

## ORIGINAL ARTICLE

# Variations in initial assessment and management of inflammatory bowel disease across Great Britain and Ireland

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**Background:** There are no published data from Great Britain and Ireland detailing the initial management of children with inflammatory bowel disease (IBD).

**Aims:** To prospectively record the initial investigation and treatment of children aged less than 16 years with newly diagnosed IBD.

**Methods:** For 13 months, between June 1998 and June 1999, 3247 paediatricians, adult gastroenterologists, and surgeons across the UK and Ireland were prospectively surveyed each month and asked to report every newly diagnosed case of childhood IBD. Reporters subsequently completed a postal questionnaire about each case.

**Results:** A total of 739 new IBD cases were reported from 172 institutions. Significant variations were observed in the investigation and treatment of these cases, when examined by number of cases reported per institution, or by the specialists providing care. There were wide regional variations in the proportion of children having access to paediatric gastroenterology services. Overall, one third of children received care from an adult service, and a tenth care exclusively from an adult gastroenterologist. Children with Crohn's disease who had some or all of their care from adult services were more likely to receive systemic steroids and less likely to receive dietary therapy; those with ulcerative colitis were more likely to receive rectal steroids and to have surgery. Height and weight were also less likely to be recorded in those whose care involved adult services.

**Conclusion:** Current specialist provision, and initial investigation and treatment of IBD, is heterogeneous. Optimisation of care is likely to be achieved by greater access to specialist paediatric gastroenterology services for all those with suspected IBD.

Inflammatory bowel disease (IBD) in those aged less than 16 years, presents at a median age of 12–13 years.<sup>1–2</sup> Studies suggest that the incidence has probably increased.<sup>1–4</sup> Ideally children, no matter where they live, should receive the same high standard of care, including access to appropriate specialists. Anecdotally however there appears to be considerable variation in the nature of the specialist care provided across Great Britain and Ireland, with much care being provided by adult services. This may be of relevance, because as well as important psychological and family issues, childhood onset IBD is characterised by physiological and pathological differences from adult onset disease. In particular, the disease may be more extensive, with the potential for significant growth impairment resulting in short adult stature.<sup>5–9</sup>

Modern guidelines on the provision of tertiary services for children and adolescents emphasise the importance of care being provided in an age appropriate setting.<sup>10</sup> In order to learn more about the current provision of services for children with IBD, we undertook a prospective survey of newly diagnosed cases across Great Britain and Ireland.<sup>1</sup> This paper describes significant variation in the specialists providing care, variation in initial investigations undertaken, and variation in the treatment given to new cases of childhood IBD.

## METHODS

For 13 months between 1 June 1998 and 30 June 1999 new cases of childhood inflammatory bowel disease (IBD) were prospectively identified in Great Britain and Ireland as previously described.<sup>1</sup> This survey aimed to be as

comprehensive as possible by collecting data on all known incident cases of IBD. A total of 1852 paediatric specialists were surveyed through the well validated British Paediatric Surveillance Unit (BPSU) of the Royal College of Paediatrics and Child Health,<sup>11</sup> and through the Paediatric Register of Inflammatory Bowel Disease (PRIBD), set up in 1997 to record data from 53 UK centres. A total of 1395 adult gastroenterologists and surgeons were prospectively surveyed through the newly established British Society of Gastroenterology Research Unit (BSGRU).

Participants were mailed a surveillance card each month to report new cases of IBD diagnosed in individuals aged less than 20 years in the preceding month. If a case was reported, a detailed or "full" postal questionnaire was then sent out by the BPSU to gather further information about each case. The BSGRU sent out an initial "abbreviated" questionnaire to establish the diagnosis and then followed this up with a longer secondary questionnaire, which contained fewer fields than the "full" BPSU questionnaire. Some paediatricians preferred to report details only to the Paediatric Register of Inflammatory Bowel Disease (PRIBD). Cases were reported to the PRIBD on a monthly basis using an abbreviated

