



# UK Inflammatory Bowel Disease Audit 3rd Round

Report of the results for the national organisational audit of paediatric inflammatory bowel disease services in the UK

Prepared by the  
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
- Crohn's and Colitis UK

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**\*Note on the term “site” used throughout this report**

Lead clinicians (in every instance a Consultant Paediatric Gastroenterologist) that were initially contacted within each Trust/Health Board to register to take part in the UK IBD Audit 3<sup>rd</sup> round (2<sup>nd</sup> for Paediatric Gastroenterology) were asked to participate and collect data on the basis of a unified specialist paediatric gastroenterology unit which would be registered as a named “site”.

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.

## 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<sup>1</sup>. Up to 25% of cases will present in childhood years<sup>2</sup> with a marked rise in incidence of paediatric IBD noted, especially in Crohn's Disease, in the UK and other countries over the past few decades.

The UK Inflammatory Bowel Disease Audit 1st Round in 2006 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 1<sup>st</sup> audit 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 (<16 years of age at the date of admission) in the 2<sup>nd</sup> audit round so that the UK IBD Audit could become a truly comprehensive audit encompassing IBD patients of all ages. Please note in the 2010 audit the definition of a "paediatric patient" changed to patients aged 16 years and under rather than the <16 years of age that was captured in the 2008 audit.

The participation of paediatric sites in the UK Paediatric IBD Audit in 2008 was 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 2008 report highlighted that, paediatric IBD services in the UK were consultant led and supported in many sites by IBD clinical nurse specialists, dieticians and psychologists. However, there were still sites where this additional multidisciplinary support did not exist or where it remained inadequate. The report also highlighted specific issues, such as the lack of both adequate toilet facilities and dedicated ward areas.

The UK IBD Audit 2<sup>nd</sup> round (1<sup>st</sup> for Paediatric Sites) in 2008 measured Paediatric IBD Services against standards agreed by the UK IBD Audit Steering Group. For the Paediatric Organisational Audit element of the 3<sup>rd</sup> round (2<sup>nd</sup> for Paediatric sites) that is addressed in this report the Steering Group tried to align the dataset directly alongside 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 by a collaboration of six health professional societies (including BSPGHAN) and Crohn's and Colitis UK, the IBD patients' organisation. The aim of the IBD National 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 that meet specific minimum standards. Some of the agreed standards that should be in place for staffing and facilities are population dependent, based on a BSPGHAN estimate of a catchment population for a specialist paediatric gastroenterology unit of 2 million people<sup>3</sup>. It was recommended that IBD Services (both Paediatric and Adult) should meet the standards by September 2010. We therefore asked participating sites to complete the dataset for their own Paediatric IBD Service "as at" 1<sup>st</sup> September 2010.

The 2008 National Report addressed the Organisation & Structure of Paediatric IBD Services as well as the Processes of Clinical Care for up to 40 paediatric IBD patients per site who were admitted to hospital for reasons primarily related to IBD. These 2 elements have been split for the 2010 round and this report addresses only the Organisation & Structure of Paediatric IBD Services across the UK. The report on the Processes of Clinical Care for Paediatric IBD Patients will be launched in spring 2012.

## Summary

Paediatric gastroenterology sites participated, for the second time, in the UK IBD Audit in 2010 (which is the third round of participation for the adult sites). Thus, for the first time, there are comparative data for those paediatric sites who participated in both 2008 and 2010. In 2010, 25 paediatric sites registered to participate with 24 returning data. Of these sites, 23 returned data in both rounds. 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 2008 are also compared. The adult UK IBD Audit 3rd round data, where relevant, have also been included for reference.

Publication of these paediatric audit data again helps to cement the increasingly strong professional relationship between paediatric and adult gastroenterologists as well as their respective professional bodies. Whilst there are clearly some important age-specific aspects of care that apply to the management of IBD in children, there is a far larger body of generic aspects of IBD care that apply to patients of all ages.

This report highlights that in 2010, paediatric IBD services in the UK continue to be consultant led. There has been a significant increase in the number of paediatric gastroenterology/IBD clinical nurse specialists working across the UK compared to 2008 and an increase in both the number of WTE paediatric consultant gastroenterologists and paediatric surgeons. Specific questions were asked for the first time in 2010 about essential supporting services and the results revealed that, in paediatric IBD Services, defined access to a nutritional support team is almost universal (in 92% of sites), 83% have a colleague in adult gastroenterology with an interest in adolescent IBD and two thirds have defined access to psychology. There are however still sites where this additional multidisciplinary support either does not exist or it remains inadequate. Compared to 2008, adequate toilet facilities have improved with fewer beds per toilet and the number of sites with dedicated paediatric gastroenterology ward areas has increased. Just under a quarter of sites were recruiting paediatric IBD patients to clinical research studies, an encouraging figure which will hopefully be built upon in future years.

Results from the adult gastroenterology third round (2010) of the UK IBD Audit showed that a high number of adult sites indicated that they still look after IBD patients aged 16 and under and that, where they do so, there is an inadequate provision of essential age-appropriate supporting services.

The datasets for the third round of this national audit were directly set against national IBD service standards launched in February 2009. The organisational data was collected from each site as of 1<sup>st</sup> September 2010, the date by which all NHS Trusts/Health Boards are expected to implement these standards. Sites are encouraged to access and contribute towards the Shared Document Store on the IBD Quality Improvement Project (IBDQIP) website: [www.ibdqip.co.uk](http://www.ibdqip.co.uk) which provides access to tools that sites can use to implement change within their IBD Service. The results indicate that specialist paediatric gastroenterology sites are, on the whole, meeting the IBD Standards. They also serve to highlight issues that can be addressed by departments of health and professional bodies on a national level to promote subsequent improvement at a local level where required.

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 National IBD Service Standards and take any necessary action to improve their paediatric IBD Services locally.
- Professional organisations should direct changes for issues that need to be addressed at a national level.

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.  
2. Benchimol El et al. *Inflammatory Bowel Diseases* 2011; 17(1):423-39.0  
3. British Society of Gastroenterology, Hepatology and Nutrition: Guide for purchasers of Paediatric Gastroenterology, Hepatology and Nutrition Services. (2003) <http://bspghan.org.uk/information/guides.shtml>

## Key Findings and Recommendations for action

The Key Findings and Recommendations from this 2010 UK IBD Audit 3<sup>rd</sup> round (2<sup>nd</sup> for Paediatric sites) are presented in line with the 6 core areas (A to F) of the National Service Standards for the healthcare of people who have Inflammatory Bowel Disease (IBD). The results quoted below in the key findings are, in each case, referenced either 1 to 4 in relation to the key data found in the corresponding tables 1 to 4 on pages 15 to 19 which show:

- 1 Combined 2010 Key indicator data from all of the 24 participating sites compared to “Your Site” data
- 2 Comparisons of combined key indicator data from 2008 and 2010 for the 23 sites participating in both rounds
- 3 Selected key indicator data from the concurrent 2010 National Results for the Organisation of Adult Inflammatory Bowel Disease Services in the UK
- 4 The full combined UK-wide data for the 2010 round (2<sup>nd</sup> for Paediatrics) from all 24 participating sites

### General Hospital Demographics and Inpatient Activity

#### Key findings:

- On average 178 paediatric IBD patients were managed by each site and they saw an average of 32 new IBD patients in the 12 months prior to the audit<sup>1</sup>, a far higher ratio of new patients than adult IBD Services (60 new patients from an average of 788)
- Whilst 78 % (18/23) sites indicated that they maintained a register of IBD patients<sup>1</sup> half of them had to estimate when asked to identify how many IBD patients their paediatric IBD Service manages<sup>4</sup>. This fact raises the question of whether existing registers are updated on a regular basis and used effectively
- Whilst the number of sites that have guidelines for the management of Acute Severe Colitis has increased across the 2008 and 2010 rounds (from 44% to 61%) 9 out of 23 sites still do not have them<sup>2</sup>

#### Key recommendations:

- All sites should capture clinical data about their IBD patients on regularly maintained databases to support the management of their care. A national register towards which local sites could contribute should be developed to provide accurate numbers of incidence of IBD
- The average for the number of patients managed by each paediatric site is potentially lower than the reality given that sites were asked not to include the number of patients with inflammatory bowel disease type unclassified (IBDU) in their totals. The UK IBD Audit Steering Group should try to address the issue of how to include these patients in future rounds
- Given the rarity of admissions for Acute Severe Colitis plans should be made to ensure that a guideline for the management of this condition is available in all sites

