



# National report of the results of the UK IBD audit 3rd round inpatient experience questionnaire responses

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



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## Executive summary

### Background

The inflammatory bowel diseases (IBD), 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 attributed to relapsing patients<sup>1</sup>. Up to 25% of cases will present in childhood years with a marked rise in the incidence of paediatric IBD noted in the UK over the past few decades.

The UK IBD audit 1st round was the first UK-wide audit performed within gastroenterology care for adults. It demonstrated wide variation in the resources and quality of care for adult IBD patients across the UK with particular deficits in some fundamental aspects of IBD care. Following the first round members of the UK IBD audit steering group met with representatives of the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and agreed to include paediatric gastroenterology in the 2nd audit round so the UK IBD audit could become a truly comprehensive audit encompassing IBD patients of all ages. During this 3rd round of audit, the inclusion of inpatient experience and primary care questionnaires provided the opportunity to give an even fuller picture of the provision of IBD care throughout the UK.

### Overall summary

Inpatient questionnaires were received from one third of adults and children. The full results are presented for the UK overall and divided into adults and children where possible. Most IBD patients reported positive experiences of hospital care with 40% rating their overall care as excellent. One in ten (9.9%) of adult patients expressed dissatisfaction by rating their overall care as only fair (7%) or poor (2.9%). No paediatric patients rated their care as poor, 6.7% rated it as only fair. All stakeholders are encouraged to familiarise themselves with the range of individual questions and the overall responses for the UK – there are many aspects of the patient experience that identify areas for potential improvement but also a great deal of positive information.

The single question that correlated most strongly with overall satisfaction was a patients rating of how well doctors and nurses worked together – confirming that good teamwork is the key to delivering a high quality experience. Selected questions produced composite scores for six core domains of acute care in adults (consistency & coordination of care; treatment with respect & dignity; involvement; doctors; nurses and cleanliness). All were strongly correlated with overall satisfaction. Scores for all domains of care were consistent across England, Scotland, Wales and Northern Ireland.

When compared with average trust scores for general inpatients (national inpatient survey), scores for adult IBD patients in two domains (consistency & coordination of care and nursing) were in the range of the poorest 20% of trusts. This suggests sub-optimal experiences for IBD patients in these areas. It is suggested that a key driver for improvement would be better provision of specialist IBD nurses with job plans that allow sufficient time to deliver ward based care and educational support for general nurses. Over one third of adults reported receiving no visit from a specialist nurse during their stay.

Several specific areas are highlighted. One fifth of adult IBD patients rated hospital food as poor, a quarter found the food unappetising and more than one in ten reported receiving too little food or that hospital food was not suitable for their dietary needs. Results were similar for paediatrics. Just over one third of adult IBD reported a visit from a dietician compared to nearly three quarters of children with IBD. Eighty five percent of adult IBD patients experienced pain during their stay in hospital of whom over half indicated that the pain was usually severe. Over a quarter stated that they were in pain all or most of the time and 16% complained of not enough pain medication. Results for children were similar but inadequate pain medication was reported in 12%. At least one in ten patients reported sub-optimal aspects of discharge information such as lack of information about drug side effects, the danger signs to

watch for or how to manage their condition after going home. These are aspects of care that all teams should review locally.

## Key findings

- One in ten (9.9%) adult respondents to the survey rated their overall inpatient care as only fair (7%) or poor (2.9%)
- No paediatric patients rated their care as poor, 6.7% rated it as only fair
- For both adults and children with IBD, overall care satisfaction correlated most strongly with their rating of how well doctors and nurses worked together. This confirms that good teamwork is fundamental to delivering a quality patient experience. As expected, patients place high importance on consistent, co-ordinated care from medical and nursing staff who have knowledge of their condition
- Composite scores across six domains of acute adult care were comparable across all the countries involved in the audit, suggesting no major national differences
- When compared with general inpatients (pooled scores for Trusts from the National Inpatient Survey, 2009), IBD patients appeared to give relatively poorer rating for consistency and coordination of care and nursing care
- Hospital food was rated as poor by one in five adults and one in ten children. At least one in ten of all IBD patients reported that the food provided was 'not enough'. Over half of adults and a quarter of children reported receiving no visit from a dietician.
- Eight out of every ten IBD patients experienced some pain during their inpatient stay. Around a quarter reported being in pain all or most of the time. Over one in ten IBD patients rated their analgesic medication as 'not enough'
- At least one in ten patients reported sub-optimal aspects of discharge information such as lack of information about drug side effects, the danger signs to watch for or how to manage their condition after going home

## Key recommendations

- All admitted IBD patients should receive input from specialist multidisciplinary teams with experience of managing these complex disorders
- Local IBD teams should consider whether the general nursing staff has sufficient awareness and knowledge of IBD and initiate appropriate educational interventions and care pathways to support high quality nursing. The routine involvement of a specialist IBD nurse in the day-to-day care of IBD patients at ward level is seen as a potential driver to improving the overall experience of nursing care
- All hospitalised patients with active IBD require routine documentation of nutritional intake, weight measurement and dietetic review. Nursing care plans should identify nutrition as a key element of day-to-day care
- Ward medical and nursing teams should review their local Trust policies and current practice with regard to the frequency and effectiveness of pain assessment and provision of analgesia
- Discharge policies for IBD patients require local review to ensure that patients receive good quality pre-discharge information regarding medication, self-care and follow-up plans

## Background information and introduction

### The burden of inflammatory bowel disease

Although ignored by the National Service Framework programme, UC and CD are common causes of 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 has been estimated that up to 0.5% of European and North American populations are affected. IBD commonly presents in the second and third decade but much of the recent increase has been observed in childhood, notably with CD in children increasing three fold in 30 years. IBD is not curable, UC and CD are lifelong conditions following an unpredictable relapsing and remitting course. 25% of UC patients 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 throughout the UK by auditing individual patient care and the provision and organisation of IBD service resources.

As with the 1st and 2nd rounds of the audit, the 3rd round reports of organisational audit data (published May 2011) and clinical audit data (published February 2012) have enabled participating sites to compare or benchmark their performance against national statistics. Following the data collection, analysis and reporting phases of all audit rounds, intervention strategies are used to improve the provision and quality of IBD care. Such strategies include the widespread dissemination of results, the availability of the national reports through the Royal College of Physicians website and the hosting of regional meetings to discuss findings and share learning.

Data from all rounds is presented at key professional and patient meetings, previously including those of the British Society of Gastroenterology (BSG), Association of Coloproctology of Great Britain and Ireland (ACPGBI), British Dietetic Association (BDA), Royal College of Nursing Crohn's and Colitis Specialist Interest Group and Crohn's and Colitis UK.

The specific aims of the UK IBD audit set out at the inception of the project were to:

1. Assess processes and outcomes of care delivery (inpatient and outpatient) in IBD
2. Enable Trusts to compare their performance against national standards
3. Identify resource and organisational factors that may account for observed variations in care
4. Facilitate, develop and institute an intervention strategy to improve quality of care.
5. Repeat the audit to prove that change has occurred
6. Establish measures for healthcare services to use to compare quality of IBD services
7. Develop a sustainability programme to maintain quality of care.

### Availability of the report in the public domain

Full and executive summary copies of this report 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) The national report will be made available to the Department of Health in England, Healthcare Improvement Scotland, NHS Wales and the Department of Health, Social Services and Public Safety in Northern Ireland.

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.

# Analysis of the results of IBD inpatient questionnaire responses

## Response rate and patient characteristics

The response rate for adult and paediatric patients was 33.7% and 32.2%, respectively. The characteristics of responders and non-responders are summarised in Table 1. Compared to adult non-responders, the adult responders to the survey tended to be older and more likely to be female. Those with ulcerative colitis were more likely to respond than those with Crohn's disease and there was also a higher response rate among adult elective surgical patients than emergency admissions. No significant differences for paediatric cases, albeit numbers are much smaller.

## Questionnaire responses

The responses to each experience question in the IBD questionnaire are presented in Appendix B. The pooled data are provided for all IBD patients across the UK as a whole and separately for adult and paediatric patients.

## Overall satisfaction with inpatient care

The questionnaire contained a satisfaction question (*'Overall, how would you rate the care you received?'*) which asked patients to give their overall subjective rating of inpatient care from 'poor' to 'excellent'. This question was positioned at the end of the questionnaire in order that patients' answers would be influenced by having first responded to multiple items asking about specific aspects of the inpatient experience.

Overall, one in ten respondents (9.9%) reported their care as having been either poor or only fair. This was taken as reflecting dissatisfaction with inpatient care. The characteristics of dissatisfied versus satisfied adult patients are compared in Table 2 by means of odds ratios (values less than one indicate sub-groups with lower rates of dissatisfaction compared to the reference). For adult IBD patients overall, dissatisfaction was less likely to be expressed by male patients or by older age-groups. Although there was a tendency for overall dissatisfaction to be reported less often in ulcerative colitis versus Crohn's disease, this was not statistically significant. No significant differences were observed when comparing surgical versus non-surgical cases or elective versus emergency admissions.

A basic correlation analysis was performed to determine which individual questionnaire items correlated most strongly with the 'overall satisfaction' question. The top twelve items, in order of strength of relationship are shown in Table 4, for both adult and paediatric IBD patients alongside the findings from a similar analysis of the 2009 National Inpatient Survey of general inpatients. In all cases, the same question about teamwork (*'How would you rate how well the doctors worked together?'*) was the strongest predictor of overall satisfaction rating. Although there are differences in the precise content of the top twelve for adults and paediatric patients, it is very clear that aspects of medical and nursing communication are key predictors of overall satisfaction.

## Patient experience across core domains of acute inpatient care

A number of core domains of acute care were identified previously by the Picker Institute from analysis of the National Inpatient Survey of general inpatients<sup>2</sup>. These domains (shown in Appendix A) comprise a selection of questions covering key aspects of the patient experience that have strong correlation with overall satisfaction rating among general inpatients. The IBD inpatient survey included most of the relevant questions for six of the core domains of acute care.

Responses to these items were analysed using the Picker Institute methodology. Scores can range between zero (worst possible score) and 100 (best possible score). The domain score is calculated by taking the mean score for each patient of the questions which comprised that domain. For domains which were comprised of multiple questions, a patient had to have answered at least half of those questions for their domain score to be calculated.