**Abbreviations:** 5-ASA, 5-aminosalicylate; BPSU, British Paediatric Surveillance Unit; BSGRU, British Society of Gastroenterology Research Unit; CD, Crohn's disease; CI, confidence interval; IBD, inflammatory bowel disease; IC, indeterminate colitis; OGD, oesophagoduodenoscopy; PRIBD, Paediatric Register of Inflammatory Bowel Disease; RR, relative risk; UC, ulcerative colitis

questionnaire with similar, though fewer, fields to the full BPSU questionnaire. Although most centres reported to both studies we were aware that a few reporters did not, and we therefore accessed the PRIBD database at the end of the BPSU and BSGRU surveys. Details of height and weight were not collected for those cases identified via the PRIBD.

England is the most populous country in the United Kingdom. The BPSU divides it into 14 regions corresponding to the regional health authorities prior to the 1994 reorganisation of the National Health Service. In addition we undertook analyses by country—that is, between England, Scotland, Wales, Northern Ireland, and the Republic of Ireland.

## RESULTS

The mean monthly return of reporting cards was 94% in the BPSU survey and 46% in the BSGRU survey.<sup>1</sup> The BPSU, BSGRU, and PRIBD received 972, 641, and 422 reports respectively during the study period. Thirty seven reports were excluded because they were mistaken notifications, 538 were duplicates, 584 confirmed IBD cases were aged over 16.0 years at diagnosis, 61 cases were diagnosed outside the study period, two cases were foreign, 28 reports had a final diagnosis not of IBD, and in 46 instances, despite repeated attempts, follow up of the initial card report was not possible.

There were thus 739 incident IBD cases aged less than 16 years diagnosed between 1 June 1998 and 30 June 1999 in Great Britain and Ireland: 431 Crohn's disease, 11 orofacial granulomatosis, 86 indeterminate colitis, and 211 ulcerative colitis cases. The BPSU, BSGRU, and PRIBD surveys contributed 88%, 8%, and 4% of these cases respectively.

A complete BPSU questionnaire was returned in 83% (615/739) of cases and an "abbreviated" questionnaire in 17% (124/739) of cases, either a partially completed BPSU questionnaire, a BSGRU questionnaire, or a PRIBD questionnaire. From these responses details of the specialists providing care were available in 94% (696/739) of cases and details of treatment in 84% (623/739) of cases. Details of what investigations had been undertaken were available for most children, for example 86% (642/739) of cases had colonoscopy. There were varying and slightly smaller figures for other investigative modalities.

### "Size" of reporting centre

Reports were received from 172 centres. Centres were empirically divided into "small" centres (1–5 reports), "medium" centres (6–10 reports), and "large" centres (>11 reports) depending on the numbers of incident cases reported during the study. A total of 34% (250/739) of cases were reported from "small" centres, 15% (111/739) from "medium" sized centres, and 51% (378/739) from "large" centres.

Thus the majority of centres reported either one or two cases (64%, 110/172). The largest centre reported 43 new cases over 13 months. Twenty seven teaching hospitals reported 53% (391/739) of cases and 145 district general hospitals 47% (348/739) of cases.

There were significant regional variations across England in the proportion of cases reported from small, medium, and large centres (ranges 7–87%, 7–39%, and 3–93% respectively; all  $p < 0.001$ ,  $\chi^2$  test). While some regions appeared to have an obvious "hub" to which nearly all cases were referred, most did not.

### Investigations

A greater proportion of all IBD cases reported from large centres had an oesophagoduodenoscopy (OGD), colonoscopy, or barium follow through and a smaller proportion a barium enema or sigmoidoscopy, compared to those cases reported from small centres (RR 2.74 (95% CI 2.12 to 3.54), RR 1.37

(95% CI 1.24 to 1.51), RR 1.28 (95% CI 1.11 to 1.47), RR 0.51 (95% CI 0.28 to 0.92), and RR 0.45 (95% CI 0.34 to 0.58) respectively, all  $p < 0.001$ ). Cases reported from large centres were less likely to have had "dual investigation" by both colonoscopy and sigmoidoscopy compared to those from small centres (RR 0.68 (95% CI 0.47 to 0.97),  $p = 0.035$ ).

