



UK Inflammatory Bowel Disease Audit 3rd Round

Executive summary report of the results for the national organisational audit of adult inflammatory bowel disease services in the UK

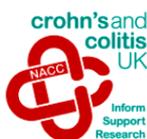
Prepared by the
The UK IBD Audit Steering Group
on behalf of

- 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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HQIP
Healthcare Quality
Improvement Partnership



BSPGHAN
working for children with
digestive and liver disorders
British Society of Paediatric Gastroenterology Hepatology and Nutrition



**Healthcare
Improvement
Scotland**

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REPORT INFORMATION

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Target audience	Executives of NHS trusts, commissioners, medical directors, clinicians, managers
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Description	<p>This report has been compiled for executives, managers, commissioners and clinicians involved in IBD services and should be read in conjunction with the full site report also issued in May 2011. This document summarises the full report of the National Results for the Organisation of Adult Inflammatory Bowel Disease Services in the UK based on how sites measured against the National IBD Service Standards (www.ibdstandards.org.uk) at the 1st September 2010. It shows your own site performance compared to national figures from 202 adult IBD services across the UK that participated in this round. This should provide a guide to where local remediation may be required.</p>
Related publications	<p>Individual full site report of the Organisation of Adult Inflammatory Bowel Disease Services available from your local registered site lead.</p> <p>Individual full site report of the Process of care for Adult patients admitted to hospital with Inflammatory Bowel Disease that will be available from your local registered site lead in Spring 2012.</p> <p>National Service Standards for the healthcare of people who have Inflammatory Bowel Disease (IBD) (www.ibdstandards.org.uk)</p>
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UK IBD Audit 3rd Round (2010) – National results for the Organisation & Structure of Adult IBD Services

Background

The Inflammatory Bowel Diseases, Ulcerative Colitis (UC) and Crohn's Disease (CD), are common causes of gastrointestinal morbidity affecting up to 0.5% of western populations. There are an estimated 240,000 people in the UK with IBD. The total cost of IBD to the NHS now probably exceeds £1 billion based on an average cost of £3,000 per patient per year¹ and may be considerably more as recent cost estimates have not accounted for the rapid expansion in the use of biological drugs.

National Service Standards for the healthcare of people who have Inflammatory Bowel Disease were published in February 2009 by a collaboration of professional and patient organisations. (<http://www.ibdstandards.org.uk>) The 3rd round Organisational Audit has a dataset directly aligned against the National Service Standards and therefore the data collected differs in a number of respects from that of the first and second rounds.

It was recommended that IBD Services should meet the standards by September 2010 and participating sites were asked to complete the dataset for their IBD Service "as at" that date. Some of the agreed standards that should be in place for staffing and facilities are population dependent, based on the need for cross-cover and the IBD Standards based these on a defined population of 250,000.

The reports for rounds 1 and 2 assessed the Organisation & Structure of IBD Services as well as the Processes of Clinical Care for up to 40 patients per site who were admitted to hospital for reasons primarily related to IBD. These 2 elements have been split for the 3rd round and this report addresses only the Organisation & Structure of Adult IBD Services across the UK. The report on the Processes of Clinical Care will be launched in spring 2012.

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 Audit data is also approved by the Department of Health for inclusion in Trust Quality Accounts.

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

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.

Summary of National Results

Organisation and structural data from the 3rd round UK IBD audit has shown sustained improvement in many aspects of patient care providing clear evidence of the commitment of many clinicians to quality improvement in IBD. Over 90% of acute Trusts and Health Boards in the UK participated in this round.

Clinical activity has remained stable but there has been a significant drop in the number of operations performed over the 3 rounds of audit, raising interesting questions about changing management of IBD.

There has been sustained improvement in the number of sites which have at least some provision of IBD nurses (although most of these sites still have less than the minimum level of this specialist nursing support recommended in the IBD Standards). There has been a rapid expansion in the provision of dedicated gastrointestinal wards, now seen in 90% of sites. Multidisciplinary working is widespread with three quarters of sites having IBD Multidisciplinary Team meetings.

One area of particular improvement is access to specialist advice with over 90% of sites reporting that they see relapsing patients within 7 days, 90% having a telephone helpline and 80% providing written information on who to contact in the event of a relapse. 99% of sites state that they provide written information on IBD to patients.

There has also been improvement in the provision of joint or parallel clinics, availability of laparoscopic surgery, guidelines for the management of acute severe ulcerative colitis, patient involvement in service development and use of IBD databases although some of these remain at relatively low levels.