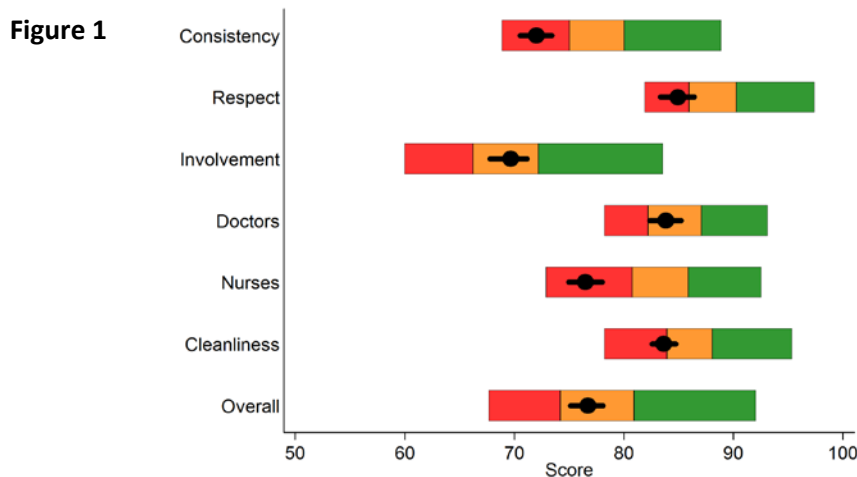
In general, the average ratings across the core domains of acute care suggest a good quality patient experience for adult patients (Table 3). Scores for consistency of care and involvement in care were lower than for other domains, suggesting potential areas for targeted improvement. The domain scores analysed by the Picker methodology revealed significantly lower scores across several domains in Crohn's disease compared to ulcerative colitis, albeit the magnitude of differences was small. This might reflect differences in the spectrum of clinical presentations and management of the two conditions.

The core domains identified previously as predictors of overall satisfaction for general hospital inpatients were confirmed to be important determinants of overall satisfaction for IBD patients. There were strong associations between overall satisfaction rating and each of the core sub-domain scores for IBD patients overall (Table 5). These findings were consistent across patient subgroups (UC and CD; emergencies and electives). This confirms the validity of the selected questions and domains as predictors of overall care satisfaction for IBD patients.

In all cases the analysis showed that for every increase in sub-domain scores of 1 unit (on the scale of 0-100), the likelihood of a poor or fair overall rating decreased. The exact magnitude of the decrease is given by the odds ratio (OR). For example, in all IBD patients, the OR for cleanliness is 0.95. This means that for every 1 unit that the cleanliness sub-domain score increased, the likelihood of patients reporting an overall rating of poor or fair fell by 5%. All analyses were adjusted for age and gender.

Data from the National Inpatient Survey is usually analysed at Trust level, with pooling of responses of samples of patients for each hospital to give average ratings at institutional-level. The sample size for the IBD inpatient survey does not allow for inter-hospital comparisons. However, it is possible to compare the overall experience of IBD patients (pooled data for all responders) with the distribution of Trust-level average values seen for general inpatients in the NIS. This analysis follows the same methodology used by Picker, and weights responses based on age, gender and type of admission (emergency or elective).

Figure 1 shows that overall scores across several domains for IBD patients fall within the lowest (poorest) 20% of Trust average scores seen for general inpatients. Interpretation of this data requires care but the results raise the possibility that several aspects of the inpatient experience of IBD patients are somewhat poorer than for the average person admitted to hospital, notably in consistency of care and nursing care domains. In Figure 1, the bars show the range of Trust-level scores for each sub-domain. The red region shows the scores of the lowest 20% of trusts, the orange region is for the middle 60% and the green region represents the top 20% of trusts. The mean score, and 95% confidence intervals, for IBD patients are shown as the black marker.



Comparison of overall satisfaction rating and core domain scores showed no significant differences in patient experience between England, Scotland, Wales and Northern Ireland (Table 6). This suggests relatively consistent care experiences across the United Kingdom for patients with IBD.



## Responses to individual questionnaire items: overall findings

The profile of responses to all questionnaire items are provided as an Appendix B, with data presented overall and for adult and paediatric cases separately. A number of key messages are highlighted below. Teams should consider whether their own inpatient service is focused on delivering high quality experiences in these areas.

### Toilet & bathroom facilities

Twelve question items asked about aspects of the ward (B1 to B12), including two specific questions about toilet facilities (B6 and B10). Ninety five percent (95%) of adult and paediatric respondents indicated a suitable bathroom was located close by when needed but it is disappointing that 15% of adults reported that toilets and bathrooms were either not very or not at all clean. Furthermore, 28% of adults reported having used the same bathroom/shower area as the opposite sex.

### Food

Eight items focussed on food and nutrition (B13 to B20). One fifth of adult IBD patients (19.9%) rated hospital food as poor, 26% found the food unappetising, 16% reported receiving 'too little' food and 15% stated that the hospital food was not suitable for their dietary needs. Results were similar for paediatrics. Only 38% of adult IBD reported a visit from a dietician during their inpatient stay, compared to 71% of paediatric patients. Given the vital role of maintaining good nutrition in IBD, these findings are of concern. Nutrition teams and dieticians have a key role in driving improvements in these areas. All hospitalised patients with IBD require nutritional assessment and advice.

### Doctors & Nurses

Overall responses to individual questions regarding ward doctors (C1 to C8) and nurses (D1 to D9) were positive. Adult IBD patients expressed somewhat greater levels of complete confidence and trust in medical staff than nursing staff (72% versus 58%), with a similar pattern in paediatrics (81% versus 65.9%). Whereas half of patients (51%) were of the opinion that all their doctors knew enough about their condition or treatment only a quarter (25%) had this opinion of knowledge among nursing staff, with similar findings in paediatrics (62% versus 33%). The general trend for a lower overall rating of ward nursing experience compared to medical staff is consistent with the analysis of composite scores for the core domains of acute care, which identified adjusted scores for nurses as lying within the lowest 20% of average Trust scores (Figure 1). However, 17% of adult IBD patients felt that there were never enough nurses on duty (compared to just 5% for paediatrics). Only 60% of adults indicated that they had a visit from a specialist nurse during their inpatient stay (76% in paediatrics). These findings suggest room for improving the general nursing experience for IBD patients, most notably among adults. IBD nurses should take a lead in driving improvements in overall ward nursing care and education. Staffing levels and job plans should reflect the need to provide a greater degree of specialist nursing input into this patient group.

As illustrated in the core domains of acute care (Figure 1), the composite scores for IBD patients for consistency and coordination of care fall within the lowest 20% of average Trust scores for general inpatients. This is based on two selected questions (E1 and H2). Thirteen percent of patients (13%) reported that staff members would often say different things about care and treatment. Twelve percent (12%) of IBD patients rated team working for doctors and nurses as either fair or poor.

### Pain

Five questions were asked about pain. IBD patients frequently experienced pain during their stay in hospital. Eighty five percent (85%) of adult respondents reported some pain, with 52% indicating that pain was usually severe and 42% as moderate. Eighty seven (87%) of those adults reporting any pain indicated that they requested pain relief medication. Of concern, 28% of those with pain indicated that they were in pain all or most of the time and 16% complained of not receiving enough pain relief. Results for children were similar although inadequate pain medication was reported in 12%. This

suggests a significant room for improvement in the management of inpatient pain among IBD patients of all ages.

### Leaving hospital

Eleven questions (G1 to G11) asked about aspects of discharge arrangements and information about treatment on discharge. These identified significant areas for improvement. In terms of the general discharge process, 13% of IBD patients felt that they were not involved in decisions about discharge and 13% reported insufficient notice was provided for family or someone close. Questions relating to information and advice about discharge medicines revealed that only 6% reported not receiving an explanation of the purpose of the treatments but 32% recalled no instruction about side effects to watch out for. Eleven percent (11%) reported receiving no written information about discharge medicines. It is concerning that 30% of patients reported that no staff member had told them about danger signals to watch for after going home and 17% felt that they were not given enough information about how to manage their condition after discharge. Forty percent (40%) reported that they did not receive a copy of the letters sent between hospital and family doctor (GP). These findings suggest that teams should review their information policy for discharge of IBD patients with a particular emphasis on the role of pharmacists and IBD nurses in the discharge process and the provision of written information.

## Tables of results

**Table 1: Characteristics of responders and non-responders to the IBD inpatient survey**

Adult patients	Responders N=2028	Non-responders N=4143	
Patient age, median (IQR)	43 (31, 59)	37 (26, 51)	*
Male	867 (42.8%)	2099 (50.7%)	*
Female	1161 (57.2%)	2044 (49.3%)	
UC	1056 (57.1%)	1993 (48.1%)	*
CD	972 (47.9%)	2150 (51.9%)	
Elective or Transfer	1624 (80.1%)	3501 (84.5%)	*
Non-Elective	404 (19.9%)	342 (15.5%)	
Operated	673 (33.2%)	1154 (27.9%)	*
Not-operated	1352 (66.8%)	2980 (72.1%)	

Paediatric patients	Responders N=167	Non-responders N=351	
Patient age, median (IQR)	13 (11, 15)	13 (11, 15)	
Male	94 (56.3%)	221 (63.0%)	
Female	73 (43.7%)	130 (37.0%)	
UC	51 (30.5%)	125 (35.6%)	
CD	116 (69.5%)	226 (64.4%)	
Elective / Transferred from another site for surgery	24 (14.4%)	53 (15.1%)	
Non-Elective	143 (85.6%)	298 (84.9%)	
Operated	35 (21.0%)	79 (22.6%)	
Not-operated	132 (79.0%)	271 (77.4%)	

**Table 2: Demographic and clinical factors associated with dissatisfaction with inpatient care: Adult IBD population**

(n=2,016 respondents to the overall satisfaction question)

Demographic and clinical factors associated with dissatisfaction with inpatient care: Adult IBD population (n=2,016 respondents to the overall satisfaction question)					
	Satisfied n=1817	Not satisfied n=199	OR	95% Confidence Interval	
Crohn's	862 (89.2%)	104 (10.8%)	1.00	Ref	
UC	955 (91.0%)	95 (9.0%)	0.82	0.62 1.11	*
Female	1011 (87.7%)	142 (12.3%)	1.00	Ref	
Male	806 (93.4%)	57 (6.6%)	0.50	0.37 0.69	
No surgery	1208 (90.0%)	135 (10.0%)	1.00	Ref	
Surgery	606 (90.5%)	64 (9.5%)	0.95	0.69 1.29	
Non-elective	1453 (90.0%)	162 (10.0%)	1.00	Ref	
Elective	364 (90.8%)	37 (9.2%)	0.91	0.63 1.33	
≤35 years	576 (87.8%)	80 (12.2%)	1.00	Ref	
36-50 years	489 (87.3%)	71 (12.7%)	1.05	0.74 1.47	
51-65 years	442 (93.6%)	30 (6.4%)	0.49	0.32 0.76	*
66+ years	310 (94.5%)	18 (5.5%)	0.42	0.25 0.71	*

[Odds ratio for being dissatisfied with care, as indicated by an overall rating of care as 'poor' or only 'fair']