These associations remained significant when small, medium, and large centres were compared.

### Treatment

Cases of Crohn's disease were more likely to be treated with diet and less likely to be treated with systemic steroids in large and medium centres, compared to small centres (fig 1), and were also less likely to receive rectal 5-aminosalicylate (5-ASA) preparations ( $p < 0.01$ ,  $\chi^2$  test). Comparison between large, medium, and small centres showed that the association between size of centre and steroid use remained but that the association for diet did not reach significance (fig 1). In this analysis the association with rectal 5-ASA became non-significant, but that for rectal steroids became significant ( $p = 0.014$ ,  $\chi^2$  test), with the greatest use being reported from small centres.

For cases of ulcerative colitis, significant variations were observed in the use of systemic 5-ASA by centre size, comparing large centres with small centres or large and medium centres with small centres (RR 0.78 (95% CI 0.66 to 0.92),  $p = 0.006$ ; and RR 0.83 (95% CI 0.72 to 0.96),  $p = 0.027$ , respectively).

Rectal steroids were used less for all types of IBD in large centres compared to small centres, and this was particularly so for Crohn's disease (RR 0.44 (95% CI 0.22 to 0.89),  $p = 0.02$ ; and RR 0.14 (95% CI 0.03 to 0.67),  $p < 0.01$ , respectively).

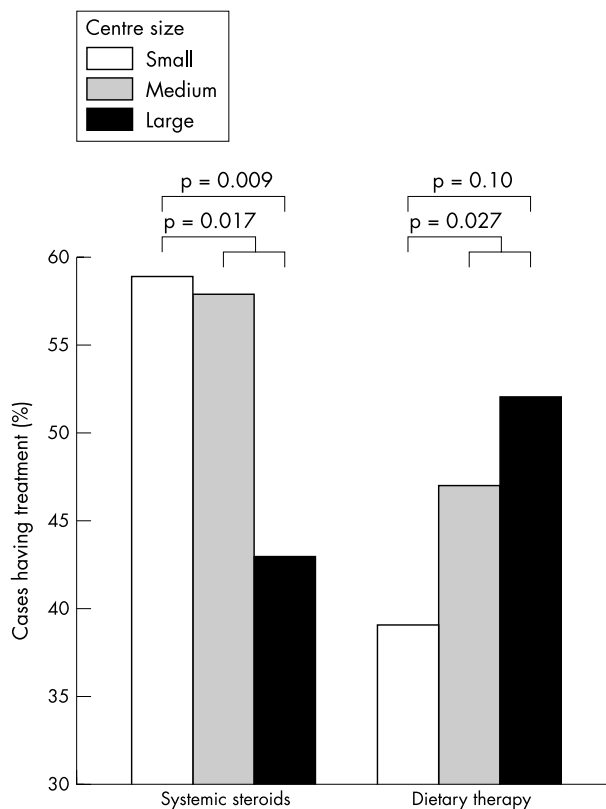


Figure 1 Treatment of Crohn's disease by reporting centre size.

**Table 1** Specialist teams by centre size

Centre size	One specialist				Two specialists			
	Paed GI	Paed	Adult GI	Sur (P)	Paed GI + another	Adult GI + another	Other combinations	3 or more specialists
Small	10	19	58	1	53*	58	18	31
Medium	26	9	5		37	7	10	12
Large	165	1	2		142**	9	2	20

GI, gastroenterologist; Sur (P), paediatric surgeon.

Cases where "adult GI" was the second doctor: \*includes 7 cases, \*\*includes 4 cases.

### Type of specialist

The majority of children received care from more than one type of specialist (table 1). There were significant differences in the composition of the teams providing care, depending on the "size" of the reporting institution (fig 2).

### Involvement of adult services

Thirty per cent (211/696) of children received care from either an adult gastroenterologist or an adult surgeon, and a further 3% (18/696) from both an adult surgeon and an adult gastroenterologist. Thus 33% (229/696) of children had been involved with adult services; their median age was 13.6 years compared to 12.1 years for those whose care had not involved an adult gastroenterologist and/or surgeon ( $p < 0.001$ , Mann-Whitney).