## 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:

- There has been a significant increase in the median number of WTE paediatric gastroenterology/IBD nurse specialists at each site rising from 1 WTE in 2008 to 1.5 WTE in 2010<sup>2</sup>. 83% (19/23) of sites, versus compared to 61% (14/23) in 2008 now have at least some provision of this service and where they do have this provision in 2010 they all meet the minimum of having 0.5 WTE specialist nursing provision as set out in the IBD Standards<sup>2</sup>
- There was also an increase from 2008 to 2010 in the median number of WTE paediatric consultant gastroenterologists (2 to 2.2), and the median number of WTE paediatric surgeons (4.5 to 5.5) the number of sites with a designated paediatric gastroenterology ward (6/23 to 8/23) and a move towards the minimum standard of 1 easily-accessible toilet per 3 beds on these designated wards (a median of 4.0 in 2008 to 3.3 in 2010)<sup>2</sup>
- 39% (78/202) of adult sites indicated that they look after IBD patients aged 16 and under<sup>3</sup>. 46% (36/78) of these sites that look after patients aged 16 and under indicated that they had a specific paediatric to adult transition policy<sup>3</sup>. Only 47% (37/78) had a surgeon with suitable paediatric experience
- For patients aged 16 and under having endoscopy at these 78 adult sites 53% (41/78) had an endoscopy area with age-appropriate facilities, 56% (44/78) had someone with training and/or extensive experience in paediatric endoscopy and 68% (53/78) had an anaesthetist with paediatric training
- 67% (16/24) of sites have defined access to a psychologist with an interest in IBD<sup>4</sup>
- 83% (20/24) of sites have regular timetabled meetings to discuss IBD patients and these take place on a weekly basis in 65% of these 20 sites<sup>4</sup>
- The median waiting time for an urgent clinic appointment for suspected IBD patients is 7 days<sup>4</sup>
- All sites have dietetic support for the provision of dietary and nutritional advice and the institution of exclusive liquid enteral nutritional therapy as primary treatment<sup>4</sup>
- 83% (20/24) of sites provide access to endoscopy within 72 hours of admission for relapsing patients with urgent colonic biopsies available within 48 hours also available in 83% of sites<sup>4</sup>
- 71% (17/24) of sites do not have formal arrangements for annual outpatient review<sup>4</sup>

### Key recommendations:

- All sites should have a paediatric gastroenterology/IBD nurse specialist.
- There is room for further expansion in paediatric gastroenterology consultants so that all centres can provide safe and full 24hr cover for the service.
- There is room to improve further both the number of toilets available per inpatient beds and the number of designated wards or beds for paediatric gastroenterology patients.
- Uptake of annual review could be facilitated by the agreement of key components of a paediatric annual review at a national level
- In line with Standard A12 all young people with IBD should be looked after in an age appropriate setting with support from professionals with suitable paediatric experience

### **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:**

- Only 26% (6/23) of sites have shared care protocols of paediatric IBD patients with GPs but all sites share results of patient's disease activity and treatment changes with GPs<sup>1</sup>

#### **Key recommendations:**

- Sites should continue to improve liaison with GPs about paediatric IBD patients – developing a national format for the communication of results to GPs could help to address this issue

### **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:**

- 80% of sites (20/24) provide a clear pathway for the patient to discuss their treatment with the multidisciplinary team<sup>4</sup> and 91% (21/24) provide written information to the patient about whom to contact in the event of a relapse<sup>1</sup>
- All sites have arrangements to expedite specialist review of relapsed patients<sup>4</sup>. Relapsing patients can expect to be seen for specialist review within 7 days at 91% (21/24)<sup>1</sup> of sites and within 5 days at 65% (15/23)<sup>4</sup>
- All sites provide telephone access to contact an IBD specialist with 92% (22/23) generally responding within 48 hours<sup>1</sup>
- Only 26% (2/23) offer patients a choice about different ways for follow up beyond the traditional method of review in an outpatient clinic<sup>4</sup>
- 61% (14/23) of sites do not offer open forums or meetings for patients with IBD and their carers<sup>1</sup> and 36% (8/23) have no activities or systems in place to involve patients in giving their views on the development of the local IBD Service<sup>4</sup>

#### **Key recommendations:**

- All sites should provide clear written pathways for patient access to specialist care.
- All relapsed patients should be seen within 7 days
- Patient involvement in the type of care that they receive should be increased
- Patient organisations should be involved in the development of services. The use of Patient Panels is one method of doing so and sites should contact Crohn's and Colitis UK for more information on how to develop them

### **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:**

- 96% (22/23) of sites provide specific information to patients with newly diagnosed IBD<sup>4</sup> but only 43% (10/23) provide patients with a written care plan<sup>1</sup>
- All sites provide contact details for patient organisations and 87% of sites (20/23) have regular contact with IBD patient organisations<sup>4</sup>
- Only 65% (15/23) provide educational opportunities for patients and their carers<sup>1</sup>
- 96% (22/23) have access to translation services if needed<sup>4</sup> with 39% (9/23) providing information on IBD in different languages<sup>1</sup>

#### **Key recommendations:**

- All sites should provide education opportunities for patients and their carers to enable them to understand their illness, the options for treatment and to support them in managing their own care. Sites should share their model of providing these educational opportunities with other sites via their national specialist organisations
- A model written care plan could be designed at national level to help increase the number of sites offering this form of information for patients
- Sites should consider holding joint patient forums and educational meetings with nearby sites to increase the number of opportunities where these are available to patients
- Increased interaction with patient organisations and charities should help sites in meeting this standard

### **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:**

- 78% (18/23) of sites indicated that they maintain a register of their IBD patients<sup>1</sup>. This raises the question of how these registers are used and maintained as when asked how many IBD patients are managed by their IBD Service, 50% of sites said that their given figure was an estimate<sup>1</sup>
- 57% (13/23) of sites capture clinical data about their patients<sup>1</sup> but only 4 of these 13 sites use this system in real time to support the management of patients<sup>4</sup>

#### **Key recommendations:**

- Each hospital should work towards having maintaining a database of all IBD patients under their care to allow accurate and up to date recording of all patient data
- In sites where data on all patients cannot be captured priority should be given to specific patient groups e.g. those receiving biological therapy

- Sites should engage with work on developing a National IBD Patient Registry to contribute to continuous improvement in patient care, access to that care across the UK, and to support IBD research. The Registry will provide local, regional and national data in order to better define the pattern of Ulcerative Colitis and Crohn's Disease. Engaging in this process will also improve understanding of the long term outcomes and inform commissioning and service design

### **Standard F – Evidence-based practice and research**

A service that is knowledge-based and actively supports service improvement and clinical research

#### **Key findings:**

- Paediatric gastroenterology/IBD nurse specialists only received a median of 2 days IBD specific training during the specified 12 month period<sup>4</sup>
- Less than a quarter of sites (5/23) enter patients into MCRN supported trials<sup>1</sup>
- 22% (5/23) hold annual review days of their service<sup>1</sup>

#### **Key recommendations:**

- Paediatric gastroenterology/IBD nurse specialists must have sufficient opportunities to maintain their specialist knowledge and skills and to keep up to date with rapidly changing treatment options. Sites should have adequate specialist nurse provision within their service to offer cross cover for their colleagues when they are attending training. National study days could be instigated for these specialist nurses
- The number of sites entering paediatric IBD patients into clinical trials is encouraging but still too small
- All sites should hold an annual review day for their multidisciplinary IBD team members to reflect on their service, identify areas for improvement and agree a plan for making these improvements

## **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. Up to 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 2008 round this 2010 report enables each participating site to compare or benchmark their performance against national statistics. Following the 2008 round the UK IBD Audit Steering Group directed a widespread dissemination of results to participating sites through the registered site clinical leads (normally a Consultant Paediatric Gastroenterologist) as well as hospital board management. The 2008 National Report was available publicly via the UK IBD Audit section within the Clinical Effectiveness and Evaluation Unit area of the Royal College of Physicians website. Following the publication of the national report for 2008 the UK IBD Audit hosted a meeting for the leads of specialist paediatric gastroenterology sites to review and discuss the audit results. Data from the 2008 round was also presented at key professional and patient national meetings including those of the: British Society of Paediatric Gastroenterology, Hepatology and Nutrition, 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 (now Crohn's and Colitis UK).

### **Audit Governance**

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

Since the 2<sup>nd</sup> round (1<sup>st</sup> for Paediatric Gastroenterology) in 2008 the UK IBD Audit encompasses IBD patients of all ages having worked with the British Society of Paediatric Gastroenterology, Hepatology and Nutrition to develop a separate dataset which measures against standards that are specific to the Organisation of Paediatric IBD Services in the UK at specialist paediatric gastroenterology sites across the UK. The National Report for the Organisation of Adult Inflammatory Bowel Disease Services in the UK will therefore be published separately by the UK IBD Audit Steering Group in conjunction with this Paediatric Report.

The UK IBD Audit 3<sup>rd</sup> round (2010) is commissioned by the Healthcare Quality Improvement Partnership as part of the [National Clinical Audit and Patient Outcomes Programme \(NCAPOP\)](#) with additional financial support from NHS Quality Improvement Scotland.

The audit is co-ordinated by the Clinical Effectiveness and Evaluation unit (CEEu) of the Clinical Standards Department of the Royal College of Physicians of London. Each site 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 the 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](mailto:ibd.audit@rcplondon.ac.uk)

### **Who participated in the 2010 round of the audit?**

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 24 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 and IT departments.

The audit of the organisation of Paediatric IBD services was intended to be 'as of 1st September 2010' (together with activity data for all admissions for IBD (including multiple admissions for IBD for the same patient) from 1<sup>st</sup> September 2009 through to 31<sup>st</sup> August 2010).

