

## RESEARCH

# Inflammatory bowel disease in the UK: is quality of care improving?

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## ABSTRACT

**Objective** A national audit conducted in 2005/6 showed unacceptable quality of care for inpatients with inflammatory bowel disease (IBD) in the UK. This was re-audited in 2007/8 and 2010/11. The aim of this study is to examine the quality of care provided for inpatients with IBD in the UK.

**Design** A programme of engagement and re-audit in 128 hospitals in the UK providing care for adult patients with IBD admitted to hospital between 1 June 2005 and 31 May 2006, 1 September 2007 and 31 August 2008 and 1 September 2010 and 31 August 2011.

**Interventions** Wide dissemination of the results, selected site visits, development of national service standards, and the development of an online document repository.

**Main outcome measures** Mortality, medical and surgical treatment, specialist nursing and dietetic care were audited.

**Results** Data from 1953, 2016 and 1948 patients with ulcerative colitis (UC) and 2074, 2109 and 1900 patients with Crohn's disease (CD) were audited in 2005/6, 2007/8 and 2010/11, respectively. The mortality rate fell from 1.7% to 0.8% ( $p=0.034$ ) in UC and from 1.3% to 0.8% ( $p=0.226$ ) in CD. The proportion of inpatients reviewed by an IBD specialist nurse has risen from 23.7% to 44.9% in UC and from 18.1% to 39.9% ( $p<0.001$ ) in CD. Anti-tumour necrosis factor therapy has increased in UC and CD ( $p<0.001$ ) while ciclosporin prescription has slightly fallen in UC. Laparoscopic surgeries have significantly increased in UC and CD ( $p<0.001$ ).

**Conclusions** The results show clear evidence of improvement in most aspects of the quality of care for IBD inpatients.

## INTRODUCTION

This report addresses the treatment and care of patients with inflammatory bowel disease (IBD) requiring admission to hospital in the UK. IBD, ulcerative colitis

(UC) and Crohn's disease (CD), affect about one person in every 250 in the UK population.<sup>1 2</sup> The total annual cost of IBD to the NHS now probably exceeds £1 billion based on an average cost of £3 000 per patient per year,<sup>3</sup> and may be considerably more as recent cost estimates have not accounted for the rapid expansion in the use of biological drugs. Patients are looked after by specialist gastroenterology services across the UK.

## PROBLEM

In 2005/6 a national audit against guidelines published by the British Society of Gastroenterology (BSG) in 2004<sup>4</sup> demonstrated unacceptable variation and deficiencies in care across the country. Inpatient mortality was 1.5%, specialist nursing care was lacking, essential tests were not being performed and prophylaxis against thromboembolism and osteoporosis was haphazard.

## KEY MEASURES FOR IMPROVEMENT

Quality of care was audited twice (in 2005/6 and 2008/9) against the guidelines published by the BSG in 2004.<sup>4</sup> The third audit round was conducted in 2010/11, following the publication in 2009, and wide dissemination, of national standards,<sup>5</sup> developed by a multidisciplinary working group involving patient groups and professional societies (Association of Coloproctology of Great Britain and Ireland, British Dietetic Association (gastroenterology specialist group), BSG, British Society of Paediatric Gastroenterology, Hepatology and Nutrition, National Association for Colitis and Crohn's Disease (now known as Crohn's and Colitis UK), Primary Care Society for Gastroenterology and Royal College of Nursing (Crohn's and colitis

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special interest group)). Key measures assessed in all three audits were inpatient mortality, hospital admission rates, review by IBD specialist nurses, review by dietitians, sending of stool samples for standard stool culture (SSC) and *Clostridium difficile* toxin (CDT), prescription of prophylactic heparin and bone protection agents, the rate of surgical intervention and prescription of biological therapy or ciclosporin in steroid-resistant cases.