Of those children cared for by adult services, 65 were reported to have been managed solely by an adult gastroenterologist; the median age of this group was greater than that of children whose care was shared with paediatric services (median age 15.0 years versus 13.0 years,  $p < 0.001$ , Mann-Whitney); however, it included two children aged less than 5 years and three aged between 5 and 10 years.

### Investigations

If care had involved an adult gastroenterologist and/or an adult surgeon, children were more likely to have had a sigmoidoscopy or barium enema and less likely to have had a colonoscopy, OGD, or barium follow through (RR 2.07 (95% CI 1.64 to 2.61), RR 2.94 (95% CI 1.71 to 5.07), RR 0.70 (95% CI 0.62 to 0.78), RR 0.35 (95% CI 0.26 to 0.46), RR 0.79 (95% CI 0.68 to 0.91) respectively, all  $p < 0.001$ ; table 2). Conversely if a paediatric gastroenterologist had been involved in initial management, children were more likely

to have had a colonoscopy, OGD, and barium follow through and less likely to have had a sigmoidoscopy or barium enema (RR 1.47 (95% CI 1.30 to 1.66), RR 3.64 (95% CI 2.59 to 5.11), RR 1.29 (95% CI 1.11 to 1.49), RR 0.49 (95% CI 0.39 to 0.61), RR 0.34 (95% CI 0.20 to 0.58) respectively, all  $p < 0.001$ ). The combination of sigmoidoscopy and colonoscopy was more likely to have taken place if care had involved an adult surgeon (RR 2.18 (95% CI 1.30 to 3.63),  $p < 0.01$ ).

### Medical treatment

Children with Crohn's disease whose care involved an adult gastroenterologist were more likely to have received systemic steroids and less likely to have received dietary therapy at diagnosis (RR 2.19 (95% CI 1.34 to 3.57),  $p = 0.001$ ; and RR 0.73 (95% CI 0.51 to 1.03)  $p = 0.047$ , respectively); those with ulcerative colitis were more likely to have received rectal steroids, and to have been treated with a low fibre or restriction diet (RR 1.89 (95% CI 1.14 to 3.16),  $p = 0.02$ ; and RR 4.36 (95% CI 1.29 to 14.75),  $p = 0.01$ , respectively). In contrast, if initial care involved a paediatric gastroenterologist, children with Crohn's disease were less likely to receive systemic steroids (RR 0.84 (95% CI 0.75 to 0.94),  $p = 0.0022$ ), and those with ulcerative colitis were less likely to receive rectal steroids (RR 0.52 (95% CI 0.29 to 0.94),  $p = 0.031$ ).

### Surgery

All four cases of ulcerative colitis that had had surgery were treated by adult services ( $p < 0.01$ , Fisher's exact test).

### Histology

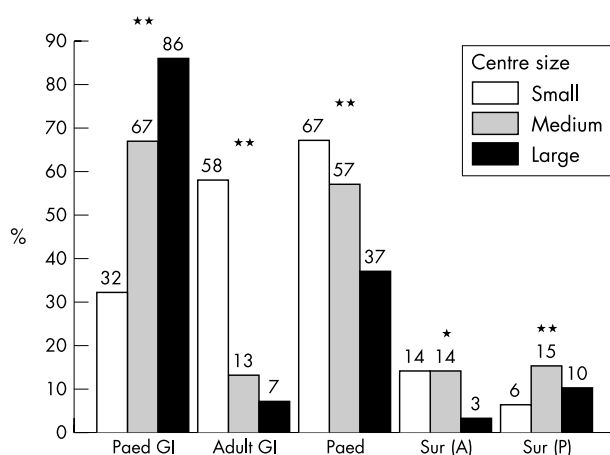
Specimens for histology were reported as not being taken in 29/739 (4%) cases; 24 cases of Crohn's disease, four of ulcerative colitis, and one indeterminate colitis. This was more likely to have occurred if an adult gastroenterologist and/or surgeon had been involved in care (RR 7.16 (95% CI 3.10 to 16.51),  $p < 0.001$ ).

