present ☐ f) Not documented ☐

3.1.4 In the first seven days following admission, how often was CRP monitored?

a) Daily ☐ b) Every 2-3 days ☐ c) Every 4-6 days ☐

d) Once ☐ e) Not documented ☐

3.1.5 **At any point following the first 72-hours of steroid therapy was the patient's CRP level reported to be greater than 45mg/L?**

Yes ☐

No ☐

Not documented ☐

3.2 Monitoring of Colitis – Radiology

3.2.1 **Was a plain abdominal X-Ray performed?**

Yes ☐

No ☐

i. Date requested ☐☐/☐☐/☐☐

ii. Date performed ☐☐/☐☐/☐☐

iii. Date reported by Radiologist ☐☐/☐☐/☐☐

3.2.2 **Was toxic megacolon present in the x-ray?** Yes ☐ No ☐ N/A ☐

i. If yes, was a repeat x-ray or CT Scan performed? Yes ☐ No ☐

ii. Date performed ☐☐/☐☐/☐☐

Section 4: Medical Interventions

4.1 Use of Anti-thrombotic therapy

4.1.1 **Was the patient given prophylactic heparin?** Yes ☐ No ☐

4.2 Steroid therapy

4.2.1 **Were IV corticosteroids prescribed during this admission?**

i. Yes ☐

ii. No, but oral corticosteroids were prescribed ☐

iii. No, neither IV or Oral corticosteroids were prescribed during this admission ☐

4.2.2 **Which of the following steroids were initially prescribed?**

Prednisolone ☐

Budesonide ☐

Hydrocortisone ☐

i. Initial dose ☐☐☐ Mg/day

4.2.3 **Date therapy initiated or increased:** ☐☐/☐☐/☐☐

4.2.4 **At any point following the first 72-hours of steroid therapy did the patient produce stools at a frequency greater than 8 per day?** Yes ☐ No ☐

Not documented ☐

4.2.5 **Did the patient respond to corticosteroids and not require any other significant therapy for Ulcerative Colitis?** Yes ☐ No ☐

4.3 Other Therapies: Which other therapies did the patient receive?

4.3.1 **Ciclosporin** ☐

i. Start Date ☐☐/☐☐/☐☐

ii. Did the patient achieve remission on ciclosporin therapy? Yes ☐ No ☐

4.3.2 **Anti TNF-α** ☐

i. Start Date ☐☐/☐☐/☐☐

ii. Did the patient achieve remission on Anti TNF-α therapy? Yes ☐ No ☐

4.3.3 **Clinical Trial** ☐ **please specify:**

i. Start Date ☐☐/☐☐/☐☐

ii. Did the patient achieve remission from the clinical trial? Yes ☐ No ☐

4.3.4 **Significant Other therapies** ☐ **please specify:**

i. Start Date ☐☐/☐☐/☐☐

ii. Did the patient achieve remission on other therapy? Yes ☐ No ☐

4.3.5 **Surgical therapy** ☐ **On the audit website 4.3.5 must be ticked if you want to enter Surgical Intervention data in section 5*

4.4 Initiating Ciclosporin Therapy

What were the pre-treatment results for:

4.4.1 **Creatinine** ☐☐☐ µmol/L **i.** Date sample taken: ☐☐/☐☐/☐☐

Not Documented ☐

4.4.2 **Magnesium** ☐.☐☐ mEq/L **i.** Date sample taken: ☐☐/☐☐/☐☐

Not Documented ☐

4.4.3 **Cholesterol** ☐☐.☐ mmol/L **i.** Date sample taken: ☐☐/☐☐/☐☐

Not Documented ☐

4.4.4 **How was the ciclosporin initially administered?** Oral ☐ IV ☐

i. What was the initial daily dose? ☐.☐ mg/kg

4.5 Monitoring Ciclosporin Therapy

4.5 **After *three days* of ciclosporin therapy, how often were serum ciclosporin levels checked?**

a) Daily ☐ b) Every two days ☐ c) Every three days ☐

d) Once a week ☐ e) Less than once a week ☐ f) Not documented ☐

Section 5: Surgical Interventions

5.1 Surgical Therapy

5.1.1 What date was the decision to operate made? ☐☐/☐☐/☐☐

Not Known ☐

5.1.2 Who made the decision to operate?

a) Consultant Paediatric Surgeon ☐
b) Consultant Colorectal Surgeon ☐
c) Consultant GI Surgeon (non-colorectal) ☐
d) Consultant General Surgeon ☐
e) Other Consultant Surgeon ☐
f) Specialist Registrar ☐
g) Other (please specify) ☐