### **Presentation of Results**

Key Indicator results are given for the Organisation & Structure of Paediatric IBD Services and selected 2010 Adult IBD Services data.

Key indicator results:

- Table 1 Shows Key Indicator data from the overall UK 2010 results, including site medians and Inter-Quartile range (IQR) statistics. Alongside each summary we give the results from YOUR SITE for each participating site.
- Table 2 Compares Key Indicator data from the 2008 and 2010 UK IBD Audit rounds for those sites that participated in both rounds with the same site composition.
- Table 3 Shows selected data from the concurrent National Results for the Organisation of Adult Inflammatory Bowel Disease Services in the UK
- Table 4 presents the complete 2010 UK-wide results for this 3<sup>rd</sup> round of the UK IBD Audit (2<sup>nd</sup> for Paediatric Gastroenterology). The Your Site column shows where participating sites will be able to view their comparative site data in their individual site reports
- The tables in Section 5 show site-specific Key Indicator data for 2010 for each of the 24 specialist paediatric gastroenterology sites that participated in this round.

**Table 1: 2010 UK Key indicator data from all 24 participating sites compared to “Your Site” data. Key data items are listed under the related IBD Standard.**

(1 site only entered data for Standard A. The results shown as % with related numbers in brackets are therefore out of 24 in Standard A and out of 23 for Standards B to F)

		UK 2010 (as at 1 <sup>st</sup> Sept 2010)	Your Site (as at 1 <sup>st</sup> Sept 2010)
<b>Hospital Demographics</b>			
How many IBD patients does your service manage?	Median (IQR)	178 (136, 281)	
This figure is an estimate:		50% (12)	
This figure is from a site IBD database		50% (12)	
Of these IBD patients, how many have <b>Ulcerative Colitis</b> :	Median (IQR)	60 (42, 76)	
Of these IBD patients, how many have <b>Crohn’s Disease</b> :	Median (IQR)	123 (89, 157)	
How many new IBD patients have you seen in the last 12 months?	Median (IQR)	32 (23, 50)	
<b>Standard A1 – The IBD Team</b>			
How many WTE Paediatric Gastroenterologists are there on site?	Median (IQR)	2.1 (1.4, 3.6)	
How many WTE Paediatric Surgeons are there on site?	Median (IQR)	5.4 (4.2, 7.0)	
How many WTE Paediatric IBD/Gastroenterology Nurse Specialists are there on site?	Median (IQR)	1.5 (0.9, 2.0)	
Sites with at least 0.5 WTE Paediatric IBD/Gastroenterology Nurse Specialists on site?		Yes = 83% (20)	
Sites with <u>at least some</u> * Paediatric IBD/Gastroenterology Nurse Specialist provision *=greater than 0 WTE		Yes = 83% (20)	
How many WTE Paediatric Dieticians are allocated to gastroenterology?	Median (IQR)	1.5 (0.9, 2.0)	
Is there a named Paediatric Histopathologist with an interest in gastroenterology attached to the IBD Team?		Yes = 75% (18)	
Is there a named Paediatric Radiologist with an interest in gastroenterology attached to the IBD Team?		Yes = 63% (15)	
Is there a named Paediatric Pharmacist with an interest in gastroenterology attached to the IBD Team?		Yes = 75% (18)	
<b>Standard A2 – Essential Support Services</b>			
Do you have defined access to the following personnel with an interest in IBD:		Yes = %	
	Psychologist	67% (16)	
	Counsellor	13% (3)	
	Rheumatologist	54% (13)	
	Ophthalmologist	29% (7)	
	Obstetrician	17% (4)	
	Nutritional Support Team	92% (22)	
	A GP working with the IBD team providing input into your outpatients clinics	4% (1)	
	Adult Consultant Gastroenterologist with an interest in adolescent gastroenterology	83% (20)	
<b>Standard A3 – Multidisciplinary Working</b>			
Do you have regular timetabled meetings to discuss IBD patients?		Yes = 83% (20)	
If yes, how often do they take place?			
	Weekly	65 (13)	
	Fortnightly	0 (0)	
	Monthly	25 (5)	
	Other	10 (2)	
Are the decisions recorded in the patients’ clinical records?		Yes = 80% (16)	
Who from the IBD Team regularly attends the IBD meetings?			
	Consultant Paediatric Gastroenterologists	100% (20)	
	Consultant Paediatric Surgeons	25% (5)	
	IBD Clinical Nurse Specialist	90% (18)	
	Paediatric Gastroenterology Dietitian	60% (12)	
Sites that hold joint gastroenterology/colorectal surgery clinics (where IBD patients are seen).		Yes = 42% (10)	
Sites that hold parallel gastroenterology/colorectal surgery clinics (where IBD patients are seen).		Yes = 29% (7)	
Do you have a defined arrangement for joint medical/surgical discussion with patients whose clinical condition will not wait for the next available clinic?		Yes = 88% (21)	

	UK 2010 (as at 1 <sup>st</sup> Sept 2010)	Your Site (as at 1 <sup>st</sup> Sept 2010)
<b>Standard A4 – Referral of Suspected IBD Patients</b>		
What is the waiting time for an urgent IBD clinic appointment?	Median (days)	7(5,11)
<b>Standard A5 – Access to nutritional support and therapy</b>		
Sites with a hospital multidisciplinary nutrition team		Yes = 79% (19)
Do IBD patients have access to a paediatric dietitian for	a) General Dietary Advice b) Nutritional Support	100% (24) 100% (24)
Can you refer patients with Crohn's Disease to the paediatric dietitian for exclusive liquid enteral nutritional therapy as primary treatment?		Yes = 100% (24)
<b>Standard A6 – Arrangements for the use of immunosuppressive and biological therapy</b>		
How is established immunosuppressive therapy monitored?		
	By the GP	21 (5)
	By a dedicated monitoring service	33 (8)
	During clinic visits	58 (14)
	A combination of Primary and Secondary care monitoring	71 (17)
<b>Standard A7 – Surgery for IBD</b>		
Sites where surgeons perform ileo-anal pouch surgery on site		Yes = 75%(18)
If yes, how many ileo-anal pouch operations performed between 1 <sup>st</sup> Sept 09 and 31 <sup>st</sup> Aug 2010: Median (IQR)		1 (0,3)
<b>Standard A8 – Inpatient Facilities</b>		
Sites with a designated Paediatric Gastroenterology ward on site		Yes = 33% (8)
If yes, Beds per lavatory on the ward:	Median (IQR)	3.3 (3.5,4.0)
Are any of the toilets mixed-sex?		Yes = 88% (7/8)
<b>Standard A9 – Access to Diagnostic Services</b>		
Is there access to endoscopy within 72 hrs of admission for patients admitted with relapse?		Yes = 83% (20)
Are histological reports available within 5 working days?		Yes = 79% (19)
Are urgent colonic biopsies available within 2 working days?		Yes = 83% (20)
<b>Standard A10 – Inpatient Care</b>		
Are patients admitted with known or suspected IBD discussed with a Consultant Gastroenterologist and/or Colorectal Surgeon within 24 hours of admission?		Yes = 88% (21)
Sites with guidelines for the management of Acute Severe Colitis		Yes = 63% (15)
<b>Standard A11 – Outpatient Care</b>		
Does your site have formal arrangements for Annual Review?		Yes = 29% (7)
<b>Standard B1 – Arrangements for shared care</b>		
Is there a defined protocol in place between the IBD Service and GPs for shared outpatient management?		Yes = 26% (6)
<b>Standard C2 – Rapid access to specialist advice</b>		
Is there written information for patients with IBD on whom to contact in the event of a relapse?		Yes = 91% (21)
Sites where relapsing IBD patients can expect to be seen for specialist review within 7 days		Yes = 91% (21)
Sites where patients have access to contact an IBD specialist by :	Telephone	100% (23)
	Drop-in clinic	0%
	Email	65% (15)
	None	13 (3)
What is the average length of time taken to respond to these contacts?	<48 Hours	Yes = 96% (22)
	>48 hours	Yes = 4% (1)
Who normally responds?	Nurse	Yes = 70% (16)
	Doctor	Yes = 30% (7)
<b>Standard C3 – Supporting patients to exercise choice between treatments</b>		
Are patients provided with written information about IBD?		Yes = 100% (23)
<b>Standard C5 – Involvement of patients in service improvement</b>		
Does your hospital offer open forums/meetings for patients with IBD and/or their carers?		Yes = 39% (9)
Sites that have Patient Panel meetings in place to involve patients in giving their views on the development of the IBD service		Yes = 17% (4)

<b>Standard D1 – Provision of Information</b>	
Do you provide information on IBD in languages other than English?	Yes = 39% (9)
Do you provide patients with a written care plan?	Yes = 43% (10)
Do you provide written information for patients regarding surgery?	Yes = 55% (12)
<b>Standard D2 – Education for Patients</b>	
Does your service provide education opportunities for patients?	Yes = 65% (15)
<b>Standard E1 – Register of patients under the care of the IBD service</b>	
Is a register of IBD patients maintained?	Yes = 78% (18)
<b>Standard E2 – Developing an IBD Database</b>	
Do you capture clinical data about the IBD patients under your care on a database?	Yes = 57% (13)
<b>Standard F2 – Research</b>	
Is your site currently recruiting patients to any MCRN supported studies?	Yes = 22% (5)
<b>Standard F3 – Service Development</b>	
Does your IBD Team hold an annual review day to review the IBD Service?	Yes = 22% (5)