The access to dietetic services appears to be very good but clinical data from the previous rounds of audit showed that relatively few IBD patients actually saw a dietician during an admission. Clinical audit data, available in 2012, will demonstrate if this continues to be the case. There may be a need to ensure that the services that are available do actually reach patients.

There has been a very small improvement in the number of beds per toilet but this remains below acceptable levels and 24% of toilets are mixed sex. The provision of psychological support or counselling remains at very low levels and business cases to enhance the IBD team are seldom successful.

Relatively few patients aged 16 or below are cared for in adult hospitals but it is clear that services for these individuals are suboptimal. This possibility should be examined by each site as a matter of urgency.

There should be a continued focus on multidisciplinary working to ensure that this vital aspect of IBD care is not eroded by other increasing pressures. Other areas for improvement include improving links with primary care and improving education and training opportunities for IBD nurses which appear to be at pitiful levels.

These data have demonstrated continuing sustained quality improvement in IBD care with the National IBD Service Standards clearly impacting on this process. It is important that this continues and 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 in order that quality improvement in IBD care continues to be monitored and sustained.
- All NHS Trusts/Health Boards should review their local audit results in relation to the new IBD National Service Standards and take any necessary action to improve their IBD Services.
- Professional organisations should support and direct change, at a national level, for the issues identified in this report as requiring improvement

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 Section 6 of 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 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 202 sites participating in 2010.

Table 1

		UK 2010 (as at 1 st Sept 2010)	Your Site (as at 1 st Sept 2010)
Inpatient Activity			
How many patients does your adult IBD Service Manage?	Median (IQR)	788 (500, 1497)	
This figure is an estimate		Yes = 85% (171)	
This figure is from a database		Yes = 15% (31)	
Standard A1 – The IBD Team			
Does the IBD Service have a named clinical lead?		Yes = 76% (154/202)	
Sites with <u>at least</u> 1.5 WTE IBD Nurse Specialists on site		Yes = 21% (43/202)	
Sites with <u>at least</u> 0.5 WTE Dieticians allocated to gastroenterology		Yes = 60% (122/202)	
Standard A3.1 – Multidisciplinary Working			
Do you have regular timetabled IBD Team meetings to discuss IBD patients?		Yes = 75% (152/202)	
Standard A3.2 – Medical/Surgical Interaction			
Sites that hold joint or parallel gastroenterology/colorectal surgery clinics (where IBD patients are seen)		Yes = 56% (114/202)	
Standard A5 – Access to nutritional support and therapy			
Sites with a hospital multidisciplinary nutrition team		Yes = 72% (146/202)	
Standard A8 – Inpatient Facilities			
Sites with a designated Gastroenterology ward on site		Yes = 89% (180/202)	
If yes, Beds per lavatory on the ward:	Median (IQR)	4 (3,6)	
Standard A10 – Inpatient Care			
Sites with guidelines for the management of Acute Severe Colitis		Yes = 79% (159/202)	
Standard A12 – Arrangements for the Care of Children and Young People who have IBD			
Does your unit have a specific paediatric to adult transition policy?		Yes = 36% (73/202)	
Standard B1 – Arrangements for the shared care			
Is there a defined protocol in place between the IBD Service and GPs for shared outpatient management?		Yes = 34% (68/201)	
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 = 79% (159)	
Sites where relapsing IBD patients can expect to be seen for specialist review within 7 days		Yes = 88% (176/201)	
Standard D1 – Provision of information			
Do you provide patients with a written care plan?		Yes = 33% (67/201)	

Key findings and recommendations from the full national report, based upon the results from data entered by 202 adult 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.



IBD Standards



Standard A. High quality clinical care

Standard B. Local delivery of care

Standard C. Maintaining a patient-centred service

Standard D. Patient education and support

Standard E. Information technology and audit

Standard F. Evidence-based practice and research

General Hospital Demographics & Inpatient Activity

Key findings:

- The number of admissions for both ulcerative colitis and Crohn's disease has remained stable
- The median number of operations performed per site for both ulcerative colitis and Crohn's disease has significantly reduced over 3 rounds of audit (for ulcerative colitis a median of 11 in 2006, 10 in 2008 and 8 in 2010 and for Crohn's disease a median of 17 in 2006, 13 in 2008 and 12 in 2010)
- Patients aged 16 and under are admitted to adult services widely but in small numbers. Age specific services for these patients are substandard
- Although the use of IT has widely increased many sites do not know how many patients they treat, with 85% of sites indicating that they had to estimate this figure