5.1.3 What was the date of surgery? ☐☐/☐☐/☐☐

5.1.4 Was the patient seen by a stoma nurse during this admission? Yes ☐ No ☐

i. If yes, what date was the patient first seen by a stoma nurse? ☐☐/☐☐/☐☐

5.1.5 What was the grade of the operating surgeon?

a) Consultant Paediatric Surgeon ☐
b) Consultant Colorectal Surgeon ☐
c) Consultant GI Surgeon (non-colorectal) ☐
d) Consultant General Surgeon ☐
e) Other Consultant Surgeon ☐
f) Specialist Registrar ☐
g) Associate Specialist ☐
h) Other (please specify) ☐

5.1.6 What was the grade of the assisting surgeon?

a) Consultant Paediatric Surgeon ☐
b) Consultant Colorectal Surgeon ☐
c) Consultant GI Surgeon (non-colorectal) ☐
d) Consultant General Surgeon ☐
e) Other Consultant Surgeon ☐
f) Specialist Registrar ☐
g) Associate Specialist ☐
h) Other (please specify) ☐

5.1.7 What were the indications for surgery? (select all that apply)

a) Failure of Medical Therapy ☐
b) Toxic megacolon ☐
c) Bleeding ☐
d) Obstruction ☐
e) High Grade Dysplasia ☐
f) Low Grade Dysplasia ☐
g) Ungraded Dysplasia ☐
h) Cancer ☐
i) Perforation ☐
j) Abscess ☐
k) Formation of ileostomy ☐
l) Other indication (specify below) ☐

5.1.8 Type of intervention:

a) Subtotal colectomy	☐	e) Ileoanal pouch without stoma	☐
b) Protocolectomy	☐	f) Formation of ileostomy	☐
c) Proctectomy	☐	g) Other (specify below)	☐
d) Ileoanal pouch with stoma	☐		

i Was the surgery done laparoscopically/ laparoscopically-assisted? Yes ☐ No ☐

5.1.9 Was the ASA status recorded pre-operatively? Yes ☐ No ☐

i. If yes, what was the status? 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ N/A ☐

5.2 Surgical Complications

5.2.1 Did the patient suffer from any of these complications with their surgery? (select all that apply)

a) Wound Infection	☐	i) Small bowel obstruction	☐
b) Rectal stump complications	☐	j) Ileus requiring parenteral nutrition	☐
c) Intra-abdominal bleeding	☐	k) Cardiac	☐
d) Intra-abdominal sepsis	☐	l) Respiratory	☐
e) Anastomotic leakage	☐	m) Clostridium difficile-associated diarrhoea (CDAD)	☐
f) Stoma complications	☐	n) Other (please specify below)	☐
g) Deep vein thrombosis (DVT)	☐		
h) Pulmonary embolus (PE)	☐	o) No Complications	☐

Section 6: Discharge Arrangements

6.1 Discharge Arrangements

6.1.1 Was the patient taking oral steroids on discharge? Yes ☐ No ☐ N/A ☐

6.1.2 Was a steroid reduction programme stated on discharge? Yes ☐ No ☐ N/A ☐

6.1.3 Were bone protection agents prescribed? Yes ☐ No ☐ N/A ☐

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Paediatric Crohn's Disease Proforma

Pre-section: Patient Demographics

A **Auditor Discipline:** a) Consultant ☐ b) Other medical staff ☐ c) Nurse ☐ d) Manager ☐
e) Clinical Audit ☐ f) Other (please specify): ☐

B **Patient Audit Number:** (Once you begin to enter this case onto the audit website it will be allocated a Patient ID number, record this on the paper form for reference) ☐☐☐☐

C **What was the patient's age at admission?** ☐☐

D **Gender:** Male ☐ Female ☐

E **What are the first 2 characters of the patient's postcode?** ☐☐

Section 1: Admission / Mortality

1.1 Admission

1.1.1 **What was the date of admission to this hospital?** ☐☐/☐☐/☐☐

1.1.2 **What was the primary reason for admission to this hospital?**

*Please note that if option **c) Elective admission for surgery** was the primary reason for admission then you do not need to answer the following questions:

- Section 1: Questions 1.1.3 1.1.4 1.2.1 1.2.2 1.2.3 1.2.4 and 1.2.5
- Section 2: Questions 2.1.1 through to 2.1.5 2.2.1 and 2.2.2 2.3.1 and 2.3.2 2.5.1 through to 2.5.4
- Section 3: Questions 3.2.1 through to 3.2.3 3.3.1 and 3.3.2 3.4.1

a) Emergency admission for active Crohn's Disease ☐
b) Planned admission for active Crohn's Disease ☐
c) Elective admission for surgery ☐
d) New diagnosis of Crohn's Disease ☐

*If none of the above options a) – d) can be chosen please disregard this patient's notes and choose the next case to enter

1.1.3 **What was the source of admission?**

a) General Practitioner (GP) ☐
b) Accident and Emergency (A&E) ☐
c) Outpatients Department (OPD) (Includes referrals from a formally booked IBD telephone clinic) ☐
*(*please also see the note at the start of section 6)*
d) Other hospital ☐
e) Not Documented ☐

1.1.4 **What duration of new or relapse symptoms did the patient report prior to their admission?**

a) Less than two weeks ☐
b) Two to three weeks ☐
c) Four to eight weeks ☐
d) More than eight weeks ☐
e) Not Documented ☐

1.2 Admitting Specialty

1.2.1 Which specialty was responsible for the patient's care 24 hours after admission?

a) Acute Medicine ☐ b) Paediatric Gastroenterology ☐ c) Paediatric Surgery ☐

d) General Paediatrics within a paediatric GI network ☐ e) Adult Gastroenterology ☐ f) Colorectal Surgery ☐

g) General Medicine ☐ h) General Surgery ☐ i) General Paediatrics ☐

j) Other ☐ please specify:

1.2.2 Was the patient transferred to a specialist gastroenterology ward?

a) Medical ☐ b) Joint ☐ c) Surgical ☐ d) Not transferred ☐

1.2.3

i. What date was the patient first seen by a Consultant Paediatric Gastroenterologist? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

ii. What date was the patient first seen by a Consultant Paediatrician with an interest in Gastroenterology? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

iii. What date was the patient first seen by an adult Consultant Gastroenterologist? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

1.2.4

i. What date was the patient first seen by a Consultant Paediatric Surgeon? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

ii. What date was the patient first seen by a Consultant Colorectal Surgeon? ☐☐/☐☐/☐☐ Not Seen ☐ Not required ☐

1.2.5 Was the patient visited by a Paediatric IBD Nurse/GI Nurse specialist during admission? Yes ☐ No ☐

1.3 Discharge/Mortality

1.3.1 Did the patient die during admission? Yes ☐ No ☐

If yes

i. Date of death ☐☐/☐☐/☐☐

ii. Primary cause of death: _____

iii. Please use this space to enter any further details of death if required:
(max of 300 characters)

If no

1.3.2 Date of discharge ☐☐/☐☐/☐☐

1.4 Co-morbidity

1.4.1 Does the patient have any important co-morbid diseases? (please select all that apply)

a) Heart Disease ☐	b) Renal Failure ☐
c) Respiratory ☐	d) Diabetes ☐
e) Liver Disease ☐	f) Stroke ☐
g) None of the above ☐	h) Other (Please specify below) ☐

1.5 Medication on Admission

1.5.1 What treatment was the patient taking for Crohn's Disease on admission? (select all that apply)

a) 5-ASA ☐	f) Corticosteroids ☐
b) Azathioprine ☐	g) Dietary Therapy ☐
c) Mercaptopurine ☐	h) anti-TNF-α ☐
d) Methotrexate ☐	i) None ☐
e) Antibiotics ☐	j) Other (e.g. trial medicine please specify below) ☐