**Table 2: Comparison of key indicator data from 2008 and 2010 for the 23 sites\* that participated in both rounds with the same site composition**

(\*One of the sites that took part in both rounds only entered data against Standard A in 2010)

		National 2008 (as at 1 <sup>st</sup> Sept 2008)	National 2010 (as at 1 <sup>st</sup> Sept 2010)	p value
<b>Standard A1 – The IBD Team</b>				
How many WTE Paediatric Gastroenterologists are there on site?	Median (IQR)	2 (1,3)	2.2 (1.4,3.6)	0.309
How many WTE Paediatric Surgeons are there on site?	Median (IQR)	4.5 (3,6)	5.5 (4.7,7)	0.051
How many WTE IBD/Gastro Nurse Specialists on there on site?	Median (IQR)	1 (0-1)	1.5 (0.8,2)	0.017
Sites with <u>at least some</u> IBD Nurse Specialist provision	Median (IQR)	Yes = 61% (14)	Yes = 83% (19)	0.102
<b>Standard A3 – Multidisciplinary Working</b>				
Timetabled meetings (where IBD patients are discussed ) take place between Consultant Gastroenterologists and Consultant Paediatric Surgeons		22% (5)	22% (5)	1
Sites that hold joint paediatric gastroenterology/paediatric surgery clinics (where IBD patients are seen)		57% (13)	44% (10)	0.376
Sites that hold parallel paediatric gastroenterology/paediatric surgery clinics (where IBD patients are seen)		26% (6)	26% (6)	1
<b>Standard A5 – Access to nutritional support and therapy</b>				
Sites with a hospital multidisciplinary nutrition team	Median (IQR)	91% (21)	78% (18)	0.218
<b>Standard A7 – Surgery for IBD</b>				
Sites where surgeons perform ileo-anal pouch surgery on site		65% (15)	74% (17)	0.522
If yes, how many ileo-anal pouch operations performed: Median (IQR)		0 (0,1)	1 (0,3)	0.141
<b>Standard A8 – Inpatient Facilities</b>				
Sites with a designated Gastroenterology ward on site		26% (6)	35% (8)	0.522
If yes, Beds per lavatory on the ward:	Median (IQR)	4 (3.3,7)	3.3 (2.5,4)	0.169
<b>Standard A10 – Inpatient Care</b>				
Sites with guidelines for the management of Acute Severe Colitis		44% (10)	61% (14)	0.238
<b>Standard C2 – Rapid access to specialist advice</b>				
Sites that provide written information for patients with IBD on whom to contact in the event of a relapse	Median (IQR)	74% (18/23)	91% (20/22)	0.242
Sites where relapsing IBD patients can expect to be seen for specialist review within 7 days		87% (20/23)	91% (20/22)	0.673
Sites where patients have access to contact an IBD specialist by :				
	Telephone	100% (23/23)	100% (22/22)	1
	Drop-in clinic	9% (2/23)	0% (0/22)	0.157
	Email	52% (12/23)	64% (14/22)	0.436
<b>Standard E2 – Developing an IBD Database</b>				
Sites that capture clinical data about the IBD patients under their care		48% (11/23)	59% (13/22)	0.015

**Table 3: Shows selected data from the concurrent 2010 National Results for the Organisation of Adult Inflammatory Bowel Disease Services in the UK**

	<b>UK 2010 202 Adult Sites (as at 1<sup>st</sup> Sept 2010)</b>
<b>Inpatient Activity</b>	
Number of admissions of patients aged 16 and under at the date of admission who were discharged from the care of adult services between 1st September 2009 and 31st August 2010 with a primary diagnosis of <b>Ulcerative Colitis</b> :	Median (IQR) 0 (0,2) (Total across 202 = 343)
Number of admissions of patients aged 16 and under at the date of admission who were discharged from the care of adult services between 1st September 2009 and 31st August 2010 with a primary diagnosis of <b>Crohn's Disease</b> :	Median (IQR) = 0 (0,3) (Total across 202 = 680)
<b>Standard A12 – Arrangements for the Care of Children and Young People who have IBD</b>	
Does your IBD Service look after any patients aged 16 and under?	Yes = 39% (78/202)
If Yes, is this done by, or in conjunction/discussion with, either a paediatric gastroenterologist or a paediatrician with an interest in gastroenterology?	Yes = 73% (57/78)
For paediatric patients undergoing endoscopy, is there:	
An appropriate endoscopy area with age appropriate facilities?	Yes = 53% (41/78)
Someone with training or extensive experience in paediatric endoscopy?	Yes = 56% (44/78)
An Anaesthetist with paediatric training?	Yes = 68% (53/78)
If yes, does your IBD Service have any of the following personnel with suitable paediatric experience?	
A Surgeon	Yes = 47% (37/78)
A radiologist (performing and reporting)?	Yes = 58% (45/78)
A dietitian (including the use of exclusive enteral feeding)?	Yes = 72% (56/78)
An IBD/GI Nurse Specialist?	Yes = 31% (24/78)
If yes, is transition co-ordinated by a named individual?	Yes = 95% (69/73)
Does your unit have a specific paediatric to adult transition policy?	Yes = 36% (73/202)
Sites that look after any patients aged 16 and under that have a specific paediatric to adult transition policy	Yes = 46% (38/78)

## Section 2: Introduction

### Aims of the UK IBD Audit

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: <http://www.rcplondon.ac.uk>

### Availability of audit results in the public domain

Full and executive summary copies of the UK IBD Audit 3<sup>rd</sup> Round (2010) National Results for the Organisation of Paediatric Inflammatory Bowel Disease Services in the UK will be available in the public domain via the Royal College of Physicians, London external website: [www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)

A limited number of key data results for each of the 24 individual sites participating in this round are published in the public domain in Section 5 of this report as agreed upon site registration for this audit. These data items were agreed by the Steering Group as giving an indication of how an IBD Service is resourced and organised in relation to the National Service Standards for the healthcare of people who have Inflammatory Bowel Disease (IBD). They are not a definition of clinical quality.

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.

The Care Quality Commission may be given access to site-specific data for sites in England to support its Quality Risk Profiles.

## **Section 3: Methods**

### **Standards used in the 3<sup>rd</sup> round (2010) data collection process**

A copy of the full dataset used in the 2010 Audit of the Organisation of Paediatric IBD Services in the UK is shown in Appendix 2. The UK IBD Audit Steering Group developed the dataset to measure against 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>).

### **Data collection tool**

The web based data collection 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 online data entry web tool by using unique identifiers and passwords and data could be saved during as well as at the end of an input session.

### **Definition of a 'site'**

Lead clinicians contacted within each specialist paediatric gastroenterology unit were asked to collect data on the basis of a unified Paediatric IBD Service.

### **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" (in every case a consultant paediatric gastroenterologist) from each site was then identified following local discussion. This "audit lead" was responsible for 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 1<sup>st</sup> September and 31<sup>st</sup> October 2010.

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

Each participating site was provided with an appropriate login and password and help booklets. A telephone and email helpdesk was provided by the Clinical Effectiveness and Evaluation unit (CEEu) at the Royal College of Physicians, London in order to answer any individual queries.

### **Data required**

The audit of the site organisation of Paediatric IBD services was as at 1st September 2010. Some organisational questions related to admissions and operations for IBD during the 12 month period from 1<sup>st</sup> September 2009 to 31<sup>st</sup> August 2010. In total, organisational audit data was received from 24 sites.

## **Inpatient Activity data - Inclusion and Exclusion criteria**

Admissions (medical and surgical) were to be counted towards the inpatient activity questions for 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. Sites were asked to confirm IBD as the primary reason for admission by checking these against a list of relevant ICD-10 discharge codes.

Day cases were to be excluded in the admissions activity data, 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 as were patients aged 17 and over on the date of admission (for this Paediatric audit).

## **Presentation of results**

The 2010 audit question numbers have been added within the results in Table 4 to facilitate reference to the actual questions in the 2010 audit datasets. These may differ from the 2008 audit question numbers therefore question numbers are not included in table 2 which compares key indicator data across the 2008 and 2010 rounds.

National results are presented as percentages for categorical data and as median and inter-quartile range (IQR) for numerical data.

**Table 4: Organisation & Structure of Paediatric IBD services in the UK as at 1st September 2010**

National data relates to the average from the 24 specialist paediatric gastroenterology sites\* across the UK that participated and the space under “Your Site” indicates where participating sites can view their comparative site-specific data in their individual site reports.

\*1 of the 24 sites only entered data against questions in Standard A.