**Table 3: Scores for core domains of acute inpatient care for adults with IBD**

All adult patients	All IBD patients			Ulcerative colitis			Crohn's disease			
	N	Mean	SD	N	Mean	SD	N	Mean	SD	
Overall satisfaction	2016	75.6	25.8	1050	77.2	25.3	966	73.9	26.2	*
Consistency	2028	68.8	26.2	1056	72.0	24.9	972	65.3	27.2	*
Respect	2016	83.2	27.3	1050	85.1	25.5	966	81.1	29.0	*
Involvement in care	2024	69.8	27.7	1054	71.6	27.0	970	67.9	28.3	*
Doctors	2017	81.7	25.4	1052	83.2	24.2	965	80.1	26.7	*
Nurses	2026	75.0	27.1	1055	76.4	26.1	971	73.4	28.2	*
Cleanliness	2019	81.4	19.4	1054	82.5	18.8	965	80.1	20.1	*
Emergency admissions	All IBD patients			Ulcerative colitis			Crohn's disease			
	N	Mean	SD	N	Mean	SD	N	Mean	SD	
Overall satisfaction	1245	74.0	26.8	650	75.3	26.1	595	72.6	27.5	
Consistency	1249	67.0	26.6	651	70.6	25.1	598	63.1	27.7	*
Respect	1240	81.7	28.7	648	83.5	26.6	592	79.8	30.7	*
Involvement in care	1248	68.0	28.4	650	69.5	28.1	598	66.4	28.5	
Doctors	1242	79.1	27.0	649	80.5	25.7	293	77.7	28.3	
Nurses	1248	73.4	27.7	651	74.9	26.6	297	71.7	28.8	*
Cleanliness	1244	80.2	20.1	649	80.9	19.7	595	79.3	20.5	
Elective admissions	All IBD patients			Ulcerative colitis			Crohn's disease			
	N	Mean	SD	N	Mean	SD	N	Mean	SD	
Overall satisfaction	395	78.1	25.3	187	81.3	24.7	208	75.2	25.7	*
Consistency	398	72.2	26.4	187	75.1	25.9	211	69.6	26.6	*
Respect	398	83.7	26.3	187	86.1	24.2	211	81.5	27.9	
Involvement in care	396	74.6	26.3	187	77.8	24.4	209	71.7	27.6	*
Doctors	398	86.4	22.2	187	88.6	20.4	211	84.5	23.5	
Nurses	397	77.5	26.1	186	78.2	24.4	211	76.9	27.5	
Cleanliness	396	82.9	18.0	187	85.6	16.5	209	80.5	19.0	*

**Table 4: Top 12 strongest correlations with overall satisfaction (individual question level)**

Top 12 strongest correlations with overall satisfaction (individual question level)			
Rank	Adult questionnaire responses	Paediatric questionnaire responses	National inpatient survey 2009
1.	How would you rate how well the doctors and nurses worked together?	How would you rate how well the doctors and nurses worked together?	How would you rate how well the doctors and nurses worked together?
2.	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	Before you received any treatments (e.g. an injection, dressing, physiotherapy) did a member of staff explain what would happen?	Overall, did you feel you were treated with respect and dignity while you were in the hospital?
3.	Overall, were you treated with kindness and understanding while you were in the hospital?	Overall, were you treated with kindness and understanding while you were in the hospital?	Did you have confidence and trust in the nurses treating you?
4.	How would you rate the courtesy of your nurses?	Were you involved as much as you wanted to be in decisions about your care and treatment?	Did you have confidence and trust in the doctors treating you?
5.	Did you have confidence and trust in the nurses treating you?	Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?	Do you think the hospital staff did everything they could to help control your pain?
6.	In your opinion, did the nurses who treated you know enough about your condition or treatment?	If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?	When you had important questions to ask a nurse, did you get answers that you could understand?
7.	How would you rate the courtesy of your doctors?	Were you involved as much as you wanted to be in decisions about your care and treatment?	Did you find someone on the hospital staff to talk to about your worries and fears?
8.	Did you have confidence and trust in the doctors treating you?	As far as you know, did nurses wash or clean their hands between touching patients?	In your opinion, how clean was the hospital room or ward that you were in?
9.	When you had important questions to ask a nurse, did you get answers that you could understand?	In your opinion, did the nurses who treated you know enough about your condition or treatment?	Were you involved as much as you wanted to be in decisions about your care and treatment?
10.	Did you get enough help from staff to eat your meals?	Were you told how to take your medication in a way you could understand?	Did you get enough help from staff to eat your meals?
11.	Do you feel that you received enough information from the hospital on how to manage your condition after your discharge?	If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?
12.	In your opinion, did the doctors who treated you know enough about your condition or treatment?	When you had important questions to ask a nurse, did you get answers that you could understand?	When you had important questions to ask a doctor, did you get answers that you could understand?

**Table 5: Association between overall satisfaction rating and core domain scores for adults with IBD**

Domain	All IBD patients			*
	OR	95% Confidence interval		
Consistency	0.93	0.93	0.94	*
Respect	0.94	0.93	0.95	*
Involvement in care	0.95	0.94	0.95	*
Doctors	0.95	0.95	0.96	*
Nurses	0.94	0.93	0.95	*
Cleanliness	0.95	0.94	0.95	*
Domain	Ulcerative colitis			*
	OR	95% Confidence interval		
Consistency	0.93	0.93	0.94	*
Respect	0.94	0.93	0.95	*
Involvement in care	0.95	0.94	0.95	*
Doctors	0.95	0.95	0.96	*
Nurses	0.94	0.93	0.95	*
Cleanliness	0.95	0.94	0.95	*
Domain	Crohn's disease			*
	OR	95% Confidence interval		
Consistency	0.93	0.93	0.94	*
Respect	0.94	0.93	0.95	*
Involvement in care	0.95	0.94	0.95	*
Doctors	0.95	0.95	0.96	*
Nurses	0.94	0.93	0.95	*
Cleanliness	0.95	0.94	0.95	*

**Table 6: Overall satisfaction rating and scores for core domains of acute inpatient care across the UK: Adult IBD patients**

<b>Overall satisfaction</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
England	1671	75.3	25.8
Northern Ireland	91	78.8	27.6
Scotland	110	75.0	26.0
Wales	144	77.3	24.5
<b>Consistency</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
England	1679	68.5	26.3
Northern Ireland	92	70.4	28.1
Scotland	112	70.3	24.8
Wales	145	70.3	25.8
<b>Respect</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
England	1669	83.1	27.4
Northern Ireland	91	82.4	30.2
Scotland	112	85.3	24.8
Wales	144	82.6	26.7
<b>Involvement in care</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
England	1675	69.5	27.7
Northern Ireland	92	69.5	28.5
Scotland	112	71.9	26.9
Wales	145	72.4	27.2
<b>Doctors</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
England	1670	81.5	25.3
Northern Ireland	92	80.2	26.9
Scotland	110	85.0	24.2
Wales	145	83.1	27.0
<b>Nurses</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
England	1677	74.6	27.1
Northern Ireland	92	78.8	26.2
Scotland	112	80.4	25.4
Wales	145	73.3	28.8
<b>Cleanliness</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
England	1671	81.6	19.2
Northern Ireland	92	81.6	21.8
Scotland	112	83.4	17.6
Wales	144	77.4	21.6

## Appendices

### Appendix A: Questions that comprise the 6 sub-domains

1. Consistency and coordination
  - E1 – Sometimes in hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you?
  - H2 – How would you rate how well the doctors and nurses worked together?
2. Treatment, respect and dignity
  - H1 – Overall, did you feel you were treated with respect and dignity while you were in the hospital?
3. Involvement in care
  - E2 – Were you involved as much as you wanted to be in decisions about your care and treatment?
  - E3 – How much information about your condition or treatment was given to you?
  - E7 – Did you find someone on the hospital staff to talk to about your condition or treatment?
  - G1 – Did you feel you were involved in decisions about your discharge from hospital?
4. Doctors
  - C3 – When you had important questions to ask a doctor, did you get answers that you could understand?
  - C5 – Did you have confidence and trust in the doctors treating you?
5. Nurses
  - D1 – When you had important questions to ask a nurse, did you get answers that you could understand?
  - D3 – Did you have confidence and trust in the nurses treating you?
6. Cleanliness
  - B9 – In your opinion, how clean was the hospital ward that you were in?
  - B10 – How clean were the toilets and bathrooms that you used in hospital?
  - C8 – As far as you know, did doctors wash or clean their hands between touching patients?
  - D9 – As far as you know, did nurses wash or clean their hands between touching patients?



## Appendix B: Full questionnaire responses results table

	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
<b>Section A - Admission to hospital</b>	n	%	n	%	n	%
<b>A1 Was your most recent hospital stay planned in advance or an emergency?</b>						
1. Emergency or urgent (EU)	1533/2028	75.6	85/167	50.9	1618/2195	73.7
2. Waiting list or planned in advance (WP)	453/2028	22.3	75/167	44.9	528/2195	24.1
3. Something else (SE)	42/2028	2.1	7/167	4.2	49/2195	2.2
<b>A2 Following arrival at the hospital, how long did you wait before being admitted to a bed on a ward?</b>						
1. Less than an hour (<1)	198/2018	9.8	67/166	40.4	593/2184	27.1
2. 1-2 hours (01-Feb)	526/2018	26.0	17/166	10.3	306/2184	14.0
3. At least 2 but less than 4 hours (02-Apr)	289/2018	14.3	33/166	19.9	408/2184	81.7
4. At least 4 but less than 8 hours (04-Aug)	375/2018	18.6	6/166	3.6	401/2184	18.4
5. 8 hours or longer (>8)	395/2018	19.6	4/166	2.4	177/2184	8.1
6. Cant remember (NK)	173/2018	8.6	2/166	1.2	64/2184	2.9
7. I did not have to wait (NW)	62/2018	3.1	37/166	22.3	235/2184	10.8
<b>A3 How would you rate the courtesy of the staff who admitted you?</b>						
1. Excellent (E)	813/2023	40.2	77/167	46.1	890/2023	40.6
2. Very good (VG)	709/2023	35.1	64/167	38.3	773/2023	35.3
3. Good (G)	334/2023	16.5	19/167	11.4	353/2023	16.1
4. Fair (F)	120/2023	5.9	6/167	3.6	126/2023	5.7
5. Poor (P)	35/2023	1.7	1/167	0.6	36/2023	1.6
6. Don't know/Cant say (NK)	12/2023	0.6	0/167	0	12/2023	0.5

	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
<b>Section B - The hospital and ward</b>	n	%	n	%	n	%
<b>B1 While in hospital, did you ever stay in a critical care area (Intensive care unit, High dependency unit or Coronary care)?</b>						
1. Yes (Y)	415/2025	20.5	13/166	7.8	428/2191	19.5
2. No (N)	1527/2025	75.4	146/166	87.9	1673/2191	76.4
3. Don't know/cant say (NK)	83/2025	4.1	7/166	4.2	90/2191	4.1
<b>B2 While in hospital, did you ever stay in a specialist ward that cared mainly for patients with bowel conditions (a gastroenterology ward)?</b>						
1. Yes (Y)	1106/2013	54.9	61/165	37.0	1167/2178	53.6
2. No (N)	752/2013	37.4	94/165	57.0	846/2178	38.8
3. Don't know/cant say (NK)	155/2013	7.7	10/165	6.1	165/2178	7.6
<b>B3 When you were first admitted to a bed on a ward, did you share a sleeping area, for example a room or a bay, with patients of the opposite sex?</b>						
1. Yes (Y)	231/2017	11.5	76/167	45.5	307/2184	14.1
2. No (N)	1786/2017	88.5	91/167	54.5	1877/2184	85.9
<b>B4 During your stay in hospital, how many wards did you visit?</b>						
1. 1 (1)	861/2019	42.6	115/165	69.7	976/2184	44.7
2. 2 (2)	803/2019	39.8	31/165	18.8	834/2184	38.2
3. 3 or more (3)	347/2019	17.2	18/165	10.9	365/2184	16.7
4. Don't know/cant remember (NK)	8/2019	0.4	1/165	0.6	9/2184	0.4