1.6 Smoking Status

1.6.1 What is the smoking status of the patient?

a) Current smoker ☐	b) Lifelong non-smoker/ ex-smoker ☐
c) Not documented ☐	

1.7 Patient History

1.7.1 Did the patient have a pre-admission diagnosis of Crohn's Disease? Yes ☐ No ☐

1.7.2 What is the extent of the disease? (please select all that apply)

a) Small bowel ☐ b) Colonic ☐ c) Ileo-colonic ☐ d) Perianal ☐

e) Panenteric ☐ f) Not known ☐ g) Other (please specify below) ☐

1.7.3 Has the patient had previous admissions to your hospital with Crohn's Disease in the last two years? Yes ☐ No ☐

i. If yes, how many times in the two years prior to this admission? ☐☐

Section 2: Assessing the Severity of Crohn's Disease

2.1 Severity of Crohn's Disease

2.1.1 Was diarrhoea recorded as a symptom upon admission? Yes ☐ No ☐ Patient has Stoma ☐

2.1.2 How many stools were passed in the first full day following admission? ☐☐ Not documented ☐

2.1.3 What was the highest recorded pulse rate during the first full day following admission? ☐☐☐ bpm

Not documented ☐

2.1.4 What was the highest temperature recorded during the first full day following admission? ☐☐.☐ °C

Not documented ☐

i. Did the patient have a fever (temperature >37.5°C on more than one occasion in 24 hours) within the first 7 days of admission? Yes ☐ No ☐ Not documented ☐

2.1.5 Following admission, what was the initial result for:

i. CRP	☐☐☐	Mg/L	Less than 5 ☐	Not documented ☐	
ii. Albumin	☐☐☐	g/L	Not documented ☐		
iii. Hb	☐☐.☐	g/dL	Not documented ☐		
iv. ESR	☐☐	mm/h^{-1}	Not documented ☐		

2.2 Exclusion of Infection

2.2.1 Was a stool sample sent for Standard Stool Culture?

Yes ☐ No ☐

i. Date sent: ☐☐/☐☐/☐☐

ii. Was it positive? Yes ☐ No ☐

iii. Date of positive sample ☐☐/☐☐/☐☐

2.2.2 Was a stool sample sent for CDT?

Yes ☐ No ☐

i. Date sent: ☐☐/☐☐/☐☐

ii. Was it positive? Yes ☐ No ☐

iii. Date of positive sample ☐☐/☐☐/☐☐

2.3 Documentation of Sepsis

2.3.1 Were antibiotics given? Yes ☐ No ☐ Not documented ☐

2.3.2 Were blood cultures taken? Yes ☐ No ☐

i. Were the cultures: Positive ☐ Negative ☐

2.4 Imaging

2.4.1 Was an Ultrasound Scan performed? Yes ☐ No ☐

i. Date requested ☐☐/☐☐/☐☐

ii. Date performed ☐☐/☐☐/☐☐

2.4.2 Was a CT Scan of the abdomen performed? Yes ☐ No ☐

i. Date requested ☐☐/☐☐/☐☐

ii. Date performed ☐☐/☐☐/☐☐

2.4.3 Was an MRI performed? Yes ☐ No ☐

i. Date requested ☐☐/☐☐/☐☐

ii. Date performed ☐☐/☐☐/☐☐

2.4.4 Was an abscess found during imaging? Yes ☐ No ☐

i. Which type of drainage was undertaken: a) Surgical ☐ b) Radiological ☐ c) Not drained ☐

2.5 Weight & Height Assessment and Dietetic Support

2.5.1 i. Was the patient's weight measured during the admission? Yes ☐ No ☐

a) What was the weight on admission? ☐☐.☐ **kg**

ii. Was the patient's height measured during the admission? Yes ☐ No ☐

b) What was the height on admission? ☐☐☐.☐ **cm**

2.5.2 Did a dietitian visit the patient? Yes ☐ No ☐

2.5.3 Was dietary treatment initiated? Yes ☐ No ☐

i. Was exclusive liquid enteral nutrition therapy prescribed? Yes ☐ No ☐

2.5.4 Was parenteral nutrition given? Yes ☐ No ☐

Section 3: Medical Interventions

3.1 Use of anti-thrombotic therapy

3.1.1 Was the patient given prophylactic heparin? Yes ☐ No ☐

3.2 Steroid Therapy

3.2.1 Were IV corticosteroids administered during this admission?

i. Yes ☐

ii. No, but oral corticosteroids were administered ☐

iii. No, neither IV or Oral corticosteroids were administered ☐

3.2.2 Which of the following steroids were prescribed?

a) Prednisolone ☐

b) Budesonide ☐

c) Hydrocortisone ☐

i. Initial Dose ☐☐☐ Mg/day

3.2.3 Date therapy initiated or increased: ☐☐/☐☐/☐☐

3.3 Treatment with anti-TNF-α During Admission

3.3.1 Was anti-TNF-α therapy given during this admission? Yes ☐ No ☐

i. If yes, what date was the anti-TNF-α therapy started during this admission? ☐☐/☐☐/☐☐