### PROCESS OF GATHERING INFORMATION

The three national audits were conducted in 2005/6, 2008/9 and 2010/11. The process was similar for each of the three rounds. Hospitals in England, Scotland, Wales, Northern Ireland and the Channel Islands, which provide a service for patients with IBD and routinely admit acutely ill patients, were invited to participate. Some participating sites provided a service that encompassed multiple hospitals, while in others the service was specific to an individual hospital. Each site identified an overall clinical lead who was responsible for data submission. Data were collected on patients with IBD admitted to hospital between 1 June 2005 and 31 May 2006<sup>6</sup> for the first round, 1 September 2007 and 31 August 2008<sup>7</sup> for the second round and 1 September 2010 and 31 August 2011<sup>8</sup> for the third round. To reduce potential bias in case selection, sites were asked to choose sequential cases rather than selecting individual cases. These three audits were all rigorously conducted by the Clinical Effectiveness and Evaluation Unit at the Royal College of Physicians (RCP) and assessed similar measures of quality.

Data were extracted from inpatient records if the primary reason for admission was IBD. Patients were excluded if IBD was not indicated as the main reason, for example, a person with known IBD admitted because of a myocardial infarction. Day cases admitted for endoscopy, drug infusions, or other reasons were excluded. Patients with a diagnosis of indeterminate colitis, and those aged 16 years and under on the date of admission were also excluded.

The audits were led by a collaborative partnership between gastroenterologists (represented by the BSG), colorectal surgeons (Association of Coloproctology of Great Britain and Ireland), patients (National Association for Colitis and Crohn's Disease) and physicians (RCP). The audits were funded by the Health Foundation and the Health Quality Improvement Partnership, with additional funding from Health Improvement Scotland. They were coordinated by the Clinical Effectiveness and Evaluation Unit, RCP, and guided by a multidisciplinary IBD Audit Steering Group that oversaw the preparation, conduct, analysis and reporting of the audit.

### DATA ANALYSIS

Data were exported electronically from the data collection website into STATA V.12.1 software for

analysis. Only those sites that took part in all three rounds and were configured in the same manner in each round were compared. Patient data are presented as percentages with numerator/denominator. Comparisons across the three rounds of audit were made using a  $\chi^2$  test, with a p value of less than 0.05 taken to be statistically significant.

### ANALYSIS AND INTERPRETATION

The first IBD audit in 2005/6 was the first UK-wide audit performed within gastroenterology. It demonstrated a noticeable variation in the resources and quality of care for IBD patients across the UK.<sup>6</sup> The second round in 2007/8 identified that many services for patients with IBD had improved, but noted that there was still a wide variation in the provision of care and many services had not improved at all.<sup>7</sup>

### STRATEGY FOR CHANGE

Following the first audit, the UK IBD Audit Steering Group developed intervention strategies to ensure improvement, which were enhanced following the publication of national standards after the second audit. These strategies included the widespread dissemination of results to site clinical leads and hospital management.<sup>7 8</sup> This enabled each participating site to compare or benchmark their performance against national statistics. The results of the audits were made publicly available via the UK IBD audit section of the RCP website. Regional meetings were held throughout the UK to discuss the audit results following both rounds of the audit. Data from all three audit rounds were also presented at key professional and patient meetings. Sites were encouraged to identify three actions to improve their service.<sup>7 8</sup>

A number of participating sites collaborated with members of the UK IBD Audit Steering Group to develop a model 'action plan' for IBD services that addressed the key messages from the first round report.<sup>7</sup> The model action plan was accessible via the internet and contained freely adaptable reference documents such as care pathways, model business cases for IBD clinical nurse specialist posts and patient information leaflets that could be downloaded and edited to meet local requirements. Visits to selected hospitals were carried out following the first audit round, during which a clinical member of the IBD Audit Steering Group worked alongside the health professional team responsible for IBD care to develop an action plan for their IBD service that would address areas for improvement identified in their site-specific report. Data from the audit was made available to the Healthcare Commission to assist in their screening process to determine which hospitals would receive an inspection as part of the annual health check in 2008/9.<sup>9</sup> Audit reports were available in the public domain. Although these reports did not identify individual hospital results, they allowed patients

(eg, through Crohn’s and Colitis UK) to lobby for improvement across IBD services. Particular hospitals did share their individual results with patients at open forums or patient panel meetings, enabling those patients to support proposals for improvement.