<b>B5 While staying in hospital, did you ever use the same bathroom or shower area as patients of the opposite sex?</b>						
1. Yes (Y)	574/2018	28.4	96/166	57.8	670/2184	30.7
2. Yes, because it had specialist bathing equipment that I needed (YS)	23/2018	1.1	3/166	1.8	26/2184	1.2
3. No (N)	1334/2018	66.1	57/166	34.3	1391/2184	63.7
4. I did not use a shower or bathroom (NU)	21/2018	1.0	2/166	1.2	23/2184	1.0
5. Don't know/cant remember (NK)	66/2018	3.3	8/166	4.8	74/2184	3.4
<b>B6 When you needed to use a toilet or bathroom, was there a suitable one located close by?)</b>						
1. Yes (Y)	1913/2010	95.2	159/167	95.2	2072/2177	95.2
2. No (N)	78/2010	3.9	7/167	4.2	85/2177	3.9
3. I did not use a toilet or bathroom (NU)	13/2010	0.6	1/167	0.6	14/2177	0.6
4. Don't know/cant remember (NK)	6/2010	0.3	0/167	0	6/2177	0.3
<b>B7 For most of your stay, what type of room or ward were you in?</b>						
1. A room by myself (M)	552/1981	27.9	70/166	42.2	622/2147	29.0
2. A room with one other patient (OP)	0	0	0	0	0	0
3. A bay with 2-6 other patients, within a larger ward (B)	1256/1981	63.4	77/166	46.4	1333/2147	62.1
4. A large, open-plan ward (LW)	173/1981	8.7	19/166	11.4	192/2147	8.9
<b>B8 Were you given enough privacy while you were on the ward?</b>						
1. Yes always (Y)	1274/2008	63.4	101/166	60.8	1375/2174	63.2
2. Yes sometimes (YS)	616/2008	30.7	58/166	34.9	674/2174	31.0
3. No (N)	118/2008	5.9	7/166	4.2	125/2174	5.7
<b>B9 In your opinion, how clean was the hospital room or ward that you were in?</b>						
1. Very clean (C.)	1132/2015	56.2	101/167	60.5	1233/2182	56.5
2. Fairly clean (FC)	777/2015	38.6	63/167	37.7	840/2182	38.5
3. Not very clean (NVC)	88/2015	4.4	2/167	1.2	90/2182	4.1
4. Not at all clean (NC)	18/2015	0.9	1/167	0.6	19/2182	0.9
<b>B10 How clean were the toilets and bathrooms that you used?</b>						
1. Very clean (C.)	815/2016	40.4	87/167	52.1	902/2183	41.3
2. Fairly clean (FC)	865/2016	42.9	72/167	43.1	937/2183	42.9
3. Not very clean (NVC)	250/2016	12.4	5/167	3.0	255/2183	11.7
4. Not at all clean (NC)	68/2016	3.4	3/167	1.8	71/2183	3.2
5. I did not use the toilet or bathroom (NU)	18/2016	0.9	0/167	0	18/2183	0.8
<b>B11 Did you see posters or leaflets on the ward asking patients and visitors to wash their hands or to use hand wash gels?</b>						
1. Yes (Y)	1929/2019	95.5	161/166	97.0	2090/2185	95.6
2. No (N)	31/2019	1.5	0/166	0	31/2185	1.4
3. Cant remember (CR)	59/2019	2.9	5/166	3.0	64/2185	2.9
<b>B12 Were hand wash gels available for patients and visitors to use?</b>						
1. Yes (Y)	1912/2015	94.9	160/167	95.8	2072/2182	95.0
2. Yes, but they were empty (YE)	41/2015	2.0	5/167	3.0	46/2182	2.1
3. I did not see any hand wash gels (NS)	26/2015	1.3	0/167	0	26/2182	1.2
4. Don't know/cant remember (NK)	36/2015	1.8	2/167	1.2	38/2182	1.7

Section B continued - Food	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
	n	%	n	%	n	%
<b>B13 How would you rate the hospital food?</b>						
1. Very good (VG) <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Go to B14	284/2015	14.1	12/167	7.2	296/2182	13.6
2. Good (G) <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Go to B14	624/2015	31.0	48/167	28.7	672/2182	30.8
3. Fair (F) <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Go to B14	665/2015	33.0	52/167	31.1	717/2182	32.9
4. Poor (P) <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Go to B14	400/2015	19.8	18/167	10.8	418/2182	19.2
5. I did not have any hospital food (NF) <input type="checkbox"/> Go to B16	42/2015	2.1	37/167	22.2	79/2182	3.6
<b>B14 Was the hospital food appetising? (Excludes those that answered 'I did not have any hospital food' to B13)</b>						
1. Yes always (Y)	393/1970	19.9	15/130	11.5	408/2100	19.4
2. Yes sometimes (YS)	1060/1970	53.8	90/130	69.2	1150/2100	54.8
3. No (N)	517/1970	26.3	25/130	19.2	542/2100	25.8
<b>B15 How much food were you given? (Excludes those that answered 'I did not have any hospital food' to B13)</b>						
1. Too much (TM)	76/1955	3.9	4/130	3.1	80/2085	3.8
2. The right amount (RA)	1578/1955	80.7	105/130	80.8	1683/2085	80.7
3. Too little (TL)	301/1955	15.4	21/130	16.1	322/2085	15.4
<b>B16 Were you offered a choice of food?</b>						
1. Yes always (Y)	1543/2007	76.9	93/161	57.8	1636/2168	75.5
2. Yes sometimes (YS)	399/2007	19.9	41/161	25.5	440/2168	20.3
3. No (N)	65/2007	3.3	27/161	16.8	92/2168	4.2
<b>B17 Do you have any special dietary requirements (eg a vegetarian, diabetic, food allergies)?</b>						
1. Yes (Y) <input type="checkbox"/> Go to B18	574/2013	28.5	50/161	31.2	624/2174	28.7
2. No (N) <input type="checkbox"/> Go to B19	1418/2013	70.4	107/161	66.5	1525/2174	70.1
3. Don't know (NK) <input type="checkbox"/> Go to B19	21/2013	1.0	4/161	2.5	25/2174	1.2
<b>B18 Was the hospital food suitable for your dietary needs? (Excludes those that answered 'no' or 'don't know' to B17)</b>						
1. Yes always (Y)	187/572	32.7	23/48	47.9	210/620	33.9
2. Yes sometimes (YS)	298/572	52.1	19/48	39.6	317/620	51.1
3. No never (N)	83/572	14.5	4/48	8.3	87/620	14.0
4. Don't know/cant remember (NK)	4/572	0.7	2/48	4.2	6/620	1
<b>B19 Did you get enough help from staff to eat your meals?</b>						
1. Yes always (Y)	346/2014	17.2	27/157	17.2	373/2171	17.2
2. Yes sometimes (YS)	101/2014	5.0	15/157	9.5	116/2171	5.3
3. No never (N)	74/2014	3.7	9/157	5.7	83/2171	3.8
4. I did not need help to eat my meals (NH)	1493/2014	74.1	106/157	67.5	1599/2171	73.6
<b>B20 During your hospital stay, did you have a visit from a dietician?</b>						
1. Yes more than once (Y)	375/2022	18.5	95/166	57.2	470/2188	21.5
2. Yes once (YO)	391/2022	19.3	23/166	13.9	414/2188	18.9
3. No (N)	1190/2022	58.8	43/166	25.9	1233/2188	56.3
4. Don't know/not sure (NK)	66/2022	3.3	5/166	3.0	71/2188	3.2
<b>B21 Were you given any extra nutritional supplements to take (eg special drinks or foods) at any time during your admission to help maintain or gain weight?</b>						
1. Yes (Y)	888/2016	44.1	97/164	59.1	985/2180	45.2
2. No (N)	1128/2016	55.9	67/164	40.9	1195/2180	54.8
<b>B22 Did you receive any special feed via a tube (eg placed through the nose) or directly into your veins during your admission?</b>						
1. Yes (Y)	379/2011	18.9	68/166	41.0	447/2177	20.5
2. No (N)	1632/2011	81.1	98/166	59.0	1730/2177	79.5

Section C - Doctors	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
	n	%	n	%	n	%
<b>C1 Was there one doctor in overall charge of your care?</b>						
1. Yes (Y)	1400/2013	69.6	127/166	76.5	1527/2179	70.1
2. No (N)	409/2013	20.3	33/166	19.9	442/2179	20.3
3. Don't know (NK)	204/2013	10.1	6/166	3.6	210/2179	10.1
<b>C2 During your stay in hospital, did the doctor in overall charge of your care (consultant) arrange for you to be seen by another specialist (ie a different medical or surgical specialist)?</b>						
1. Yes (Y)	984/2007	49.0	95/166	57.2	1079/2173	49.6
2. No (N)	805/2007	40.1	50/166	30.1	855/2173	39.3
3. Don't know (NK)	218/2007	10.9	21/166	12.6	239/2173	11.0
<b>C3 When you had important questions to ask a doctor, did you get answers that you could understand?</b>						
1. Yes (Y)	1216/2014	60.4	106/166	63.9	1322/2180	60.6
2. Yes to some extent (YS)	621/2014	30.8	48/166	28.9	669/2180	30.7
3. No (N)	97/2014	4.8	4/166	2.4	101/2180	4.6
4. I had no need to ask (NN)	80/2014	4.0	8/166	4.8	88/2180	4.0
<b>C4 If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?</b>						
1. Yes completely (Y)	1040/2013	51.7	111/166	66.9	1151/2179	52.8
2. Yes to some extent (YS)	704/2013	35.0	47/166	28.3	751/2179	34.5
3. No (N)	106/2013	5.3	2/166	1.2	108/2179	5.0
4. I did not have worries or fears (NW)	163/2013	8.1	6/166	3.6	169/2179	7.8
<b>C5 Did you have confidence and trust in the doctors treating you?</b>						
1. Yes always (Y)	1458/2016	72.3	134/165	81.2	1592/2181	73.0
2. Yes sometimes (YS)	477/2016	23.7	29/165	17.6	506/2181	23.2
3. No (N)	81/2016	4.0	2/165	1.2	83/2181	3.8
<b>C6 How would you rate the courtesy of your doctors?</b>						
1. Excellent (E)	1050/2016	52.1	95/166	57.2	1145/2182	52.5
2. Very good (VG)	636/2016	31.5	56/166	33.7	692/2182	31.7
3. Good (G)	229/2016	11.4	13/166	7.8	242/2182	11.1
4. Fair (F)	78/2016	3.9	2/166	1.2	80/2182	3.7
5. Poor (P)	23/2016	1.1	0/166	0	23/2182	1.0
<b>C7 In your opinion, did the doctors treating you know enough about your condition or treatment?</b>						
1. All of the doctors knew enough (A)	1012/2021	50.1	105/167	62.9	1117/2188	51.0
2. Most of them knew enough (M)	681/2021	33.7	49/167	29.3	730/2188	33.4
3. Only some knew enough (S)	256/2021	12.7	10/167	6.0	266/2188	12.2
4. None of them knew enough (N)	38/2021	1.9	1/167	0.6	39/2188	1.8
5. Cant say (CD)	34/2021	1.7	2/167	1.2	36/2188	1.6
<b>C8 As far as you know, did doctors wash or clean their hands between touching patients?</b>						
1. Yes always (Y)	1164/2019	57.6	115/167	68.9	1279/2186	58.5
2. Yes sometimes (YS)	228/2019	11.3	11/167	6.6	239/2186	10.9
3. No (N)	76/2019	3.8	2/167	1.2	78/2186	3.6
4. don't know/cant remember (NK)	551/2019	27.3	39/167	23.3	590/2186	27.0