3.3.2 Is there evidence of a chest x-ray performed in the three months prior to the initiation of anti-TNF-α therapy? Yes ☐ No ☐

i. If yes, what was the date of the chest x-ray? ☐☐/☐☐/☐☐

3.4 Clinical Trials

3.4.1 Was the patient entered into a Clinical Trial on this admission? Yes ☐ No ☐

i. If yes, please give further details of the trial here:

ii. Clinical Trial Start Date ☐☐/☐☐/☐☐

Section 4: Surgical Interventions

4.1 Surgical Therapy

4.1.1 Did the patient have surgery on this admission? Yes ☐ No ☐

4.1.2 What date was the decision to operate made? ☐☐/☐☐/☐☐ Not known ☐

4.1.3 Which Surgeon made the decision to operate?

a) Consultant Paediatric Surgeon ☐

b) Consultant Colorectal Surgeon ☐

c) Consultant GI Surgeon (non-colorectal) ☐

d) Consultant General Surgeon ☐

e) Other Consultant Surgeon ☐

f) Specialist Registrar ☐

g) Other ☐

please specify:

4.1.4 Was the patient seen by a stoma nurse during this admission? Yes ☐ No ☐

If yes, what date was the patient first seen by a stoma nurse? ☐☐/☐☐/☐☐

4.1.5 What was the date of surgery? ☐☐/☐☐/☐☐

4.1.6 What was the grade of the operating surgeon?

a) Consultant Paediatric Surgeon ☐
b) Consultant Colorectal Surgeon ☐
c) Consultant GI Surgeon (non-colorectal) ☐
d) Consultant General Surgeon ☐
e) Other Consultant Surgeon ☐
f) Specialist Registrar ☐
g) Associate Specialist ☐
h) Other ☐
please specify:

4.1.7 What was the grade of the assisting surgeon?

a) Consultant Paediatric Surgeon ☐
b) Consultant Colorectal Surgeon ☐
c) Consultant GI Surgeon (non-colorectal) ☐
d) Consultant General Surgeon ☐
e) Other Consultant Surgeon ☐
f) Specialist Registrar ☐
g) Associate Specialist ☐
h) Other ☐
please specify:

4.1.8 What were the indications for surgery? (Please select all that apply)

a) Failure of Medical Therapy ☐	e) Stoma complications ☐	i) Dysplasia ☐
b) Obstruction ☐	f) Perineal disease ☐	j) Cancer ☐
c) Intra-abdominal Abscess ☐	g) Toxic megacolon ☐	k) Perforation ☐
d) Intra-abdominal fistula ☐	h) Bleeding ☐	l) Other (please specify below) ☐

4.1.9 Type of intervention: (Please select all that apply)

a) Segmental/Extended Colectomy ☐	f) Resection of Intra-abdominal Fistula ☐	k) Formation of ileostomy or colostomy ☐
b) Subtotal Colectomy ☐	g) Protectomy ☐	l) Revision of Stoma ☐
c) Protocolectomy ☐	h) Completion Protectomy ☐	m) Perineal procedure ☐
d) Stricturoplasty ☐	i) Ileocolonic Resection ☐	n) Other intervention (please specify below) ☐
e) Ileal/Jejunal Resection ☐	j) Drainage of abscess ☐	

i Was the surgery done laparoscopically/ laparoscopically-assisted? Yes ☐ No ☐

4.1.10 Was the ASA status recorded pre-operatively? Yes ☐ No ☐

If yes, what was the status? 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ N/A ☐

4.2 Surgical Complications

4.2.1 Did the patient suffer from any of these complications following their surgery? (select all that apply)

a) Wound Infection ☐	f) Stoma complications ☐	k) Respiratory ☐
b) Rectal stump complications ☐	g) Deep vein thrombosis (DVT) ☐	l) Clostridium difficile-associated diarrhoea (CDAD) ☐
c) Intra-abdominal bleeding ☐	h) Pulmonary embolism (PE) ☐	m) Other (please specify below) ☐
d) Intra-abdominal sepsis ☐	i) Ileus requiring TPN ☐	
e) Anastomotic leakage ☐	j) Cardiac ☐	n) No complications ☐