The first audit was conducted against guidelines for the management of IBD published by the BSG in 2004.<sup>4</sup> National service standards for the services, treatment and care of people who have IBD were published by a multidisciplinary working party in 2009.<sup>5</sup> The standards cover the structures, processes and outcomes expected of a high quality service, and the aim was to ensure that ‘IBD patients receive consistent, high-quality care and that IBD services throughout the UK are knowledge-based, engaged in local and national networking, based on modern IT, and meet specific minimum standards’.<sup>5</sup> It was recommended that IBD services should meet the required standards by September 2010.

**EFFECTS OF CHANGE**

Seventy-five per cent of trusts and health boards that admitted IBD patients participated in the first round UK IBD audit.<sup>6</sup> Participation has increased to 93% and 90%, respectively, in rounds 2 and 3 (table 1).<sup>7 8</sup>

In each audit round we reviewed the quality of care of approximately 4000 patients admitted to 128 comparable hospitals that contributed data to all three audits over 12 months in each round. This comparison is thus confined to just over 50% of UK hospitals that took part in all three audits, but represents a spectrum of hospitals from across the UK. Roberts *et al*<sup>10</sup> reported 17 547 admissions with similar criteria identified in hospital episode statistics for the whole of England over 24 months from 1998 to 2000, which suggests that case ascertainment of 16 cases per month per hospital in these UK-wide audits was very good.

**COMPARISON OF THE THREE UK IBD AUDIT ROUNDS**

We compared the data from the 128 sites that took part in all three rounds (with the same site composition in each round) (tables 2 and 3). Although we

cannot be certain that case ascertainment and review was rigorously undertaken in each site, there were 1952, 2016 and 1948 comparable cases of UC (table 2) and 2074, 2109 and 1900 comparable cases with CD in the 2006, 2008 and 2010 audit rounds, respectively (table 3).

For UC, the inpatient mortality rate fell from 1.7% (34/1953) in the first round, 1.5% (31/2016) in the second round, to 0.8% (16/1948) in the third round (p=0.034). For CD, the inpatient mortality rate dropped from 1.3% (27/2074) in 2006, 1.1% (23/2109) in 2008, to 0.8% (15/1900) in 2010 (p=0.226). There was no difference in the comorbidity of inpatients between the three audit rounds, which might contribute to this change in mortality rate.

The number of admissions for both UC and CD remained almost the same, but we observed a reduction in the re-admission rate in the 2 years before the audited admission, especially for patients with UC (p<0.001). This drop in the re-admission rates may be due to more responsive outpatient services. By the third audit 94% of sites offered expedited review, 92% reporting that they see patients within 7 days of referral, supported a telephone helpline (95%), and provided written information on who to contact in the event of a relapse (80%).<sup>11</sup>

The collection of stool samples after admission from patients with diarrhoea due to UC has increased significantly between 2006 and 2010, including SSC (SSC increased from 65.9% to 80.8%) and CDT (CDT increased from 53.9% to 75.2%); (p<0.001). There was a significant reduction in the number of stool samples positive for CDT from the second to the third rounds of the audit (4.2% to 1.6%). This suggests that *C difficile* is decreasing in the population,<sup>12 13</sup> but also may reflect the work of health-associated infection control teams in all trusts. Interestingly, the third audit round showed a slight drop in the collection of stool samples for SSC (p=0.003) and CDT testing (p<0.001) from CD patients with diarrhoea compared with 2008. The reason for this drop is not clear.

The prescription of prophylactic heparin increased significantly for both UC (from 54.3% in the first

**Table 1** Summary of the number of sites and patients for the three rounds

Year	Number and percentage of NHS sites submitting data	Patients with UC	Patients with CD
2005/6	200 sites (75%)	Total 2767 Elective 397 Non-elective 2370	Total 2914 Elective 556 Non-elective 2358
2007/8	209 sites (93%)	Total 2981 Elective 537 Non-elective 2444	Total 3154 Elective 698 Non-elective 2456
2010/11	198 sites (90%)	Total 3049 Elective 595 Non-elective 2554	Total 3122 Elective 551 Non-elective 2571

CD, Crohn’s disease; UC, ulcerative colitis.