Key recommendations:

- All adult sites that admit patients aged 16 and under should review their service and ensure that age appropriate services are available for these patients as a matter of urgency
- The appropriate level of service provision depends on the number of patients being seen with accurate data being key to any application for increased resources. An IBD database should include a list of all individuals being treated by the service

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 steady improvement in the provision of IBD nurses but most sites remain below levels set out in the national standards of 1.5 WTE IBD nurses per 250 000 population
- Three quarters of services have a named clinical lead with relatively good support from services such as radiology and pathology
- A named pharmacist with an interest in IBD is a part of the IBD team in less than 50% of sites with only 9% of IBD meetings having regular pharmacy input
- Defined access to psychologists and counsellors with an interest in IBD is only available in 24% and 9% of sites respectively
- Multidisciplinary team meeting take place in three quarters of sites
- Access to dietetic services as reported by sites appears very good in contrast to the clinical audit data from round 2 which showed that few inpatients received any dietetic input
- Pouch surgery continues to be performed in 80% of sites with a median number of only 3 per year
- There has been a notable increase in dedicated GI wards, now present in 90% of sites
- On average there are 4 beds per toilet with 24% being mixed sex. This is below the minimum standard of 1 toilet per 3 beds
- A high level of service is provided for diagnostic services
- 80% of sites have facilities for an annual patient review with most sites using traditional clinic based models of care

Key recommendations:

- Sites should work to establish an identifiable IBD team with a named clinical lead
- Clinical pharmacy support for the IBD team should be strengthened given the high cost and complexity of the drug regimes that are often used
- Colorectal surgeons should be encouraged to enter the data on pouch operations onto the ACPGBI Ileal Pouch Registry: <http://www.acpgbi.org.uk/research/ileal>
- Sites should work to engage psychology and counselling services.
- IBD Team meetings and multidisciplinary working should remain a focus of the IBD team in the face of opposing pressures
- Any opportunity to improve the bed to toilet ratio should be grasped and IBD teams should seek to create solutions within a defined timescale.

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 one third of sites have a protocol in place with GPs for the shared outpatient management of IBD patients and where they do it is only shared with the patient in 66% of these sites, most often verbally

Key recommendations:

- Recent changes within the NHS will mean more frequent movement of patients between primary and secondary care. It therefore becomes vital that protocols are in place to ensure that the necessary access to secondary care is available in a timely manner, that the appropriate follow up is undertaken and that patients should receive a written statement of their management plan
- Agreed protocols between primary and secondary care will facilitate this and sites should work to establish these

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:

- Rapid access to specialist services is good with 94% of sites offering expedited review and 92% reporting that they see patients within 7 days of referral. A range of contact options are available in many sites
- Written information about IBD is available in 99% of sites, most commonly produced by Crohn's and Colitis UK
- A choice of follow up options is available in only 51% of sites
- Patient involvement in service improvement is at relatively low levels but is improving with a number of alternative methods being used

Key recommendations:

- Significant improvement has been made in this area and sites should be encouraged to offer a range of follow up options and to involve their patients in service development

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:

- Translation services are widely available but written information is available in languages other than English in only 35% of sites
- A written care plan for patients is only available in 33% of sites
- Formal educational opportunities for patients are available in 57% of sites
- There is very wide spread contact with patient organisations with 99% of sites giving contact information, most commonly for Crohn's and Colitis UK

Key recommendations:

- Sites should work to develop written care plans for patients if these do not exist with priority given to newly diagnosed patients and those receiving immunomodulators and biological therapies

Standard E – Information technology and audit

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

Key findings:

- A register of IBD patients is kept in 55% of sites. Some include all IBD patients, but the majority include specific treatment groups
- A real time data collection system to support the management of patients is used in 19% of sites
- Only 10% of sites submit data to other national or international audits about IBD

Key recommendations:

- Sites should ensure robust mechanisms are in place to capture at least basic data on all IBD patients

Standard F – Evidence-based practice and research

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

Key findings:

- IBD nurse education is poor with a median of only 2 days per year
- 35% of sites are participating in UKCRN portfolio IBD studies
- An annual review of the IBD Service is held in only 22% of sites

Key recommendations:

- Sites need to ensure that IBD nurses have access to sufficient educational opportunities to maintain their specialist knowledge and skills
- All sites should be encouraged to participate in clinical research
- All IBD Teams should hold an annual review of their service