Section D - Nurses	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
	n	%	n	%	n	%
<b>D1 When you had important questions to ask a nurse, did you get answers that you could understand?</b>						
1. Yes always (Y)	1012/2019	50.1	95/167	56.9	1107/2186	50.6
2. Yes sometimes (YS)	785/2019	38.9	59/167	35.3	844/2186	38.6
3.No (N)	115/2019	5.7	4/167	2.4	119/2186	5.4
4. I had no need to ask (NN)	107/2019	5.3	9/167	5.4	116/2186	5.3
<b>D2 If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?</b>						
1. Yes completely (Y)	649/2016	32.2	88/167	52.7	737/2183	33.8
2. Yes to some extent (YS)	840/2016	41.7	59/167	35.3	899/2183	41.2
3. No (N)	235/2016	11.7	11/167	6.6	246/2183	11.3
4. I did not have worries or fears (NW)	292/2016	14.5	9/167	5.4	301/2183	13.8
<b>D3 Did you have confidence and trust in the nurses treating you?</b>						
1. Yes always (Y)	1164/2019	57.6	110/167	65.9	1274/2186	58.3
2. Yes sometimes (YS)	752/2019	37.2	55/167	32.9	807/2186	36.9
3.No (N)	103/2019	5.1	2/167	1.2	105/2186	4.8
<b>D4 In your opinion were there enough nurses on duty to care for you in hospital?</b>						
1. Always or nearly always (A)	897/2014	44.5	103/166	62.0	1000/2180	45.9
2. Sometimes (S)	775/2014	38.5	54/166	32.5	829/2180	38.0
3. No (N)	342/2014	17.0	9/166	5.4	351/2180	16.1
<b>D5 If you ever needed to talk to a nurse, did you get the opportunity to do so?</b>						
1. Yes always (Y)	837/2015	41.5	81/167	48.5	918/2182	42.1
2. Yes sometimes (YS)	959/2015	47.6	76/167	45.5	1035/2182	47.4
3.No (N)	111/2015	5.5	6/167	3.6	117/2182	5.4
4. I had no need (NN)	108/2015	5.4	4/167	2.4	112/2182	5.1
<b>D6 Apart from regular nursing staff on the ward did you receive a visit from a specialist nurse while you were in hospital (eg IBD nurse, Clinical nurse specialist, Nurse Consultant or stoma nurse)?</b>						
1. Yes more than once (Y)	864/2018	42.8	107/167	64.1	971/2185	44.4
2. Yes once (YO)	337/2018	16.7	20/167	12.0	357/2185	16.3
3. No (N)	698/2018	34.6	26/167	15.6	724/2185	33.1
4. Don't know (NK)	119/2018	5.9	14/167	8.4	133/2185	6.1
<b>D7 How would you rate the courtesy of your nurses?</b>						
1. Excellent (E)	883/2007	44.0	94/167	56.3	977/2174	44.9
2. Very good (VG)	677/2007	33.7	52/167	31.1	729/2174	33.5
3. Good (G)	308/2007	15.3	17/167	10.2	325/2174	14.9
4. Fair (F)	106/2007	5.3	4/167	2.4	110/2174	5.1
5. Poor (P)	33/2007	1.6	0/167	0	33/2174	1.5
<b>D8 In your opinion, did the nurses treating you know enough about your condition or treatment?</b>						
1. All of the nurses knew enough (A)	495/2022	24.5	55/167	32.9	550/2189	25.1
2. Most of them knew enough (M)	860/2022	42.5	79/167	47.3	939/2189	42.9
3. Only some knew enough (S)	461/2022	22.8	29/167	17.4	490/2189	22.4
4. None of them knew enough (N)	95/2022	4.7	2/167	1.2	97/2189	4.4
5. Cant say (CD)	111/2022	5.5	2/167	1.2	113/2189	5.2
<b>D9 As far as you know, did nurses wash or clean their hands between touching patients?</b>						
1. Yes always (Y)	1191/2017	59.0	113/167	67.7	1304/2184	59.7
2. Yes sometimes (YS)	341/2017	16.9	20/167	12.0	361/2184	16.5
3.No (N)	62/2017	3.1	2/167	1.2	64/2184	2.9
4. don't know/cant remember (NK)	423/2017	21	32/167	19.2	455/2184	20.8

Section E - Your care and treatments	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
	n	%	n	%	n	%
E1 Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you?						
1. Yes often (Y)	273/2018	13.5	17/167	10.2	290/2185	13.3
2. Yes sometimes (YS)	806/2018	39.9	71/167	42.5	877/2185	40.1
3. No (N)	939/2018	46.5	79/167	47.3	1018/2185	46.6
E2 Were you involved as much as you wanted to be in decisions about your care and treatment?						
1. Yes definitely (Y)	963/2013	47.8	96/167	57.5	1059/2180	48.6
2. Yes to some extent (YS)	867/2013	43.1	58/167	34.7	925/2180	42.4
3. No (N)	183/2013	9.1	13/167	7.8	196/2180	9.0
E3 How much information about your condition or treatment was given to you?						
1. Not enough (NE)	477/2009	23.7	10/167	6.0	487/2176	22.4
2. The right amount (RA)	1518/2009	75.6	155/167	92.8	1673/2176	76.9
3. Too much (TM)	14/2009	0.7	2/167	1.2	16/2176	0.7
E4 While you were in hospital, were you told your diagnosis (explanation of what was wrong with you)?						
1. Yes (Y) <input type="checkbox"/> Go to E5	1299/2011	64.6	108/167	64.7	1407/2178	64.6
2. No but already knew (NKD) <input type="checkbox"/> Go to E5	564/2011	28.0	52/167	31.1	616/2178	28.3
3. No but would have like to be told(NLT) <input type="checkbox"/> Go to E5	50/2011	2.5	3/167	1.8	53/2178	2.4
4. No but did not want this info (NNW) <input type="checkbox"/> Go to E5	5/2011	0.2	0/167	0	5/2178	0.2
5. No but told later (NLD) <input type="checkbox"/> Go to E5	79/2011	3.9	4/167	2.4	83/2178	3.8
6. Don't know/cant remember (NK) <input type="checkbox"/> Go to E5	14/2011	0.7	0/167	0	14/2178	0.6
E5 Was your diagnosis explained to you in a way that you could understand? (Includes only those that answered 'yes' to E4)						
1. Yes completely (Y)	949/1288	73.7	84/106	79.2	1033/1394	74.1
2. Yes to some extent (SE)	321/1288	24.9	22/16	20.7	343/1394	24.6
3. No (N)	18/1288	1.4	0/106	0	18/1394	1.3
E6 If someone in your family or someone close to you wanted to talk to a doctor, did they have enough opportunity to do so?						
1. Yes definitely (Y)	566/2009	28.2	103/166	62.0	669/2175	30.8
2. Yes to some extent (YS)	669/2009	33.3	53/166	31.9	722/2175	33.2
3. No (N)	346/2009	17.2	6/166	3.6	352/2175	16.2
4. No friends family involved (NF)	150/2009	7.5	2/166	1.2	152/2175	7.0
5. Family didn't need or want to (FN)	215/2009	10.7	2/166	1.2	215/2175	10.7
6. I didn't want them to (NT)	63/2009	3.1	0/166	0	63/2175	3.1
E7 Did you find someone on the hospital staff to talk to about your worries and fears?						
1. Yes definitely (Y)	561/2015	27.8	85/166	51.2	646/2181	29.6
2. Yes to some extent (YS)	663/2015	32.9	48/166	28.9	711/2181	32.6
3. No (N)	311/2015	15.4	10/166	6.0	321/2181	14.7
4. No worries or fears (NW)	480/2015	23.8	23/166	13.9	503/2181	23.1
E8 Were you given enough privacy when discussing your condition or treatment?						
1. Yes always (Y)	1235/2010	61.4	106/166	63.9	1341/2176	61.6
2. Yes sometimes (YS)	588/2010	29.2	48/166	28.9	636/2176	29.2
3.No (N)	187/2010	9.3	12/166	7.2	199/2176	9.1
E9 Were you given enough privacy when being examined or treated?						
1. Yes always (Y)	1667/2016	82.7	135/166	81.3	1802/2182	82.6
2. Yes sometimes (YS)	293/2016	14.5	26/166	15.7	319/2182	14.6
3.No (N)	56/2016	2.8	5/166	3.0	61/2182	2.8