**Table 2** The results for adult IBD care—UC across the 2006, 2008 and 2010 rounds of the UK IBD audit, whenever directly comparable

	2006 (1953 comparable cases of which 1668 non-elective)	2008 (2016 comparable cases of which 1655 non-elective)	2010 (1948 comparable cases of which 1614 non-elective)
Mortality during the admission	34/1953 (1.7%)	31/2016 (1.5%)	16/1948 (0.8%)*
Previous UC related admission in the 2 years before the audit	829/1621 (51.1%)	750/1655 (45.3%)	421/1255 (33.6%)*
Inpatients' review by an IBD nurse during their admission	395/1667 (23.7%)	496/1653 (30.0%)	725/1614 (44.9%)*
Sending stool sample for SSC and CDT in non-elective patients with diarrhoea (recorded in the first full day following admission)	SSC	SSC	SSC
	738/1120 (65.9%)	857/1160 (73.9%)	961/1189 (80.8%)*
	CDT	CDT	CDT
	604/1120 (53.9%)	770/1160 (66.4%)	882/1173 (75.2%)*
Were the stool samples positive?	Not asked	SSC	SSC
		17/857 (2.0%)	24/961 (2.5%)
		CDT	CDT
		32/770 (4.2%)	14/882 (1.6%)*
Prophylactic heparin prescription for non-elective admissions	905/1668 (54.3%)	1220/1649 (74%)	1406/1614 (87.1%)*
Non-elective patients prescribed, but not responding to, corticosteroids during the admission who received either Ciclosporin or anti-TNF therapy	Ciclosporin	Ciclosporin	Ciclosporin
	108/412 (26.2%)	117/433 (27.0%)	152/655 (23.2%)
	Anti-TNF	Anti-TNF	Anti-TNF
	20/412 (4.9%)	52/433 (12.0%)	110/655 (16.8%)*
Laparoscopic or laproscopically assisted surgery for non-responding elective patients	28/274 (10.2%)	58/362 (16.0%)	145/332 (43.7%)*
Laparoscopic or laproscopically assisted surgery for non-responding non-elective patients	11/213 (5.2%)	27/207 (13.0%)	66/195 (33.9%)*
Bone protection agents prescription for UC patients on steroids	534/1300 (41.1%)	749/1347 (55.6%)	971/1396 (69.6%)*

Any statistically significant change is represented by an asterisk to the right of the 2010 data column.

CDT, *C difficile* toxin; IBD, inflammatory bowel disease; SSC, standard stool culture; TNF, tumour necrosis factor; UC, ulcerative colitis.

**Table 3** The results for adult IBD care—CD across the 2006, 2008 and 2010 rounds of the UK IBD audit, whenever directly comparable

	2006 (2074 comparable cases of which 1669 non-elective)	2008 (2109 comparable cases of which 1638 non-elective)	2010 (1900 comparable cases of which 1626 non-elective)
Mortality during the admission	27/2074 (1.3%)	23/2109 (1.1%)	15/1990 (0.8%)
Inpatients' review by an IBD nurse during their admission	302/1666 (18.1%)	394/1638 (24.1%)	650/1626 (39.9%)*
Anti-TNF therapy prescription during the admission? (only non-elective patients who are not already receiving anti-TNF therapy on admission)	58/1485 (3.9%)	77/1571 (4.9%)	118/1468 (8%)*
Prophylactic heparin prescription for non-elective admissions	933/1669 (55.9%)	1194/1633 (73.1%)	1400/1626 (86%)*
Sending stool sample for SSC and CDT in non-elective patients with diarrhoea (recorded in the first full day following admission)	SSC	SSC	SSC
	290/523 (55.5%)	340/516 (65.9%)	470/774 (60.7%)*
	CDT	CDT	CDT
	224/523 (42.8%)	307/516 (59.5%)	426/767 (55.5%)*
Dietician review of non-elective patients during the admission	465/1669 (27.9%)	461/1638 (28.1%)	583/1626 (35.9%)*
Laparoscopic or laproscopically assisted surgery for non-responding elective patients	47/374 (12.6%)	122/460 (26.5%)	147/361 (40.7%)*
Laparoscopic or laproscopically assisted surgery for non-responding non-elective patients	32/364 (8.8%)	48/320 (15%)	61/298 (20.5%)*

Any statistically significant change is represented by an asterisk to the right of the 2010 data column.

