



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

Round 3
March 2012

Paediatric executive summary report

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



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- The British Dietetic Society
- The British Society of Gastroenterology
- The British Society of Paediatric Gastroenterology, Hepatology and Nutrition
- Crohn's and Colitis UK
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- The Royal College of Nursing Crohn's and Colitis Special Interest Group
- Royal College of Physicians
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Section 1: Executive summary

Background

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

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

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

Overall summary

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

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

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

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

This report also shows that there is work to be done by the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) to address the poor levels of recording the

pubertal status of patients with Crohn’s disease and to encourage the widespread adoption of the Paediatric Ulcerative Colitis Activity Index (PUCAI) in order to inform the management of acute severe ulcerative colitis.

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

Two key action points follow:

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

Key results

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

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

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

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

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

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

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

Was a PUCAI score recorded on Day 1 in emergency admissions?		20% (13/66) Median score = 65	
Did the patient experience a thrombotic episode during the admission?		2% (3/176)	
Crohn's disease			
		2010 UK results 342 cases of which 288 were non-elective	Your Site 2010
Were Standard Stool culture (SSC) and Clostridium Difficile Toxin (CDT) samples requested in non-elective patients with diarrhoea recorded during the first full day following admission?		SSC 41% (88/214) CDT 28% (60/214)	
Did the patient see an IBD nurse during the admission? (In non-elective patients)		72% (207/288)	
Did the patient have a previous admission in the last 2 years (in patients with a pre-admission diagnosis)		52% (124/238)	
Was prophylactic Heparin prescribed? (In non-elective patients)		7% (24/342)	
If the patient underwent surgery, was it undertaken laparoscopically?	Non-Elective	36% (10/28)	
	Elective	27% (14/51)	
Was the patient's weight measured during the admission? (In non-elective patients)		99% (286/288)	
Did a dietician see the patient? (In non-elective patients)		81% (232/288)	
Percentage of patients aged 12 and over that were not asked about their smoking status		53% (136/259)	
Was pubertal status recorded in 12months prior to admission? (In patients aged over 10 at the time of the last outpatient appointment)		25% (59/237)	
Did the patient experience a thrombotic episode during the admission?		0.3% (1/342)	

Key findings

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

Recommendations

1. As highlighted in the 2010 paediatric organisational audit report, 71% of sites do not have formal arrangements for annual review. The implementation at a national level, of an agreed systematic annual review would avoid the likelihood of routine data collection items such as smoking and pubertal status being overlooked.
2. The local policy for thrombus prevention (including use of heparin) in paediatric patients with IBD should be reviewed by each paediatric IBD service

3. In line with ESPGHAN/ECCO recommendations, every paediatric patient admitted as an emergency with ulcerative colitis should have a PUCAI score recorded on admission and daily thereafter as a guide to the need for medical rescue therapy or colectomy
4. Local hospitals should develop a practice where testing for Clostridium difficile toxin is routinely carried out alongside tests for SSC in all stool samples sent for IBD patients admitted with diarrhoea
5. All paediatric CD inpatients should have growth and nutrition reviewed during their admission to ensure that any growth faltering is not overlooked

Section 2: Site specific key 2010 data items

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

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

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

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

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