4.3 Post-Operative Prophylactic Therapy

4.3.1 Was the patient prescribed any of the following drugs on discharge? (please select all that apply)

a) Azathioprine ☐	b) Mercaptopurine ☐	c) Metronidazole ☐
d) 5-ASA ☐	e) Methotrexate ☐	f) None ☐
g) Other (please specify) ☐		

Section 5: Discharge Arrangements

5.1 Discharge Arrangements

5.1.1 Was the patient taking oral steroids on discharge? Yes ☐ No ☐ N/A ☐

5.1.2 Was a steroid reduction programme stated on discharge? Yes ☐ No ☐ N/A ☐

5.1.3 Were bone protection agents prescribed? Yes ☐ No ☐

Section 6: Outpatient Visits

***For this section we are interested in data recorded at the last documented OPD visit for Crohn's Disease prior to admission.**

If the last visit initiated the admission being audited in the previous sections ignore that visit. Instead, use the details from the most recent OPD visit for review of Crohn's Disease that did not directly result in an admission.

If the patient only had one outpatient visit in the last 12 months for review of their Crohn's Disease and that visit initiated admission, ignore that visit and do not answer the questions in relation to Outpatient Visit Details (Q's 6.2.1 to 6.6.7)

6.1 Patient History

6.1.1 **Has the patient had previous outpatient visits for Crohn's Disease at this hospital in the last 12 months?** Yes ☐ No ☐

If no you do not need to answer any further questions in this section

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?** ☐☐

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? (If the patient was seen by more than one of the following staff in a single clinic visit please count each staff member individually)**

i. Consultant ☐☐ **ii.** IBD Nurse Specialist ☐☐ **iii.** Specialist Registrar ☐☐

iv. F2 **(**SHO) ☐☐

6.1.4 **What was the date of the last visit at the Outpatient Department prior to admission?** ☐☐/☐☐/☐☐

(If the last visit was the one which initiated the inpatient admission being audited in sections 1 to 5 ignore it and use the previous one)

i. If this was the only Outpatient Department visit for review of Crohn's Disease during the past 12 months did it directly initiate the admission being audited in the previous sections 1 to 5? Yes ☐ No ☐

*** If the answer to 6.1.4i is Yes then you do not need to answer any of the remaining questions from 6.2.1 onwards**

Outpatient Visit Details

6.2 Assessment of Crohn's Activity

6.2.1 **Number of liquid stools per day:** ☐☐ Not documented ☐

6.2.2 **General well being:**

Well ☐
Mild symptoms ☐
Moderate symptoms ☐
Severe symptoms ☐
Not documented ☐

6.2.3 Abdominal Pain:

None ☐
Present ☐
Not documented ☐

6.2.4 Abdominal Mass

None ☐
Present ☐
Not documented ☐

6.2.5 Did the patient report any of the following complications at this clinical visit?

Mouth ulcers	Yes ☐	No ☐	Not Documented ☐
Arthralgia	Yes ☐	No ☐	Not Documented ☐
Pyoderma Gangrenosum	Yes ☐	No ☐	Not Documented ☐
Anal fissure	Yes ☐	No ☐	Not Documented ☐
Fistula	Yes ☐	No ☐	Not Documented ☐
Erythaema Nodosum	Yes ☐	No ☐	Not Documented ☐
Abscess	Yes ☐	No ☐	Not Documented ☐
Iritis	Yes ☐	No ☐	Not Documented ☐

None documented ☐
Other ☐ Please specify:

6.2.6 What were the results for the following tests?

i. CRP	☐☐☐	Mg/L	Less than 5 ☐	Not documented ☐
ii. Albumin	☐☐☐	g/L	Not documented ☐	
iii. Hb	☐☐.☐	g/dL	Not documented ☐	
iv. ESR	☐☐	mm/h^{-1}	Not documented ☐	

6.2.7 Was the patient weighed during this clinic visit? Yes ☐ No ☐

i. Was there evidence of unintentional weight loss of more than 3kgs (or more than 10%) prior to this clinic visit? Yes ☐ No ☐ Not documented ☐

6.3 Smoking Status

6.3.1 What was the smoking status of the patient during this clinic visit?

a) Current smoker ☐
b) Lifelong non-smoker/ex-smoker ☐
c) Not documented ☐

6.4 Monitoring of immunosuppressive therapy

6.4.1 Was the patient taking any of these drugs in the 12 months prior to the start date of this admission? (please select all that apply)

Azathioprine ☐ Mercaptopurine ☐ Methotrexate ☐ None of these ☐

6.4.2 Was the patient's white blood cell (WBC) count routinely measured? Yes ☐ No ☐

6.4.3 How often was WBC monitoring performed?

At least once a month ☐ Every 2-3 months ☐ Not documented ☐ Other (Please specify) ☐

6.4.4 Did the patient's WBC fall below $3x10^9$ at any time during the 12 months prior to the start date of this admission?