CD, Crohn's disease; CDT, *C difficile* toxin; IBD, inflammatory bowel disease; SSC, standard stool culture; TNF, tumour necrosis factor.



round to 87.1% in the third round) and CD (55.9% in the first round to 86% in the third round) ( $p < 0.001$ ). One patient died from a thromboembolic event in the first round,<sup>6</sup> but no patient died from thromboembolism in the second and third rounds,<sup>7, 8</sup> suggesting anecdotally that practice improved, even before guidelines to prevent thromboembolism in hospitalised patients were published.<sup>14</sup>

The prescription of bone protection agents increased from 41% in the first round to 70% in the third round ( $p < 0.001$ ) as recommended in the BSG guidelines for the management of IBD in adults.<sup>15</sup>

According to National Institute for Health and Clinical Excellence guidelines, anti tumour necrosis factor (TNF) agents (infliximab and adalimumab) are recommended as treatment options for adults with severe active CD when there is non-response, intolerance or contraindication to conventional therapy.<sup>16</sup> Infliximab is recommended as an option for the treatment of acute exacerbations of severely active UC only in patients in whom ciclosporin is contraindicated or clinically inappropriate, or as part of a clinical trial.<sup>17</sup> The audit results showed that the use of anti-TNF therapy as a rescue therapy has increased significantly for both UC and CD ( $p < 0.001$ ). On the other hand, the use of ciclosporin in UC has dropped slightly (26% to 23%) across the three audits. This suggests a change in the choices made by clinicians when considering rescue therapy, especially with the good response rate seen with anti-TNF therapy for both CD and UC. There is no difference in efficacy of these two drugs at 3 months,<sup>18</sup> and the results of the CONSTRUCT trial comparing the clinical and cost effectiveness of the two drugs at 2 years will provide data to inform clinicians whether this change in practice is appropriate.<sup>19</sup>

The median numbers of operations performed for UC and CD significantly reduced over the three rounds of audit.<sup>11</sup> The median numbers of operations performed per site was 11 in 2006, 10 in 2008 and eight in 2010 ( $p = 0.007$ ) for UC and 17 in 2006, 13 in 2008 and 12 in 2010 ( $p = 0.015$ ) for CD.<sup>11</sup>

While the median number of operations performed for UC and CD dropped significantly, there was a significant increase in the percentage of operations performed laproscopically for both UC and CD ( $p < 0.001$ ), and on both elective and non-elective inpatients. This reflects the accumulating evidence of improved outcomes following laparoscopic colorectal surgery compared with laparotomy for IBD.<sup>20, 21</sup>

Until recently, the role of IBD nurses has been largely limited to outpatient settings. The Royal College of Nursing encourages more interaction by specialist nurses with IBD inpatients.<sup>22, 23</sup> The third audit showed a significant increase in the percentage of inpatients reviewed by an IBD specialist nurse during their admission compared to the first two audit rounds ( $p < 0.001$ ). However, most sites remain

below the establishment levels set out in the IBD standards (1.5 whole time equivalent IBD nurses per 250 000 populations).<sup>11</sup>

The national IBD standards<sup>5</sup> state that access to a dietitian should be available to all IBD patients. The availability of hospital nutrition teams rose from 62% (112/181 sites) in 2006<sup>6</sup> to 71% (146/206 sites) and 72% (146/202 sites) in 2008 and 2010, respectively ( $p = 0.003$ ) (7,8, and 11). Almost all sites reported that IBD patients have access to nutritional support or general dietary advice in the third round.<sup>8</sup> However, 60% of inpatients with CD are still not seen by a dietitian during their admission.

## NEXT STEPS

The UK IBD audits have, together with other trends in inpatient care such as the wide dissemination of national standards for the care of patients with IBD,<sup>5</sup> and a concerted engagement programme, contributed to a demonstrable quality improvement in IBD care over a relatively short period of time. A fourth audit has now started.

In conclusion, it is clear that the care of patients in the UK with IBD severe enough to warrant admission is improving, and regular audit against national standards, supported by an engagement strategy, are effective catalysts for change.

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