	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
<b>Section E continued - Pain</b>	n	%	n	%	n	%
E10 Were you ever in any pain?						
1. Yes (Y) <input type="checkbox"/> Go to E11	1723/2022	85.2	138/166	83.1	1861/2188	85.0
2. No (N) <input type="checkbox"/> Go to E15	299/2022	14.8	28/166	16.9	327/2188	14.9
E11 When you had pain was it usually severe, moderate or mild (Excludes those that answered 'No' to E10)						
1. Severe (S)	890/1711	52.0	69/134	51.5	959/1845	52.0
2. Moderate (MO)	714/1711	41.7	51/134	38.1	765/1845	41.5
3. Mild (MI)	107/1711	6.2	14/134	10.4	121/1845	6.6
E12 During your hospital stay, how much of the time were you in pain? (Excludes those that answered 'No' to E10)						
1. All or almost all (A)	481/1722	27.9	37/138	26.8	518/1860	27.8
2. Some (S)	925/1722	53.7	73/138	52.9	998/1860	53.7
3. Occasionally (O)	316/1722	18.3	28/138	20.3	344/1860	18.5
E13 Did you ever request pain relief? (Excludes those that answered 'No' to E10)						
1. Yes (Y)	1504/1721	87.4	105/138	76.1	1609/1859	86.5
2. No (N)	217/1721	12.6	33/138	23.9	250/1859	13.4
E14 Overall how much pain relief medication did you get? (Excludes those that answered 'No' to E10)						
1. Enough (E)	1399/1675	83.5	110/127	86.6	1509/1802	83.7
2. Not enough (NE)	266/1675	15.9	15/127	11.8	281/1802	15.6
3. Too much (TM)	10/1675	0.6	2/127	1.6	12/1802	0.7
	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
<b>Section E continued - Tests</b>	n	%	n	%	n	%
E15 During your stay in hospital, did you have any tests, x-rays or scans other than blood or urine tests?						
1. Yes (Y) <input type="checkbox"/> Go to E16	1717/2020	85.0	127/166	76.5	1844/2186	84.3
2. No (N) <input type="checkbox"/> Go to E17	303/2020	15.0	39/166	23.5	342/2186	15.6
E16 Did you feel you could refuse any tests that you did not agree with or did not want? (Excludes those that answered 'No' to E15)						
1. Yes completely (Y)	785/1704	46.1	49/127	38.6	834/1831	45.5
2. Yes to some extent (YS)	365/1704	21.4	25/127	19.7	390/1831	21.3
3. No (N)	153/1704	9.0	17/127	13.4	170/1831	9.3
4. No but I wanted to follow Drs advice (DA)	395/1704	23.2	36/127	28.3	431/1831	23.5
5. I was not able to (eg unconscious) (NA)	6/1704	0.3	0/127	0	6/1831	0.3
	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
<b>Section E continued - Treatments</b>	n	%	n	%	n	%
E17 Before you received any treatments (eg injection, dressing, physiotherapy) did a member of staff explain what would happen?						
1. Yes always (Y) <input type="checkbox"/> Go to E18	1320/2015	65.5	126/166	75.9	1446/2181	66.3
2. Yes sometimes (YS) <input type="checkbox"/> Go to E18	525/2015	26.0	31/166	18.7	556/2181	25.5
3. No (N) <input type="checkbox"/> Go to E18	115/2015	5.7	3/166	1.8	118/2181	5.4
4. I did not want explanation (NE) <input type="checkbox"/> Go to E18	24/2015	1.2	1/166	0.6	25/2181	1.1
5. No treatments (NT) <input type="checkbox"/> Go to F1	31/2015	1.5	5/166	3.0	36/2181	1.6
E18 Before you received any treatments (eg injection, dressing, physiotherapy) did a member of staff explain any risks/benefits in a way you could understand? (Excludes those that answered 'No treatments' to E17)						
1. Yes always (Y)	975/1979	49.3	112/162	69.1	1087/2141	50.8
2. Yes sometimes (YS)	598/1979	30.2	36/162	22.2	634/2141	29.6
3. No (N)	312/1979	15.8	11/162	6.8	323/2141	15.1
4. I did not want explanation (NE)	94/1979	4.7	3/162	1.8	97/2141	4.5

	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
	n	%	n	%	n	%
<b>Section F - Operation and procedures</b>						
F1 During your stay in hospital, did you have an operation or procedure?						
1. Yes (Y) <input type="checkbox"/> Go to F2	1276/2018	63.2	136/167	81.4	1412/2185	64.6
2. No (N) <input type="checkbox"/> Go to G1	742/2018	36.8	31/167	18.6	773/2185	35.4
F2 Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand? (Excludes those that answered 'No' to F1)						
1. Yes completely (Y)	975/1274	76.5	117/136	86.0	1092/1410	77.4
2. Yes to some extent (YS)	246/1274	19.3	17/136	12.5	263/1410	18.6
3. No (N)	39/1274	3.1	2/136	1.5	41/1410	2.9
4. I didn't want an explanation (NE)	14/1274	1.1	0/136	0	14/1410	1.0
F3 Beforehand, did a member of staff explain what would be done during the operation or procedure? (Excludes those that answered 'No' to F1)						
1. Yes completely (Y)	939/1275	73.6	113/136	83.1	1052/1411	74.6
2. Yes to some extent (YS)	271/1275	21.2	20/136	14.7	291/1411	20.6
3. No (N)	44/1275	3.4	2/136	1.5	46/1411	3.3
4. I didn't want an explanation (NE)	21/1275	1.6	1/136	0.7	22/1411	1.6
F4 Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand? (Excludes those that answered 'No' to F1)						
1. Yes completely (Y)	883/1276	69.2	111/136	81.6	994/1412	70.4
2. Yes to some extent (YS)	256/1276	20.1	19/136	14.0	275/1412	19.5
3. No (N)	33/1276	2.6	1/136	0.7	34/1412	2.4
4. I didn't have any questions (NE)	104/1276	8.1	5/136	3.7	109/1412	7.7
F5 After the operation or procedure did a member of staff explain how the operation/procedure had gone in a way you could understand? (Excludes those that answered 'No' to F1)						
1. Yes completely (Y)	856/1277	67.0	110/135	81.5	966/1412	68.4
2. Yes to some extent (YS)	333/1277	26.1	24/135	17.8	357/1412	25.3
3. No (N)	88/1277	6.9	1/135	0.7	89/1412	6.3

	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
	n	%	n	%	n	%
<b>Section G - Leaving hospital</b>						
G1 Did you feel you were involved in decisions about your discharge from hospital?						
1. Yes definitely (Y)	1070/2023	52.9	90/167	53.9	1160/2190	53.0
2. Yes to some extent (YS)	637/2023	31.5	58/167	34.7	695/2190	31.7
3. No (N)	252/2023	12.5	13/167	1.8	265/2190	12.1
4. I didn't need to be involved (NI)	64/2023	3.2	6/167	3.6	70/2190	3.2
G2 Were your family or someone close to you given enough notice about your discharge from hospital?						
1. Yes definitely (Y)	1124/2019	55.7	118/165	71.5	1242/2184	56.9
2. Yes to some extent (YS)	523/2019	25.9	36/165	21.8	559/2184	25.6
3. No (N)	277/2019	13.7	9/165	5.4	286/2184	13.1
4. No family friends involved (NF)	95/2019	4.7	2/165	1.2	97/2184	4.4
G3 Did a member of staff explain the purpose of the medicines you were to take at home in a manner you could understand?						
1. Yes definitely (Y) <input type="checkbox"/> Go to G4	1345/2022	66.5	127/167	76.0	1472/2189	67.2
2. Yes to some extent (YS) <input type="checkbox"/> Go to G4	338/2022	16.7	21/167	12.6	359/2189	16.4
3. No (N) <input type="checkbox"/> Go to G4	129/2022	6.4	6/167	3.6	135/2189	6.2
4. I didn't need an explanation (NN) <input type="checkbox"/> Go to G4	150/2022	7.4	7/167	4.2	157/2189	7.2
5. No medicines (NM) <input type="checkbox"/> Go to G7	60/2022	3.0	6/167	3.6	66/2189	3.0



<b>G4 Did a member of staff tell you about medication side effects to watch for when you went home? (Excludes those that answered 'No medicines' to G3)</b>						
1. Yes definitely (Y)	648/1965	33.0	87/161	54.0	735/2126	34.6
2. Yes to some extent (YS)	390/1965	19.8	36/161	22.4	426/2126	20.0
3. No (N)	626/1965	31.9	17/161	10.6	643/2126	30.2
4. I didn't need an explanation (NE)	301/1965	15.3	21/161	13.0	322/2126	15.1
<b>G5 Were you told how to take your medication in a way you could understand? (Excludes those that answered 'No medicines' to G3)</b>						
1. Yes definitely (Y)	1288/1959	65.7	127/161	78.9	1415/2120	66.7
2. Yes to some extent (YS)	291/1959	15.8	17/161	10.6	308/2120	14.5
3. No (N)	114/1959	5.8	4/161	2.5	118/2120	5.6
4. Didn't need to be told (NN)	266/1959	13.6	13/161	8.1	279/2120	13.2
<b>G6 Were you given clear written or printed info about your medicines? (Excludes those that answered 'No medicines' to G3)</b>						
1. Yes completely (Y)	1383/1957	70.7	127/161	78.9	1510/2118	71.3
2. Yes to some extent (YS)	307/1957	15.7	21/161	13.0	328/2118	15.5
3. No (N)	221/1957	11.3	10/161	6.2	231/2118	10.9
4. Don't know/cant remember (NK)	46/1957	2.3	3/161	1.9	49/2118	2.3
<b>G7 Did a member of staff tell you about any danger signals you should watch out for after you went home?</b>						
1. Yes completely (Y)	674/2019	33.4	88/167	52.7	762/2186	34.9
2. Yes to some extent (YS)	440/2019	21.8	35/167	21.0	475/2186	21.7
3. No (N)	608/2019	30.1	22/167	13.2	630/2186	28.8
4. Not necessary (NK)	297/2019	14.7	22/167	13.2	319/2186	14.6
<b>G8 Did hospital staff take your family or home situation into account when planning your discharge?</b>						
1. Yes completely (Y)	724/2021	35.8	61/167	36.5	785/2188	35.9
2. Yes to some extent (YS)	330/2021	16.3	25/167	15.0	355/2188	16.2
3. No (N)	334/2021	16.5	22/167	13.2	356/2188	16.3
4. Not necessary (NK)	551/2021	27.3	50/167	30.0	601/2188	27.5
5. Don't know/cant remember (NK)	82/2021	4.1	9/167	5.4	91/2188	4.2
<b>G9 Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?</b>						
1. Yes definitely (Y)	515/2016	25.5	123/167	73.6	638/2183	29.2
2. Yes to some extent (YS)	393/2016	19.5	34/167	20.4	427/2183	19.6
3. No (N)	523/2016	25.9	5/167	3.0	528/2183	24.2
4. No friends or family involved (NI)	200/2016	9.9	2/167	1.2	202/2183	9.2
5. Friends family did not want or need info (NF)	385/2016	19.1	3/167	1.8	388/2183	17.8
<b>G10 Do you feel your received enough info from the hospital on how to manage your condition after discharge?</b>						
1. Yes definitely (Y)	895/2020	44.3	114/167	68.3	1009/2187	46.1
2. Yes to some extent (YS)	603/2020	29.8	44/167	26.3	647/2187	29.6
3. No (N)	342/2020	16.9	5/167	3.0	347/2187	15.9
4. Didn't need help managing condition (NN)	180/2020	8.9	4/167	2.4	184/2187	8.4
<b>G11 Did you receive copies of letters sent between hospital doctors and your family doctor (GP)</b>						
1. Yes I received copies (Y)	1108/2018	54.9	132/166	79.5	1240/2184	56.8
2. No I didn't receive copies (N)	780/2018	38.6	20/166	12.0	800/2184	36.6
3. Not sure/don't know (NK)	130/2018	6.4	14/166	8.4	144/2184	6.6

