Executive summary 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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- British Society of Paediatric Gastroenterology, Hepatology and Nutrition
- Crohn’s and Colitis UK
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| **Related publications** | The full national report of the results of the organisational audit of paediatric inflammatory bowel disease Services.  
The full site report of the process of care for paediatric patients admitted to hospital with Inflammatory Bowel Disease that will be available in Spring 2012.  
National Service Standards for the healthcare of people who have Inflammatory Bowel Disease (IBD) (www.ibdstandards.org.uk) |
| **Contact**            | ibd.audit@rcplondon.ac.uk |
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UK IBD Audit 3rd Round (2010) – Executive Summary of the National Results for the Organisation of Paediatric IBD Services

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. Up to 25% of cases will present in childhood years 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 1st 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 2nd 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 2nd round (1st 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 3rd round (2nd 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. 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” 1st 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 of National Results

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 1st 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 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.
Site specific data in the public domain

Sites participated in the UK IBD Audit 3rd round on the understanding that a selection of site-specific data would be published in the public domain in the full National Report to be launched on the 24th May 2011. These publicly available 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 National Service Standards for the healthcare of people who have Inflammatory Bowel Disease. They were not chosen to be a definition of clinical quality.

Table 1 shows the selected key data items which will be publicly available for each participating site in the full National Report compared against the corresponding combined UK data from the 24 paediatric sites participating in 2010.

Table 1

<table>
<thead>
<tr>
<th>IBD Service Demographics</th>
<th>UK 2010 (as at 1st Sept 2010)</th>
<th>Your Site (as at 1st Sept 2010)</th>
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<tbody>
<tr>
<td>How many paediatric IBD patients does your service manage?</td>
<td>Median (IQR) 178 (136, 281)</td>
<td>50% (12)</td>
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**Standard A1 – The IBD Team**

- Does the paediatric IBD Service have a named clinical lead? 
  - Yes = 83% (20)
- Sites with at least 0.5 WTE Paediatric IBD Nurse Specialists on site 
  - Yes = 83% (20)
- Sites with at least 0.5 WTE Paediatric Dieticians allocated to gastroenterology 
  - Yes = 96% (23/24)

**Standard A3.1 – Multidisciplinary Working**

- Do you have regular timetabled meetings to discuss paediatric IBD patients? 
  - Yes = 83% (20)

**Standard A3.2 – Medical/Surgical Interaction**

- Sites that hold joint or parallel gastroenterology/colorectal surgery clinics (where IBD patients are seen) 
  - Yes = 63% (15/24)

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

- Sites with a hospital multidisciplinary nutrition team 
  - Yes = 79% (19)

**Standard A8 – Inpatient Facilities**

- 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)

**Standard A10 – Inpatient Care**

- Sites with guidelines for the management of Acute Severe Colitis 
  - Yes = 63% (15)

**Standard B1 – Arrangements for shared care**

- Is there a defined protocol in place between the IBD Service and GPs for shared outpatient management? 
  - Yes = 26% (6)

**Standard C2 – Rapid access to specialist advice**

- 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)

**Standard D1 – Provision of Information**

- Do you provide patients with a written care plan? 
  - Yes = 43% (10)

Key findings and recommendations from the full national report, based upon the results from data entered by 24 paediatric IBD Services across the UK, are shown below.
Key Findings and Recommendations for action from the National Results

The Key Findings and Recommendations for the 3rd round 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.

**General Hospital Demographics & 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, 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 half of them had to estimate when asked to identify how many IBD patients their paediatric IBD Service manages. 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

**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
**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. 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.

- 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).

- 39% (78/202) of adult sites indicated that they look after IBD patients aged 16 and under. 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. 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.

- 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.

- The median waiting time for an urgent clinic appointment for suspected IBD patients is 7 days.

- 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.

- 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.

- 71% (17/24) of sites do not have formal arrangements for annual outpatient review.

**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

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 and 91% (21/24) provide written information to the patient about whom to contact in the event of a relapse
- All sites have arrangements to expedite specialist review of relapsed patients. Relapsing patients can expect to be seen for specialist review within 7 days at 91% (21/24) of sites and within 5 days at 65% (15/23)
- All sites provide telephone access to contact an IBD specialist with 92% (22/23) generally responding within 48 hours
- Only 26% (2/23) offer patients a choice about different ways for follow up beyond the traditional method of review in an outpatient clinic
- 61% (14/23) of sites do not offer open forums or meetings for patients with IBD and their carers\(^1\) 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

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

**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. 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
- 57% (13/23) of sites capture clinical data about their patients but only 4 of these 13 sites use this system in real time to support the management of patients

**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
- Less than a quarter of sites (5/23) enter patients into MCRN supported trials
- 22% (5/23) hold annual review days of their service

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