**Hospital Demographics**

		National 24 sites % (N)	Your Site
	Which people have been involved in the collection and input of data for this form?		
	a) Consultant	88 (21)	
	b) Other medical staff	33 (8)	
	c) Nurse	46 (11)	
	d) Manager	4 (1)	
	e) Clinical Audit staff	42 (10)	
	f) Other	8 (2)	
		National 24 sites % (N)	Your Site
1	Are there any other hospitals managing IBD patients in your Trust/Health Board?		
	Yes	33 (8)	
	No	67 (16)	
		National 24 sites % (N)	Your Site
1i	If Yes to Q1, do you operate as a single integrated IBD Service across the Trust/Health Board		
	Yes	50 (4)	
	No	50 (4)	
		National 24 sites % (N)	Your Site
1ii	If No to Q1, do you operate as a separate IBD Service but within a Managed Clinical Network		
	Yes	44 (7)	
	No	56 (9)	
		National 24 sites Median (IQR)	Your Site
2	How many IBD patients does your service manage?	178 (136, 281)	

		National 24 sites % (N)	Your Site
2i	Is this figure		
	a) An estimate?	50 (12)	
	b) From your IBD database?	50 (12)	
		National 24 sites Median (IQR)	Your Site
2ii	Of these IBD patients, how many have		
	a) UC?	60 (42, 76)	
	b) Crohn's Disease?	123 (89, 157)	
		National 24 sites Median (IQR)	Your Site
3	How many new IBD patients have you seen in the last 12 months?	32 (23, 50)	

### **Inpatient Activity**

		National 24 sites Median (IQR)	Your Site
	How many patients aged 16 and under at the date of admission were discharged from the care of paediatric services between 1st September 2009 and 31st August 2010 with a primary diagnosis of		
4i	a) Ulcerative Colitis?	10 (4, 17)	
4ii	b) Crohn's Disease?	19 (7, 32)	
		National 24 sites Median (IQR)	Your Site
	How many patients aged 17 and over at the date of admission were discharged from the care of paediatric services between 1st September 2009 and 31st August 2010 with a primary diagnosis of		
4iii	a) Ulcerative Colitis?	1 (0, 8)	
4iv	b) Crohn's Disease?	3 (0, 12)	
		National 24 sites Median (IQR)	Your Site
	How many patients aged 16 and under at the date of admission were discharged from the care of paediatric services between 1st September 2009 and 31st August having had an operation where the primary indication was		
5i	a) Ulcerative Colitis?	2 (0, 3)	
5ii	b) Crohn's Disease?	4 (1, 6)	

		National 24 sites Median (IQR)	Your Site
	How many patients aged 17 and over at the date of admission were discharged from the care of paediatric services between 1st September 2009 and 31st August having had an operation where the primary indication was		
5iii	a) Ulcerative Colitis?	0 (0, 1)	
5iv	b) Crohn's Disease?	0 (0, 3)	

### **Standard A – High quality clinical care**

#### **Standard A1 – The IBD Team**

		National 24 sites % (N)	Your Site
1	Does your service have a named clinical lead?		
	Yes	83 (20)	
	No	17 (4)	
	If Yes, is this a		
	a) Consultant Paediatric Gastroenterologist	85 (17)	
	b) Consultant Paediatric Surgeon	0 (0)	
	c) Paediatric IBD/Gastro Nurse Specialist?	5 (1)	
	d) Consultant Paediatrician with a special interest in Paediatric Gastroenterology	5 (1)	
	e) Other	5 (1)	
		National 24 sites Median (IQR)	Your Site
2	How many WTE Paediatric Gastroenterologists are there on site?	2.1 (1.4, 3.6)	
		National 24 sites Median (IQR)	Your Site
3	How many WTE Paediatric Surgeons are there on site?	5.4 (4.2, 7.0)	
		National 24 sites Median (IQR)	Your Site
4	How many WTE IBD/Gastroenterology Nurse Specialists are there on site?	1.5 (0.9, 2.0)	
		National 24 sites % (N)	Your Site
4i	If Q4 = less than 0.5 WTE, has a business case for additional IBD Nurse Specialist provision been submitted?		
	Yes	25 (1)	
	No	75 (3)	
		National 24 sites % (N)	Your Site
4ii	If Q4i is Yes, was the business case successful?		
	Yes	0 (0)	
	No	100 (1)	
	Decision pending	0 (0)	

		National 24 sites % (N)	Your Site
5	How many WTE Stoma Nurses are there on site?	1 (0.5, 2)	
		National 24 sites % (N)	Your Site
5i	If Q5 = less than 0.5 WTE, has a business case for additional IBD Stoma Nurse provision been submitted?		
	Yes	0 (0)	
	No	100 (5)	
		National 24 sites % (N)	Your Site
5ii	If Q5i is Yes, was the business case successful?		
	Yes	0 (0)	
	No	0 (0)	
	Decision pending	0 (0)	
		National 24 sites % (N)	Your Site
6	How many WTE Paediatric Dietitians are allocated to gastroenterology?	1.5 (0.9, 2.0)	
		National 24 sites % (N)	Your Site
6i	If Q6 = less than 0.5 WTE, has a business case for additional Dietician provision been submitted?		
	Yes	50 (1)	
	No	50 (1)	
		National 24 sites % (N)	Your Site
6ii	If Q6i is Yes, was the business case successful?		
	Yes	0 (0)	
	No	100 (1)	
	Decision pending	0 (0)	
		National 24 sites % (N)	Your Site
7	How many WTE Administrators are attached to the IBD team?	0 (0, 1)	
		National 24 sites % (N)	Your Site
7i	If Q7 = less than 0.5 WTE, has a business case for additional Administrator provision been submitted?		
	Yes	27 (4)	
	No	73 (11)	

		National 24 sites % (N)	Your Site
7ii	If Q7i is Yes, was the business case successful?		
	Yes	23 (1)	
	No	50 (2)	
	Decision pending	25 (1)	

		National 24 sites % (N)	Your Site
8	Is there a named Paediatric Histopathologist with an interest in gastroenterology attached to the IBD Team?		
	Yes	75 (18)	
	No	25 (6)	

		National 24 sites % (N)	Your Site
9	Is there a named Paediatric Radiologist with an interest in gastroenterology attached to the IBD Team?		
	Yes	63 (15)	
	No	38 (9)	

		National 24 sites % (N)	Your Site
10	Is there a named Paediatric Pharmacist with an interest in gastroenterology attached to the IBD Team?		
	Yes	75 (18)	
	No	25 (6)	

### Standard A2 – Essential Supporting Services

		National 24 sites % (N)	Your Site
1	Please indicate if you have defined access to the following personnel with an interest in IBD		
	a) Psychologist	67 (16)	
	b) Counsellor	13 (3)	
	c) Rheumatologist	54 (13)	
	d) Ophthalmologist	29 (7)	
	e) Obstetrician	17 (4)	
	f) Nutritional Support Team	92 (22)	
	g) A GP working with the IBD team providing input into your outpatients clinics	4 (1)	
	h) Adult Consultant Gastroenterologist with an interest in adolescent gastroenterology	83 (20)	

### Standard A3 – Multidisciplinary Working

#### Standard A3.1 – IBD Team Meetings

		National 24 sites % (N)	Your Site
1	Do you have regular timetabled meetings to discuss IBD patients?		
	Yes	83 (20)	
	No	17 (4)	

		National 24 sites % (N)	Your Site
1i	If yes, how often do they take place?		
	a) Weekly	65 (13)	
	b) Fortnightly	0 (0)	
	c) Monthly	25 (5)	
	d) Other	10 (2)	
		National 24 sites % (N)	Your Site
1ii	Are these held as		
	a) Separate IBD meetings	40 (8)	
	b) Part of another meeting	60 (12)	
		National 24 sites % (N)	Your Site
1iii	Are the IBD Team Meetings minuted?		
	Yes	15 (3)	
	No	85 (17)	
		National 24 sites % (N)	Your Site
1iv	Is a record of attendance kept?		
	Yes	30 (6)	
	No	70 (14)	
		National 24 sites % (N)	Your Site
1v	Are the decisions recorded in the patients' clinical records?		
	Yes	80 (16)	
	No	20 (4)	
		National 24 sites % (N)	Your Site
1vi	Does the IBD meeting review all IBD deaths?		
	Yes	63 (12)	
	No	37 (7)	
		National 24 sites % (N)	Your Site
1vii	Does the IBD meeting review audit data?		
	Yes	45 (9)	
	No	55 (11)	
		National 24 sites % (N)	Your Site

1viii	Who from the IBD Team regularly attends the IBD meetings?	
	a) Consultant Paediatric Gastroenterologists	100 (20)
	b) Consultant Paediatric Surgeons	25 (5)
	c) IBD Clinical Nurse Specialist	90 (18)
	d) Stoma Care Clinical Nurse Specialist	15 (3)
	e) Paediatric Gastroenterology Dietitian	60 (12)
	f) Administrative support worker	5 (1)
	g) Paediatric Histopathologist	25 (5)
	h) Paediatric Radiologist	20 (4)
	i) Paediatric Pharmacist	20 (4)
	j) Other	30 (6)