	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
	n	%	n	%	n	%
<b>Sec H - Overall</b>						
H1 Overall, did you feel you were treated with respect and dignity while you were in hospital?						
1. Yes always (Y)	1414/2016	70.1	135/167	80.8	1549/2183	71.0
2. Yes sometimes (S)	526/2016	26.1	29/167	17.4	555/2183	25.4
3. No (N)	76/2016	3.8	3/167	1.8	79/2183	3.6
H2 How would you rate how well the doctors and nurses worked together?						
1. Excellent (E)	600/2014	29.8	76/165	46.1	676/2179	31.0
2. Very good (VG)	793/2014	39.4	61/165	37.0	854/2179	39.2
3. Good (G)	384/2014	19.1	18/165	10.9	402/2179	18.4
4. Fair (F)	173/2014	8.6	9/165	5.4	182/2179	9.3
5. Poor (P)	64/2014	3.2	1/165	0.6	65/2179	3.0
H3 Overall, were you treated with kindness and understanding while you were in the hospital?						
1. Yes all of the time (Y)	1329/2017	65.9	134/165	81.2	1463/2182	67.0
2. Yes some of the time (S)	633/2017	31.4	28/165	17.0	661/2182	30.3
3. No (N)	55/2017	2.7	3/165	1.8	58/2182	2.7
H4 Overall how would you rate the care received?						
1. Excellent (E)	780/2016	38.7	94/165	57.0	874/2181	40.1
2. Very good (VG)	762/2016	37.8	52/165	31.5	814/2181	37.3
3. Good (G)	275/2016	13.6	14/165	8.5	289/2181	13.2
4. Fair (F)	141/2016	7.0	5/165	3.0	146/2181	6.7
5. Poor (P)	58/2016	2.9	0/165	0	58/2181	2.7
H5 Would you recommend this hospital to your family and friends?						
1. Yes definitely (Y)	1197/2009	59.6	135/165	81.8	1332/2174	61.3
2. Yes probably (P)	617/2009	30.7	26/165	15.8	643/2174	29.6
3. No (N)	195/2009	9.7	4/165	2.4	199/2174	9.1
H6 During your hospital stay, were you ever asked to give your views on the quality of your care?						
1. Yes (Y)	346/2024	17.1	27/165	16.4	373/2189	17.0
2. No (N)	1511/2024	74.6	112/165	67.9	1623/2189	74.1
3. Don't know/cant remember (NK)	167/2024	8.2	26/165	15.8	193/2189	8.8

	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
	n	%	n	%	n	%
<b>Section J - About you</b>						
J1 Are you male or female?						
1. Male (M)	870/2028	42.9	97/167	58.1	967/2195	44.0
2. Female (F)	1158/2028	57.1	70/167	41.9	1228/2195	55.9
J2 What was your year of birth? (shown as age)						
Median	45.5		13			
IQR	(31:60)		(11:15)			
J3 How old were you when you left full-time education?						
1. 16 years or less (<=16)	1019/2014	50.6	6/163	3.7	1025/2177	47.1
2. 17 or 18years (17-18)	479/2014	23.8	2/163	1.2	481/2177	22.1
3. 19years or over (>=19)	424/2014	21.0	2/163	1.2	426/2177	19.6
4. Still in full-time education (IE)	92/2014	4.6	153/163	93.9	245/2177	11.2

	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
<b>Section J continued - Your own health state today</b>	n	%	n	%	n	%
<b>J4 Mobility</b>						
1. No problems in walked about (NP)	1411/2016	70.0	130/165	78.8	1541/2181	70.7
2. Some problems walking about (SP)	601/2016	29.8	35/165	21.2	636/2181	29.2
3. Confined to bed (CB)	4/2016	0.2	0/165	0	4/2181	0.2
<b>J5 Self-care</b>						
1.No problems with self care (NP)	1741/2018	86.3	142/165	86.1	1883/2183	86.3
2. Some problems washing or dressing myself (SP)	266/2018	13.2	22/165	13.3	288/2183	13.2
3. Unable to wash or dress myself (UD)	11/2018	0.5	1/165	0.6	12/2183	0.5
<b>J6 Usual activities</b>						
1. No problems performing usual activities NP)	947/2009	47.1	89/167	53.3	1036/2176	47.6
2. Some problems usual activities (SP)	909/2009	45.2	74/167	44.3	983/2176	45.2
3. Unable to perform usual activities (UP)	153/2009	7.6	4/167	2.4	157/2176	7.2
<b>J7 Pain / Discomfort</b>						
1. No problems with pain (NP)	803/2009	40.0	84/165	50.9	887/2174	40.8
2. Moderate pain/discomfort (MP)	1072/2009	53.4	75/165	45.4	1147/2174	52.8
3. Extreme pain/discomfort (EP)	134/2009	6.7	6/165	3.6	140/2174	6.4
<b>J8 Anxiety / Depression</b>						
1. Not anxious or depressed (NA)	1235/2009	61.5	123/166	74.1	1358/2175	62.4
2. Moderately anxious / depressed (SA)	693/2009	34.5	38/166	22.9	731/2175	33.6
3. Extremely anxious / depressed (EA)	81/2009	4.0	5/166	3.0	86/2175	3.9
<b>J9 Do you have any of the following long-standing conditions in addition to IBD? Where the response was 'Yes'</b>						
1. Deafness	100/1974	5.1	2/164	1.2	102/2138	4.8
2. Blindness	33/1974	1.7	0/164	0	33/2138	1.5
3. Physical condition	320/1974	16.2	11/164	6.7	331/2138	15.5
4. Learning disability	19/1974	1.0	6/164	3.7	25/2138	1.2
5. Mental health condition	68/1974	3.4	4/164	2.4	72/2138	3.4
6. Other eg epilepsy, cancer, HIV, diabetes	248/1974	12.6	9/164	5.5	257/2138	12.0
7. No	1367/1974	69.2	136/164	82.9	1503/2138	70.3

	Adult respondents		Paediatric respondents		Combined 'IBD' respondents	
<b>Sec K - Who completed this questionnaire</b>	n	%	n	%	n	%
<b>K1 Tick option describing who completed this questionnaire</b>						
1. Completed myself aged 12 or over (P)	2010/2025	99.3	114/167	68.3	2124/2192	96.9
2. Parent/Guardian/carer completed for child aged under 12 (A)	15/2025	0.7	53/167	31.7	68/2192	3.1

## Appendix C: Methodology and sample

### Methods

All participating sites (198 adult / 23 paediatric) were asked identify and audit 20 consecutive UC admissions and 20 consecutive CD admissions from 1st September 2010 to 31st August 2011. All patients must have been admitted to hospital with a primary diagnosis of UC or CD as identified using an ICD-10 or OPCS code and must have remained as an inpatient for greater than 24 hours, to exclude those patients admitted for scoping only. For each complete audited admission entered to the UK IBD audit web tool, the site generated a questionnaire that was sent to the patient, providing the data set used for the IBD inpatient experience questionnaire report in the UK and another that was posted to the General Practitioner (GP), providing the dataset used within the primary care questionnaire report. Each site was provided with freepost envelopes to allow and encourage both patients and GP's to return their questionnaires to the UK IBD audit team at the RCP, alternatively the option was available to allow for the individual to enter their own data directly with the provision of a web link to the UK IBD audit web tool.

Each questionnaire was allocated a unique reference number by the UK IBD audit web tool, allowing for a method of linking back each questionnaire response to the relevant admission entered as part of the clinical audit. For the first time in the UK, this has enabled analysis to include cross-referencing of organisational, clinical, inpatient experience and primary care IBD audit data across the UK while protecting and ensuring patient anonymity at all times.

### Datasets and standards used in the UK IBD audit inpatient questionnaire process

The questionnaires were based upon the core dataset developed by the Picker Institute Europe for the National Inpatient Survey 2009. The UK IBD audit steering group added less than 5 additional IBD-specific questions to this dataset.

### Data collection tool

The web 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 unique reference codes and personalised passwords that were created by the individual entering the data. Data could be saved during, as well as at the end of an input session.

### Recruitment

For the process undertaken to recruit sites to the UK IBD audit rounds please refer to the appropriate reports at: <http://www.rcplondon.ac.uk/resources/inflammatory-bowel-disease-audit>.

Each site was requested to generate and forward on the relevant information to each of the patients that they included as part of their clinical audit data set. Sites were instructed to use their local knowledge of each patient to decide whether participation in the questionnaire element was appropriate. Covering letters from Crohn's and Colitis UK were printed with each questionnaire, providing the reader with both the rationale for this element of the audit and contact information (email addresses and telephone numbers) from which further information about the UK IBD audit was available and any queries could be addressed.

### Inclusion and exclusion criteria

To be included in the inpatient experience questionnaire report analysis returned questionnaires had to be complete and have a unique cross-reference code that could link them back to an admission that had been entered in the 3rd round UK IBD clinical audit.

### Audit governance

The UK IBD audit 3rd round is a collaborative partnership between gastroenterologists (the British Society of Gastroenterology), Colorectal Surgeons (the Association of Coloproctology of Great Britain and Ireland), Patients (Crohn's and Colitis UK), Physicians (the Royal College of Physicians of London) together

**Report of the results for the national questionnaire of inflammatory bowel disease inpatient experience in the UK**  
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with Paediatric gastroenterologists (The British Society of Paediatric Gastroenterology, Hepatology and Nutrition).

This Inpatient Experience Questionnaire report follows the publication by the UK IBD audit steering group of the national organisational audit reports on adult and paediatric IBD Services in the UK reports in May 2011 and the subsequent national clinical audit reports of adult and paediatric IBD inpatient care in the UK in February 2012. These publications enable sites to benchmark both their provision of IBD service and inpatient care against national standards, and also to identify areas of improvement and monitor change from the previous round in 2008.

The audit is commissioned and funded by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) with additional funding from Healthcare Improvement Scotland. The audit is co-ordinated by the Clinical Effectiveness and Evaluation unit (CEEu) of the Royal College of Physicians of London. Each hospital identified an overall clinical lead that 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 multidisciplinary UK IBD audit steering group 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)

## Appendix D: Glossary / Abbreviations

<b>Abbreviation</b>	<b>Full title</b>
5ASA	5-Aminosalicylic acid
ACPGBI	Association of Coloproctology of Great Britain and Ireland
Anti TNF $\square$	Anti-Tumour Necrosis Factor Alpha
ASA Status	American Society of Anaesthesiologists Status
BPM	Beat Per Minute
BSG	British Society for Gastroenterology
BSPGHAN	British Society for Paediatric Gastroenterology Hepatology and Nutrition
CD	Crohn's Disease
CDT	Clostridium Difficile Toxin
CEEU	Clinical Effectiveness and Evaluation Unit
CQC	Care Quality Commission
CRP	C-Reactive Protein
$^{\circ}$ C	Degrees Celsius
F2	Foundation Doctor-Year 2
GP	General Practitioner
HQIP	Health Quality Improvement Partnership
IBD	Inflammatory Bowel Disease
IBDQIP	Inflammatory Bowel Disease-Quality Improvement Project
IQR	Inter-Quartile Range
MG/DAY	Milligrams per Day
NCAPOP	National Clinical Audit and Patient Outcomes Programme
NICE	National Institute for Health and Clinical Excellence
NSF	National Service Framework
RCN	Royal College of Nursing
RCP	Royal College of Physicians
SG	Steering Group
SHO	Senior House Officer
SSC	Standard Stool Culture
UC	Ulcerative Colitis
UK	United Kingdom

## Appendix E: Members of the UK IBD audit steering group

### 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 dietician, 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  
Dr John O'Malley, clinical director, All Day Health Centre, Arrowe Park Hospital  
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  
Ms Allison Nightingale, IBD clinical nurse specialist, Addenbrooke's Hospital  
Royal College of Physicians  
Ms Rhona Buckingham, manager, Clinical Effectiveness and Evaluation Unit  
Royal College of Physicians  
Mr Calvin Down, project manager, UK IBD audit  
Royal College of Physicians  
Ms Jane Ingham, director of clinical standards  
Royal College of Physicians  
Miss Aimee Protheroe, project coordinator, UK IBD audit

Royal College of Physicians

Dr Jonathan Potter, clinical director, Clinical Effectiveness and Evaluation Unit (*Retired May 2011*)

Royal College of Physicians

Dr Kevin Stewart, clinical director, Clinical Effectiveness and Evaluation Unit (*in post from August 2011*)

Royal College of Physicians

Professor John Williams, consultant gastroenterologist, Abertawe Bro Morgannwg University Health Board & director of Health Informatics Unit, RCP

Royal Pharmaceutical Society of Great Britain

Ms Anja St. Clair-Jones, lead pharmacist surgery and digestive diseases, Royal Sussex County Hospital



## Appendix F: UK IBD audit 3rd round clinical audit participating sites

Each of the sites listed below contributed to the 2010 round of the UK IBD audit, submitting one or more 'cases' (details of an admission for IBD) for inclusion. Inpatient Questionnaires were sent out by these sites after a case had been entered onto the UK IBD audit web tool.