Yes ☐ No ☐ Not known ☐

6.4.5 If the white blood cell count was less than $3x10^9$ what action was taken?

Reduced dose ☐ Stopped drug ☐ No action taken ☐

6.4.6 What was the outcome of the reduced white blood cell count?

No sequelae (resolved) ☐ Treatment required (e.g. prophylactic antibiotics) ☐ Admission ☐

6.5 Use of Corticosteroids

6.5.1 Was the patient taking oral corticosteroids for their Crohn's Disease in the 12 months prior to the start date of this admission? Yes ☐ No ☐

If yes

6.5.2 Was there any point at which the patient was taking oral corticosteroids continuously for more than three months? Yes ☐ No ☐

6.5.3 Were bone protection agents prescribed alongside corticosteroids? Yes ☐ No ☐

6.6 Use of anti-TNF-α therapy

6.6.1 Did the patient receive anti-TNF-α therapy in the 12 months prior to admission? Yes ☐ No ☐

If yes

6.6.2 Was the anti-TNF-α therapy <u>initiated</u> at any point in the 12 months prior to the start date of this admission? Yes ☐ No ☐

6.6.3 Did the patient have severely active Crohn's Disease at the time anti-TNF-α therapy was initiated? Yes ☐ No ☐

6.6.4 What was the CRP prior to the first anti-TNF-α infusion on record?

☐☐☐ mg/L

Less than 5 ☐

Not documented ☐

6.6.5	**Was the patient on immunosuppressive therapy at this time?**	Yes	☐	No	☐
	i. If no, is there any evidence that the patient was intolerant of these immunosuppressive therapies?	Yes	☐	No	☐
6.6.6	**Was fistulating disease the primary reason for the decision to initiate anti-TNF-α therapy?**	Yes	☐	No	☐
6.6.7	**Did the patient have a chest X-ray to exclude TB in the three months prior to initiation of anti-TNF-α therapy?**	Yes	☐	No	☐

Sites that submitted data to the audit

Site Name	Trust / Health Board Name
Addenbrooke's Hospital	Cambridge University Hospitals NHS Foundation Trust
Alder Hey Hospital	Alder Hey Children's NHS Foundation Trust
Barts and The London Children's Hospital	Barts and The London NHS Trust
Birmingham Children's Hospital	Birmingham Children's Hospital NHS Foundation Trust
Booth Hall Children's Hospital	Central Manchester and Manchester Children's University Hospital NHS Trust
Bristol Children's Hospital	United Bristol Healthcare NHS Trust
Chelsea and Westminster Hospital	Chelsea and Westminster Hospital NHS Foundation Trust
Great Ormond Street Hospital	Great Ormond Street Hospital for Children NHS Trust
Leeds General Infirmary	The Leeds Teaching Hospitals NHS Trust
Leicester Royal Infirmary Children's Hospital	University Hospitals of Leicester NHS Trust
Oxford Children's Hospital	Oxford Radcliffe Hospitals NHS Trust
Royal Aberdeen Children's Hospital	NHS Grampian
Royal Belfast Hospital for Sick Children	Belfast Health and Social Care Trust
Royal Free Hospital	Royal Free Hampstead NHS Trust
Royal Hospital for Sick Children, Edinburgh	NHS Lothian
Royal Victoria Infirmary, Newcastle	The Newcastle upon Tyne Hospitals NHS Foundation Trust
Sheffield Children's Hospital	The Sheffield Children's NHS Trust
Singleton Hospital	Abertawe Bro Morgannwg University NHS Trust
Southampton Children's Hospital	Southampton University Hospitals NHS Trust
St George's Hospital, London	St George's Healthcare NHS Trust
The Children's Hospital for Wales	Cardiff and Vale NHS Trust
The Children's Hospital Lewisham	The Lewisham Hospital NHS Trust
Yorkhill Children's Hospital	NHS Greater Glasgow & Clyde