Standard A3.2 – Medical / Surgical Interaction

		National 24 sites % (N)	Your Site
1	Do you hold joint Paediatric gastroenterology/surgery clinics (where IBD patients are seen)?		
	Yes	42 (10)	
	No	58 (14)	
		National 24 sites % (N)	Your Site
1i	If yes, how often do they take place?		
	a) Weekly	0 (0)	
	b) Fortnightly	0 (0)	
	c) Monthly	40 (4)	
	d) Other	60 (6)	
		National 24 sites % (N)	Your Site
2	Do you hold parallel Paediatric gastroenterology/surgery clinics?		
	Yes	29 (7)	
	No	71 (17)	
		National 24 sites % (N)	Your Site
2i	If yes, how often do they take place?		
	a) Weekly	71 (5)	
	b) Fortnightly	14 (1)	
	c) Monthly	0 (0)	
	d) Other	14 (1)	
		National 24 sites % (N)	Your Site
3	Do you have a defined arrangement for joint medical/surgical discussion with patients whose clinical condition will not wait for the next available clinic?		
	Yes	88 (21)	
	No	12 (3)	

#### Standard A4 – Referral of Suspected IBD Patients

	National 24 sites Median (IQR)	Your Site
1	What is the waiting time for an urgent IBD clinic appointment? (days)	7 (5, 11)
2	What proportion of your patients are referred urgently? Don't know % (N)	18 (5, 75) 58 (14)
3	What is the waiting time for a routine IBD clinic appointment?	28 (14, 42)
4	When did you last do an internal audit of the time taken from referral to being seen? a) Within the past 12 months b) More than 12 months ago c) Never	21 (5) 12 (3) 67 (16)

#### Standard A5 – Access to nutritional support and therapy

	National 24 sites % (N)	Your Site
1	Is there a hospital multidisciplinary nutrition team? Yes No	79 (19) 21 (5)
2	Do IBD patients have access to a dietitian for a) General Dietary Advice? Yes No b) Nutritional Support? Yes No	100 (24) 0 (0) 100 (24) 0 (0)
3	Can you refer patients with Crohn's Disease to the dietitian for exclusive liquid enteral nutritional therapy as primary treatment? Yes No	100 (24) 0 (0)

## Standard A6 – Arrangements for the use of immunosuppressive and biological therapy

	National 24 sites % (N)	Your Site
1		
Which of the following activities is the pharmacist involved in?		
a) Inpatient drug reviews	88 (21)	
b) Outpatient clinic	21 (5)	
c) Consultant ward rounds	58 (14)	
d) MDT Meetings	63 (15)	
e) Immunosuppressant clinic	8 (2)	
f) Applications for high cost medications	79 (19)	
g) Other	12 (3)	

	National 24 sites % (N)	Your Site
2		
How is established immunosuppressive therapy monitored?		
a) By the GP	21 (5)	
b) By a dedicated monitoring service	33 (8)	
c) During clinic visits	58 (14)	
d) A combination of Primary and Secondary care monitoring	71 (17)	

## Standard A7 – Surgery for IBD

	National 24 sites % (N)	Your Site
1		
Do surgeons perform ileo-anal pouch surgery on site?		
Yes	75 (18)	
No	25 (6)	

	National 24 sites Median (IQR)	Your Site
1i		
How many ileo-anal pouch operations were performed between 1st September 2009 and 31st August 2010?	1 (0. 3)	

## Standard A8 – Inpatient Facilities

	National 24 sites % (N)	Your Site
1		
Is there a Paediatric Intensive Therapy Unit (ITU) on site?		
Yes	71 (17)	
No	29 (7)	

	National 24 sites % (N)	Your Site
2		
Is there a Paediatric High Dependency Unit (HDU) on site?		
Yes	83 (20)	
No	17 (4)	

		National 24 sites % (N)	Your Site
2i	If Yes, is it		
	a) Medical	15 (3)	
	b) Surgical	0 (0)	
	c) Combined	85 (17)	
		National 24 sites % (N)	Your Site
3	Is there a combined Paediatric Intensive Therapy (ITU) & Paediatric High Dependency (HDU) Unit on site?		
	Yes	37 (9)	
	No	63 (15)	
		National 24 sites % (N)	Your Site
4	Is there a designated Paediatric Gastroenterology ward on site?		
	Yes	33 (8)	
	No	67 (16)	
		National 24 sites % (N)	Your Site
4i	If Yes, is the ward		
	a) for both medical and surgical patients?	50 (4)	
	b) just for medical patients, but in close proximity to the surgical wards (on the same site)?	50 (4)	
	c) just for medical patients, with no surgical ward on the same site?	0 (0)	
		National 24 sites	Your Site
		Median (IQR)	
4ii	How many beds per lavatory on the ward?	3.3, 3.5, 4.0)	
		National 24 sites % (N)	Your Site
4iii	Are any of the toilets mixed-sex?		
	Yes	88 (7)	
	No	12 (1)	

#### Standard A9 – Access to Diagnostic Services

		National 24 sites % (N)	Your Site
1	Is there access to endoscopy within 72 hrs of admission for patients admitted with relapse?		
	Yes	83 (20)	
	No	17 (4)	

		National 24 sites % (N)	Your Site
2	Are histological reports available within 5 working days?		
	Yes	79 (19)	
	No	21 (5)	
		National 24 sites % (N)	Your Site
3	Are urgent colonic biopsies available within 2 working days?		
	Yes	83 (20)	
	No	17 (4)	

#### Standard A10 – Inpatient Care

		National 24 sites % (N)	Your Site
1	Do arrangements exist for admitting existing IBD patients direct to the specialist Gastroenterology ward or area?		
	Yes	75 (18)	
	No	25 (60)	
		National 24 sites % (N)	Your Site
2	Are patients admitted with known or suspected IBD discussed with a Consultant Gastroenterologist and/or Colorectal Surgeon within 24 hours of admission?		
	Yes	88 (21)	
	No	12 (3)	
		National 24 sites % (N)	Your Site
3	Are all IBD patients admitted notified to the IBD medical or surgical specialist nurses?		
	Yes	71 (17)	
	No	29 (7)	
		National 24 sites % (N)	Your Site
4	Does your Trust have guidelines for the management of Acute Severe Colitis?		
	Yes	63 (15)	
	No	27 (9)	

#### Standard A11 – Outpatient Care

		National 24 sites % (N)	Your Site
1	Does your site have formal arrangements for Annual Review?		
	Yes	29 (7)	
	No	71 (17)	

		National 24 sites % (N)	Your Site
1i	If yes, how is this carried out?		
	a) Community clinic	0 (0)	
	b) Telephone clinic	0 (0)	
	c) Hospital review	100 (70)	
	d) E-mail review	14 (1)	
	e) Postal review	0 (0)	

		National 24 sites % (N)	Your Site
1ii	If yes, does the Annual Review include the assessment of any of the following?		
	a) FBC	100 (7)	
	b) U&E	100 (7)	
	c) Iron Studies	71 (5)	
	d) B12 Folate	71 (5)	
	e) Vitamin D	57 (4)	
	f) the need for DEXA scanning	14 (1)	
	g) the need for cancer Surveillance	14 (1)	
	h) Liver function	86 (6)	
	i) Height	100 (7)	
	j) Weight	100 (7)	
	k) Pubertal status	86 (6)	

		National 24 sites % (N)	Your Site
2	Does your site offer a range of arrangements for outpatient care?		
	Yes	58 (14)	
	No	42 (10)	

		National 24 sites % (N)	Your Site
2i	If yes, what services are offered?		
	a) Hospital Appointments	100 (14)	
	b) Guided self – management with access to support when needed	71 (10)	
	c) Primary Care follow up with links to the IBD team	0 (0)	

### **Standard B – Local delivery of care**

#### **Standard B1 – Arrangements for shared care**

		National 23 sites % (N)	Your Site
1	Is there a defined protocol in place between the IBD Service and GPs for shared outpatient management?		
	Yes	26 (6)	
	No	74 (17)	

		National 23 sites % (N)	Your Site
1i	If yes, is information about the shared care protocol given to patients?		
	Yes	83 (5)	
	No	17 (1)	
		National 23 sites % (N)	Your Site
1ii	If yes, is it given		
	a) Verbally	40 (2)	
	b) In a letter	80 (4)	
	c) In a formal written care plan	40 (2)	
		National 23 sites % (N)	Your Site
2	Is there a system for sharing of information about test results or treatment changes with GPs?		
	Yes	100 (23)	
	No	0 (0)	
		National 23 sites % (N)	Your Site
2i	If yes, is this done via:		
	a) Electronic Record	22 (5)	
	b) Letter	96 (22)	
	c) Patient Held Record	9 (2)	

### **Standard C – Maintaining a patient-centred service**

#### **Standard C1 – Information on the IBD service**

		National 23 sites % (N)	Your Site
1	Is there a clear structured pathway for the patient to discuss his / her treatment with the multidisciplinary team?		
	Yes	8 (20)	
	No	13 (3)	
		National 23 sites % (N)	Your Site
2	Is there clear guidance on how patients can seek a second opinion if they are unhappy with their care / need advice?		
	Yes	61 (14)	
	No	39 (9)	