### Height and weight

Height and weight were less likely to have been recorded if care had involved an adult gastroenterologist (RR 0.86 (95% CI 0.78 to 0.96)  $p < 0.01$ ; and RR 0.93 (95% CI 0.86 to 1.01),  $p = 0.047$ ). This was particularly the case if care had been provided solely by an adult gastroenterologist (RR 0.38 (95% CI 0.26 to 0.55); and RR 0.57 (95% CI 0.45 to 0.73), respectively; both  $p < 0.001$ ).

### Country and region

A total of 575 cases were reported from England, 71 from Scotland, 34 from Wales, 16 from Northern Ireland, and 43 from the Republic of Ireland (ROI). There were significant variations between countries in the proportion of children receiving care from a paediatric gastroenterologist, or an adult gastroenterologist and/or surgeon (fig 3), with similar differences between the 14 English regions (ranges 14–92%,  $p < 0.001$ ; and 8–71%,  $p < 0.001$ , respectively,  $\chi^2$  test).



**Figure 2** Specialist involvement by centre size. GI, gastroenterologist; Sur (A), adult surgeon; Sur (P), paediatric surgeon. \* $p < 0.05$ , \*\* $p < 0.001$ ,  $\chi^2$  test.

**Table 2** Initial investigation

	All IBD (%)	CD (%)	IC (%)	UC (%)	
OGD	48	67	42	31	**
BaFTT	65	78	59	38	**
Colonoscopy	82	82	84	78	NS
Barium enema	8	7	6	11	NS
Sigmoidoscopy	30	23	39	41	**
WCC	28	37	25	17	**
Colonoscopy + sigmoidoscopy	16	14	23	20	NS
BaFTT + WCC	16	21	14	5	**

CD, Crohn's disease; IC, indeterminate colitis; UC, ulcerative colitis; OGD, oesophagoduodenoscopy; BaFTT + WCC, barium follow through and radiolabelled white cell scan.

\*\* $p < 0.001$ ,  $\chi^2$  test.

Comparison between the five countries showed significant variations in the proportion of children receiving specific investigations or treatments, with even greater variations between the English regions (data not shown).

### Current treatment practice

The majority of children with Crohn's disease received an oral 5-ASA preparation with no clear "first choice" of systemic steroids or diet for inducing remission (table 3). (A small number of children received both of these therapies.) Polymeric feeds were more commonly used than elemental or "semi" elemental feeds. There was no relation between site of disease activity and use of systemic steroids; however, diet was more likely to have been used if there was disease activity in the terminal ileum, and an oral 5-ASA preparation if there was disease activity in the left colon (RR 1.21 (95% CI 1.05 to 1.40),  $p = 0.008$ ; and RR 1.23 (95% CI 1.02 to 1.48),  $p = 0.022$ , respectively).

Systemic steroids and oral 5-ASA preparations were the mainstay of treatment for indeterminate colitis and ulcerative colitis, although nearly a fifth of children did not receive oral 5-ASA preparations. Polymeric or elemental diet was used in nearly a fifth of children with indeterminate colitis.

### DISCUSSION

This prospective population based survey is the largest such study of childhood inflammatory bowel disease to date and the first to document provision of care across Great Britain and Ireland.<sup>1</sup> The study found considerable variation in care

**Table 3** Initial treatment

	All IBD (%)	CD (%)	IC (%)	UC (%)
Systemic steroids	56	50	56	68
Oral 5-ASA	69	62	81	79
Rectal steroids	9	4	13	20
Rectal 5-ASA	3	2	1	6
Azathioprine	6	5	7	8
Cyclosporin	1	1	1	2
Metronidazole	12	15	14	6
Surgery	3	5		2
Diet	33	47	22	9