### Paediatric sites

Addenbrooke's Hospital (Paediatric Gastroenterology unit)  
Alder Hey Children's Hospital  
Barts and The London Children's Hospital  
Birmingham Children's Hospital  
Bristol Royal Hospital for Sick Children  
Children's Services, Chelsea and Westminster Hospital  
Department of Child Health, University Hospital of Wales  
Great Ormond St Hospital, London  
Leeds General Infirmary (Paediatric Gastroenterology Unit)  
Leicester Royal Infirmary Children's Hospital  
Morrison Hospital (Paediatric Gastroenterology)  
North-East Scotland Paediatric Gastroenterology Network (Royal Aberdeen Children's Hospital, Ninewells Hospital and Raigmore Hospital combined)  
Nottingham Children's Hospital  
Oxford Children's Hospital  
Royal Belfast Hospital for Sick Children  
Royal Free Hospital (Paediatric Gastroenterology Unit)  
Royal Hospital for Sick Children, Edinburgh  
Royal Manchester Children's Hospital  
Royal Victoria Infirmary Children's Services  
Sheffield Children's Hospital  
Southampton Children's Hospital  
St George's Hospital (Paediatric Gastroenterology unit)  
Yorkhill Children's Hospital, Glasgow

### Adult sites

Aberdeen Royal Infirmary  
Addenbrooke's Hospital  
Airedale General Hospital  
Altnagelvin Area Hospital  
Antrim Area Hospital  
Arrowe Park Hospital  
Barnet General Hospital  
Barnsley District General Hospital  
Basildon Hospital  
Bedford Hospital  
Belfast City Hospital  
Blackpool Victoria Hospital  
Borders General Hospital  
Bradford Royal Infirmary  
Brighton and Sussex University Hospitals NHS Trust (Royal Sussex County & Princess Royal Hospitals Combined)  
Bristol Royal Infirmary  
Bronglais General Hospital  
Broomfield Hospital

Caerphilly District Miner's Hospital  
Calderdale & Huddersfield NHS Foundation Trust (Huddersfield Royal Infirmary and Calderdale Hospital Combined)  
Causeway Hospital  
Central Middlesex Hospital  
Chelsea & Westminster Hospital  
Chesterfield Royal Hospital  
Colchester General Hospital  
Conquest Hospital  
Countess of Chester Hospital  
County Durham & Darlington NHS Foundation Trust (Darlington Memorial Hospital and Bishop Auckland Hospital Combined)  
Craigavon Area Hospital  
Crosshouse Hospital  
Cumberland Infirmary  
Daisy Hill Hospital  
Darent Valley Hospital  
Derriford Hospital  
Dewsbury & District Hospital  
Diana, Princess of Wales Hospital  
Dorset County Hospital  
Dumfries & Galloway Royal Infirmary  
Ealing Hospital  
East and North Hertfordshire NHS Trust (Lister Hospital & Queen Elizabeth II Hospital Combined)  
East Lancashire Hospitals Trust (Royal Blackburn Hospital and Burnley District General Hospital Combined)  
East Surrey Hospital  
Eastbourne District General Hospital  
Epsom General Hospital  
Fairfield General Hospital  
Freeman Hospital  
Friarage Hospital  
Frimley Park Hospital  
Furness General Hospital  
George Eliot Hospital  
Glan Clwyd Hospital  
Glasgow Royal Infirmary  
Gloucestershire Hospitals NHS Foundation Trust (Gloucestershire Royal and Cheltenham General Combined)  
Good Hope Hospital  
Great Western Hospital  
Guy's & St Thomas' NHS Foundation Trust (Guy's & St Thomas' Hospitals Combined)  
Hairmyres Hospital  
Harrogate District Hospital  
Heart of England NHS Foundation Trust (Birmingham Heartlands Hospital and Solihull Hospital)  
Hereford County Hospital  
Hillingdon Hospital  
Hinchingsbrooke Hospital  
Homerton University Hospital  
Hull and East Yorkshire NHS Trust (Hull Royal Infirmary and Castle Hill Hospitals Combined)  
Imperial College Healthcare NHS Trust (Charing Cross, Hammersmith and St Mary's Hospitals)

Combined)  
Ipswich Hospital  
James Cook University Hospital  
James Paget Hospital  
Jersey General Hospital  
John Radcliffe Hospital  
Kent & Canterbury Hospital  
Kettering General Hospital  
King George Hospital  
King's College Hospital  
Kingston Hospital  
Lagan Valley Hospital  
Lancashire Teaching Hospital NHS Foundation Trust (Chorley District General Hospital & Royal Preston Hospital Combined)  
Leeds Teaching Hospitals NHS Trust (Leeds General Infirmary & St James's Hospital Combined)  
Lincoln County Hospital  
Luton & Dunstable Hospital  
Macclesfield District General Hospital  
Maidstone Hospital  
Manchester Royal Infirmary  
Mater Hospital  
Mayday Hospital  
Medway Maritime Hospital  
Mid Staffordshire NHS Foundation Trust (Staffordshire General Hospital & Cannock Chase Hospital Combined)  
Milton Keynes Hospital  
Monklands Hospital  
Morrison Hospital  
Musgrove Park Hospital  
Neath Port Talbot Hospital  
Nevill Hall Hospital  
New Cross Hospital  
Newham University Hospital  
Ninewells Hospital  
Norfolk & Norwich University Hospital  
North Bristol NHS Trust (Frenchay and Southmead Hospitals Combined)  
North Devon District Hospital  
North Hampshire Hospital  
North Manchester General Hospital  
North Middlesex University Hospital  
North Tyneside General Hospital  
North West London Hospitals NHS Trust (St Mark's & Northwick Park Hospitals Combined)  
Northampton General Hospital  
Nottingham University Hospital NHS trust (Queen's Medical Centre & Nottingham City Hospital Combined)  
Peterborough City Hospital (prev Peterborough district hosp until Nov 2010)  
Pilgrim Hospital  
Pinderfields General Hospital  
Poole General Hospital  
Prince Charles Hospital  
Princess Alexandra Hospital, Harlow

Princess of Wales Hospital  
Queen Alexandra Hospital  
Queen Elizabeth Hospital  
Queen Elizabeth Hospital, Gateshead  
Queen Elizabeth Hospital, Woolwich  
Queens Hospital  
Queen's Hospital, Burton  
Rotherham Hospital  
Royal Albert Edward Infirmary  
Royal Berkshire Hospital  
Royal Bolton Hospital  
Royal Bournemouth Hospital  
Royal Cornwall Hospital  
Royal Derby Hospital  
Royal Devon & Exeter Hospital  
Royal Free Hospital  
Royal Glamorgan Hospital  
Royal Gwent Hospital  
Royal Hampshire County Hospital  
Royal Liverpool University Hospital  
Royal London Hospital  
Royal Oldham Hospital  
Royal Surrey County Hospital  
Royal United Hospital, Bath  
Royal Victoria Hospital  
Royal Victoria Infirmary, Newcastle  
Russells Hall Hospital  
Salford Royal Hospital  
Salisbury District General Hospital  
Sandwell and West Birmingham Hospitals NHS Trust (City Hospital and Sandwell Hospital Combined)  
Scarborough General Hospital  
Scunthorpe General Hospital  
Sheffield Teaching Hospitals NHS Foundation Trust (Royal Hallamshire Hospital & Northern General Hospital Combined)  
Sherwood Forest Hospitals NHS Foundation Trust (King's Mill Hospital & Newark Hospital Combined)  
Shrewsbury & Telford Hospital NHS Trust (Royal Shrewsbury Hospital & Princess Royal Hospital, Telford Combined)  
South Tyneside District Hospital  
Southampton University Hospitals NHS Trust (Southampton General Hospital & Royal South Hants Hospital Combined)  
Southport & Formby District General Hospital  
St George's Hospital  
St Helier Hospital  
St Mary's Hospital  
St Richard's Hospital  
Stepping Hill Hospital  
Stirling Royal Infirmary  
Stoke Mandeville Hospital  
Sunderland Royal Hospital  
Tameside General Hospital  
The Lewisham Hospital

The Tunbridge Wells Hospital  
Torbay Hospital  
Ulster Hospital  
University College Hospital  
University Hospital Birmingham NHS Foundation Trust (Queen Elizabeth Hospital, Birmingham & Selly Oak Hospital Combined)  
University Hospital Llandough  
University Hospital of Hartlepool  
University Hospital of North Durham  
University Hospital of North Staffordshire  
University Hospital of North Tees  
University Hospital of Wales  
University Hospital, Aintree  
University Hospitals Coventry & Warwickshire NHS Trust  
University Hospitals of Leicester NHS Trust (Leicester Royal Infirmary and Leicester General Combined)  
University Hospitals of Morecombe Bay NHS Trust (Royal Lancaster Infirmary & Westmorland General Hospital Combined)  
Walsall Manor Hospital  
Warrington District General Hospital  
Warwick Hospital  
West Cumberland Hospital  
West Hertfordshire Hospitals NHS Trust (Watford General Hospital & Hemel Hempstead General Hospital Combined)  
West Middlesex Hospital  
West Suffolk Hospital  
Western General Hospital  
Western Sussex Hospital Trust (Worthing and Southlands combined)  
Weston General Hospital  
Whipps Cross University Hospital  
Whiston Hospital  
Whittington Hospital  
William Harvey Hospital  
Wishaw General Hospital  
Withybush General Hospital  
Worcestershire Acute Hospitals NHS Trust (Worcestershire Royal Hospital & Alexandra Hospital Combined)  
Wrexham Maelor Hospital  
Wycombe Hospital  
Wythenshawe Hospital  
Yeovil District Hospital  
York Hospital  
Ysbyty Gwynedd

## Appendix G: References

1. 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.
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