## Standard C2 – Rapid access to specialist advice

		National 23 sites % (N)	Your Site
1	Is there written information for patients with IBD on whom to contact in the event of a relapse?		
	Yes	91 (21)	
	No	9 (2)	
		National 23 sites % (N)	Your Site
2	Are there arrangements for expedited specialist review of these relapsed patients?		
	Yes	100 (23)	
	No		
		National 23 sites % (N)	Your Site
2i	If yes, what is the time between relapse and review?		
	a) <5 days	65 (15)	
	b) 5 – 7 days	26 (6)	
	c) 8 – 9 days	0 (0)	
	d) > 9 days	9 (2)	
		National 23 sites % (N)	Your Site
3	Do patients have access to contact an IBD Specialist by any of the following methods?		
	a) Telephone	100 (23)	
	b) Drop in clinic	0 (0)	
	c) Email	65 (15)	
	d) Other	0 (0)	
	e) None of the above	13 (3)	
		National 23 sites % (N)	Your Site
3i	What is the average length of time taken to respond to these contacts?		
	a) <48 hours	96 (22)	
	b) > 48 hours	4 (1)	
		National 23 sites % (N)	Your Site
3ii	Who normally responds?		
	a) Nurse	70 (16)	
	b) Doctor	30 (7)	
	c) Other	0 (0)	

## Standard C3 – Supporting patients to exercise choice between treatments

		National 23 sites % (N)	Your Site
1	Are patients provided with written information about IBD?		
	Yes	100 (23)	
	No	0 (0)	

	National 23 sites % (N)	Your Site
1i		
If yes is this produced by		
a) NACC	92 (21)	
b) CICRA	96 (22)	
c) Pharmaceutical	43 (10)	
d) Locally Written	65 (15)	
e) Drug Specific	74 (17)	
f) Other	9 (2)	

	National 23 sites % (N)	Your Site
1ii		
Does this information include details of treatment options so that patients can make an informed choice about their treatment?		
Yes	82 (18)	
No	18 (4)	

#### Standard C4 – Supporting patient to exercise choice between care strategies for outpatient management

	National 23 sites % (N)	Your Site
1		
Are patients offered a choice of how they wish to be followed up other than the traditional review in out patient clinic?		
Yes	26 (6)	
No	74 (17)	

	National 23 sites % (N)	Your Site
1i		
If yes, does this include any of the following?		
a) Supported Self management	0 (0)	
b) Shared care with GP	17 (1)	
c) Scheduled telephone clinic	33 (2)	
d) Other	67 (4)	

#### Standard C5 – Involvement of patients in service improvement

	National 23 sites % (N)	Your Site
1		
Does your service offer open forums or meetings for patients with IBD?		
Yes	39 (9)	
No	61 (14)	

	National 23 sites % (N)	Your Site
1		
If yes, how often do these take place?		
a) < 4 monthly	11 (1)	
b) 4 – 8 monthly	0 (0)	
c) 9 – 12 monthly	67 (6)	
d) Other	22 (2)	

	National 23 sites % (N)	Your Site
1i	Which members of staff attend these meetings?	
	a) Medical	100 (9)
	b) Surgical	56 (5)
	c) Nursing	100 (9)
	d) Other	44 (4)

	National 23 sites % (N)	Your Site
2	Are any of the following activities or systems in place to involve patients in giving their views on the development of your IBD service?	
	a) Regular patient surveys	30 (7)
	b) Individual patient representatives	9 (2)
	c) Patient panel meetings	17 (4)
	d) None	36 (8)
	e) Other	13 (3)

### **Standard D – Patient Education and Support**

#### **Standard D1 – Provision of Information**

	National 23 sites % (N)	Your Site
1	Do you provide information on IBD in languages other than English?	
	Yes	39 (9)
	No	61 (14)

	National 23 sites % (N)	Your Site
2	Do you have access to translation services if needed?	
	Yes	22 (100)
	No	0 (0)

	National 23 sites % (N)	Your Site
3	Do you have specific information for newly diagnosed patients?	
	Yes	96 (22)
	No	4 (1)

	National 23 sites % (N)	Your Site
4	Do you provide patients with a written care plan?	
	Yes	43 (10)
	No	57 (13)

		National 23 sites % (N)	Your Site
4i	If yes, for which patients		
	a) Newly diagnosed patients	70 (7)	
	b) Outpatients	50 (5)	
	c) Patients receiving immunomodulators	60 (6)	
	d) Patients receiving biological therapies	50 (5)	
	e) Other	20 (2)	

		National 23 sites % (N)	Your Site
5	Do you provide written information for patients regarding surgery?		
	Yes	55 (12)	
	No	45 (10)	

#### Standard D2 – Education for Patients

		National 23 sites % (N)	Your Site
1	Does your service provide education opportunities for patients?		
	Yes	65 (15)	
	No	35 (8)	

#### Standard D3 – Information about patient organisations

		National 23 sites % (N)	Your Site
1	Are all your patients given contact information for IBD patient organisations?		
	Yes	100 (23)	
	No	0 (0)	

#### Standard D4 – Support for patient organisations

		National 23 sites % (N)	Your Site
1	Does your IBD service have regular contact with IBD patient organisations?		
	Yes	87 (20)	
	No	13 (3)	

		National 23 sites % (N)	Your Site
1i	If yes, which ones:		
	a) National Association for Colitis and Crohn's Disease (NACC)	80 (16)	
	b) Crohn's in Childhood Research Association (CICRA)	85 (17)	
	c) The Ileostomy & Internal Pouch Support Group (IA)	10 (2)	
	d) Other	3 (5)	

## **Standard E – Information Technology and audit**

### **Standard E1 – Register of patients under the care of the IBD service**

	National 23 sites % (N)	Your Site
1		
Is a register of IBD patients maintained?		
Yes	78 (18)	
No	22 (5)	

	National 23 sites % (N)	Your Site
1i		
If yes, what are the inclusion criteria?		
a) Any patient with IBD	89 (16)	
b) Only patients treated with immunosuppressants (including biologics)	0 (0)	
c) Only patients treated with biologics	6 (1)	
d) Other	6 (1)	

### **Standard E2 – Developing an IBD Database**

	National 23 sites % (N)	Your Site
1		
Do you capture clinical data about the IBD patients under your care?		
Yes	57 (13)	
No	43 (10)	

	National 23 sites % (N)	Your Site
1i		
If yes, is this captured for:		
a) Only patients who receive hospital care for IBD?	8 (1)	
b) Any patient with a diagnosis of IBD?	85 (11)	
c) Other	8 (1)	

	National 23 sites % (N)	Your Site
1ii		
If yes, do you use this system in real time to support the management of patients?		
Yes	31 (4)	
No	69 (9)	

### **Standard E3 – Participation in Audit**

	National 23 sites % (N)	Your Site
1		
Apart from this audit, are you participating in any other national or international audits of care for IBD?		
Yes	7 (30)	
No	16 (70)	

	National 23 sites % (N)	Your Site
2		
Do you submit data (including outcomes) about patients with IBD who undergo surgery, to a national registry?		
Yes	5 (1)	
No	95 (21)	

### **Standard F – Evidence-based practice and research**

#### **Standard F1 – Training and Education**

	National 23 sites Median (IQR)	Your Site
1		
How many days of IBD Specific training did your IBD Nurse Specialist have in the past 12 months?		
Nurse 1	2 (0, 5)	
Nurse 2	0 (0, 3)	
Nurse 3	0 (0, 0)	

#### **Standard F2 – Research**

	National 23 sites % (N)	Your Site
1		
Is your site currently recruiting patients to any MCRN supported studies?		
Yes	22 (5)	
No	78 (18)	

#### **Standard F3 – Service Development**

	National 23 sites % (N)	Your Site
1		
Does your IBD Team hold an annual review day to review the IBD Service?		
Yes	22 (5)	
No	78 (18)	

**Table 5: Individual Site 2010 Key Indicator Data**

The tables in this section give named site data in alphabetical order of participating specialist paediatric gastroenterology site. Please note this describes the self reported site status on the 1st September 2010. These data items were agreed by the UK IBD Audit Steering Group as giving an indication of how an IBD Service is resourced and organised in relation to the IBD Standards. They are not a definition of clinical quality. The combined UK results from all 24 participating sites are shown for comparison.

Key Indicators	How many paediatric IBD patients does your IBD Service manage?	Does the IBD Service have a named clinical lead?	Are there at least 0.5 WTE paediatric gastro/IBD Nurse Specialists in the IBD Team?	Are there at least 0.5 WTE paediatric dieticians allocated to gastroenterology?	Is there a designated Paediatric Gastroenterology ward on site?	Is there a hospital multidisciplinary nutrition team?	Does the IBD Service provide written information for paediatric patients with IBD and/or their carers on whom to contact in the event of a relapse?	Can relapsing IBD patients expect to be seen for specialist review within 7 days of referral?	Are regular timetabled IBD Team, meetings held to discuss paediatric IBD patients?	Are joint or parallel gastroenterology/ surgery clinics held?	Are there guidelines for the management of Acute Severe Colitis?	Is a written care plan available for IBD patients and/or their carers?	Is there a defined protocol in place between the IBD Service and GPs for shared outpatient management?	
	Number of IBD patients E = an Estimate D = from a Database	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	
UK results 2010	Median = 178 50% = E	Yes = 83%	Yes = 83%	Yes = 96%	Yes = 33%	Median = 3.3	Yes = 79%	Yes = 91%	Yes = 91%	Yes = 83%	Yes = 63%	Yes = 43%	Yes = 26%	
Addenbrooke's Hospital (Paediatric Gastro unit)	150 E	Yes	Yes	Yes	No		Yes	Yes	Yes	Yes	No	No	Yes	No
Alder Hey Children's Hospital	282 D	Yes	Yes	Yes	Yes	7	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Barts and The London Children's Hospital	144 D	Yes	Yes	Yes	Yes	4	Yes	Yes	Yes	Yes	Yes	No	No	No
Birmingham Children's Hospital	280 D	No	Yes	Yes	No		Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Bristol Royal Hospital for Sick Children	400 E	No	Yes	Yes	No		No	Yes	Yes	Yes	Yes	No	No	No
Children's Services, Chelsea and Westminster Hospital	150 E	Yes	Yes	Yes	Yes	4	Yes	Yes	Yes	Yes	Yes	No	No	No
Dept of Child Health, University Hospital of Wales	180 D	Yes	Yes	No	No		Yes	Yes	Yes	Yes	Yes	Yes	No	No

Key Indicators	How many paediatric IBD patients does your IBD Service manage?		Does the IBD Service have a named clinical lead?	Are there at least 0.5 WTE paediatric gastro/IBD Nurse Specialists in the IBD Team?	Are there at least 0.5 WTE paediatric dieticians allocated to gastroenterology?	Is there a designated Paediatric Gastroenterology ward on site?	Is there a hospital multidisciplinary nutrition team?	Does the IBD Service provide written information for paediatric patients with IBD and/or their carers on whom to contact in the event of a relapse?	Can relapsing IBD patients expect to be seen for specialist review within 7 days of referral?	Are regular timetabled IBD Team, meetings held to discuss paediatric IBD patients?	Are joint or parallel gastroenterology/surgery clinics held?	Are there guidelines for the management of Acute Severe Colitis?	Is a written care plan available for IBD patients and/or their carers?	Is there a defined protocol in place between the IBD Service and GPs for shared outpatient management?	
	Number of IBD patients	E = an Estimate D = from a Database	Yes/No	Yes/No	Yes/No	Yes/No	If yes how many beds per toilet?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	
UK results 2010	Median = 178	50% = E	Yes = 83%	Yes = 83%	Yes = 96%	Yes = 33%	Median = 3.3	Yes = 79%	Yes = 91%	Yes = 91%	Yes = 83%	Yes = 63%	Yes = 63%	Yes = 43%	Yes = 26%
Great Ormond St Hospital	550	D	Yes	Yes	Yes	No		Yes	Yes	No	No	No	Yes	No	Yes
Leeds General Infirmary (Paediatric Gastro Unit)	150	E	Yes	No	Yes	Yes	2	Yes		Yes	Yes	Yes			
Leicester Royal Infirmary Children's Hospital	110	E	Yes	Yes	Yes	Yes	3.3	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Morrison Hospital (Paediatric Gastroenterology)	30	D	Yes	No	Yes	No		Yes	No	No	No	No	No	Yes	No
North-East Scotland Paediatric Gastroenterology Network (Royal Aberdeen Children's Hospital, Ninewells Hospital and Raigmore Hospital combined)	101	E	Yes	Yes	Yes	No		No	Yes	Yes	Yes	No	No	Yes	No
Oxford Children's Hospital	128	D	Yes	Yes	Yes	No		No	Yes	Yes	Yes	Yes	No	No	No
Royal Belfast Hospital for Sick Children	190	E	Yes	Yes	Yes	No		Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Royal Free Hospital (Paediatric Gastroenterology Unit)	180	E	Yes	Yes	Yes	No		Yes	Yes	Yes	Yes	No	Yes	No	No

Key Indicators	How many paediatric IBD patients does your IBD Service manage?		Does the IBD Service have a named clinical lead?	Are there at least 0.5 WTE paediatric gastro/IBD Nurse Specialists in the IBD Team?	Are there at least 0.5 WTE paediatric dieticians allocated to gastroenterology?	Is there a designated Paediatric Gastroenterology ward on site?	Is there a hospital multidisciplinary nutrition team?	Does the IBD Service provide written information for paediatric patients with IBD and/or their carers on whom to contact in the event of a relapse?	Can relapsing IBD patients expect to be seen for specialist review within 7 days of referral?	Are regular timetabled IBD Team, meetings held to discuss paediatric IBD patients?	Are joint or parallel gastroenterology/surgery clinics held?	Are there guidelines for the management of Acute Severe Colitis?	Is a written care plan available for IBD patients and/or their carers?	Is there a defined protocol in place between the IBD Service and GPs for shared outpatient management?	
	Number of IBD patients	E = an Estimate D = from a Database	Yes/No	Yes/No	Yes/No	Yes/No	If yes how many beds per toilet?	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	
UK results 2010	Median = 178	50% = E	Yes = 83%	Yes = 83%	Yes = 96%	Yes = 33%	Median = 3.3	Yes = 79%	Yes = 91%	Yes = 91%	Yes = 83%	Yes = 63%	Yes = 63%	Yes = 43%	Yes = 26%
Royal Hospital for Sick Children, Edinburgh	153	D	Yes	Yes	Yes	No		Yes	Yes	Yes	Yes	No	Yes	No	No
Royal Manchester Children's Hospital	284	D	No	Yes	Yes	Yes	3	Yes	Yes	Yes	Yes	Yes	No	No	No
Royal Victoria Infirmary Children's Services	198	D	Yes	Yes	Yes	Yes	1	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sheffield Children's Hospital	175	E	No	Yes	Yes	Yes	3.2	Yes	Yes	Yes	No	Yes	No	No	No
Southampton Children's Hospital	284	D	No	Yes	Yes	Yes	3	Yes	Yes	Yes	Yes	Yes	No	No	No
St George's Hospital (Paediatric Gastro unit)	290	E	Yes	No	Yes	No		Yes	No	Yes	Yes	Yes	Yes	Yes	No
St Mark's Hospital (Paediatric Gastroenterology)	65	E	Yes	Yes	Yes	No		Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
The Children's Hospital Lewisham	40	E	Yes	No	Yes	No		Yes	Yes	Yes	No	Yes	Yes	No	No
Yorkhill Children's Hospital	220	D	Yes	Yes	Yes	No		No	Yes	Yes	Yes	No	No	No	No

## Appendix 1

### UK IBD Audit Steering Group – May 2011

#### Chair

Dr Ian Arnott, Consultant Gastroenterologist, Western General Hospital, Edinburgh

#### Association of Coloproctology of Great Britain and Ireland

Mr Bruce George, Consultant Colorectal Surgeon, John Radcliffe Hospital

#### Association of Coloproctology of Great Britain and Ireland

Mr Graeme Wilson, Consultant Colorectal Surgeon, Western General Hospital, Edinburgh

#### British Dietetic Association

Ms Miranda Lomer, Consultant Dietitian, Guy's and St Thomas' NHS Foundation Trust

#### British Society of Gastroenterology

Dr Stuart Bloom, Consultant Gastroenterologist, University College Hospital

#### British Society of Gastroenterology

Dr Keith Bodger, Consultant Physician & Gastroenterologist, University Hospital Aintree

#### British Society of Gastroenterology

Dr Barney Hawthorne, Consultant Gastroenterologist, University Hospital of Wales

#### British Society of Gastroenterology

Dr Keith Leiper, Consultant Gastroenterologist, Royal Liverpool University Hospital

#### British Society of Gastroenterology

Professor Chris Probert, Consultant Gastroenterologist, Bristol Royal Infirmary

#### British Society of Gastroenterology

Professor Jonathan Rhodes, Professor of Medicine, University of Liverpool

#### British Society of Gastroenterology

Mrs Chris Romaya, Executive Secretary

#### British Society of Gastroenterology

Dr Ian Shaw, Consultant Gastroenterologist, Gloucestershire Royal Hospital

#### British Society of Gastroenterology

Dr Abraham Varghese, Consultant Gastroenterologist, Causeway Hospital

#### British Society of Paediatric Gastroenterology, Hepatology and Nutrition

Dr Sally Mitton, Consultant Paediatric Gastroenterologist, St George's Hospital

#### British Society of Paediatric Gastroenterology, Hepatology and Nutrition

Dr Richard Russell, Consultant Paediatric Gastroenterologist, Yorkhill Hospital, Glasgow

#### Health Services Modernisation

Mr John Frankish, Aneurin Bevan Health Board

#### Crohn's and Colitis UK (NACC)

Mr Richard Driscoll, Chief Executive

#### Crohn's and Colitis UK (NACC)

Ms Elaine Steven, Vice-President

#### Primary Care Society for Gastroenterology

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#### Royal College of Nursing Crohn's and Colitis Special Interest Group

Ms Karen Kemp, IBD Clinical Nurse Specialist, Manchester Royal Infirmary

Royal College of Nursing Crohn's and Colitis Special Interest Group  
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