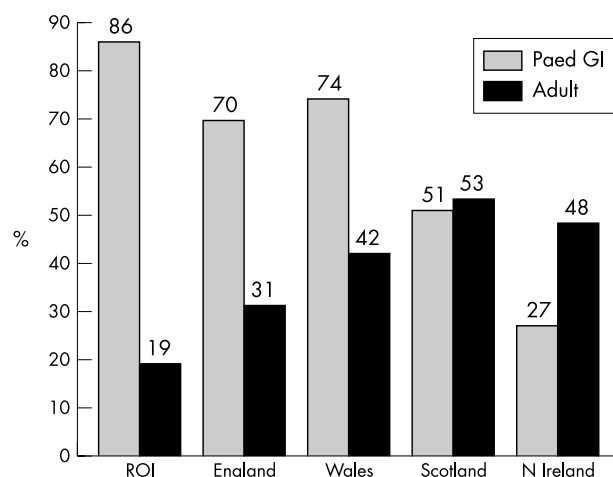
CD, Crohn's disease; IC, indeterminate colitis; UC, ulcerative colitis.

in terms of initial investigations and treatment when examined either by the number of cases reported by an institution or by the type of specialist gastrointestinal input (adult or paediatric gastroenterologist).

At present two thirds of children aged less than 16 years have some input from a paediatric gastroenterologist at diagnosis, but one tenth have their initial management provided solely by an adult gastroenterologist, and a third have some of their care provided by adult services. It is likely that there are differences in the provision of specialist paediatric gastroenterology services in Great Britain and Ireland. This survey was not designed to determine whether the observed regional variation in use of paediatric gastroenterology services was due to lack of provision of such services or failure to refer to them.

Most children (82%) had a colonoscopy at the time of diagnosis; however, nearly one third (30%) had a sigmoidoscopy and 16% both examinations. Sigmoidoscopy was more likely to be undertaken and colonoscopy less likely to be undertaken if care had involved an adult service. It has been shown in children that an incomplete colonoscopy reduces the chances of establishing an histological diagnosis.<sup>16</sup> One possible explanation is resourcing difficulties,<sup>17</sup> although differences in acceptable management practices between adult and paediatric gastroenterologists is also likely.

The greatest variation in treatment was noted for cases of Crohn's disease, with clear differences between adult and paediatric practice. Cases whose management involved an adult gastroenterologist were more likely to receive systemic steroids and less likely to receive dietary therapy. Such differences probably reflect the concern among paediatricians regarding the growth inhibiting effects of steroids, as well as the proven efficacy of enteral feeding in paediatric studies in contrast to the disappointing efficacy in adult studies.<sup>12, 13</sup> The sole use of enemas in children, as noted among those cared for by adult gastroenterologists, may reflect adult practice and be less appropriate because colitis is rarely confined solely to the rectum or left colon in children. Overall this



**Figure 3** Selected specialist involvement by country. Paed GI, paediatric gastroenterologist; adult, adult gastroenterologist and/or adult surgeon; ROI, Republic of Ireland. Variations between countries for Paed GI and Adult, both  $p < 0.001$ ,  $\chi^2$  test.



study also confirms the continuing wide usage of systemic steroids for both childhood Crohn's disease and ulcerative colitis.<sup>14</sup> While a small proportion of children will inevitably require surgery, the finding of a higher rate of surgery among adult services at the onset of disease remains unexplained.

Failure to record growth parameters, particularly for those not presenting to a paediatrician, has been previously identified; this study confirms that this continues to occur.<sup>15</sup>

A recent report commented that a significant minority of childhood IBD cases were inappropriately or inadequately investigated and treated.<sup>18</sup> It is noteworthy that in the current study the majority of units reported only one or two new cases of IBD over a 13 month period. Of the "small" institutions (reporting 1–5 cases), some appeared to have a clear lead clinician reporting all new cases, but in most institutions each report came from a different clinician (data not shown). This suggests that in many, if not the majority, of institutions there is no designated care pathway for the management of childhood IBD.

With the rapid changes in the training and manning of paediatric departments it remains to be determined whether a "hub and spoke" or "managed clinical network" can ensure that children receive high quality care in an age appropriate setting. In a number of paediatric medical and surgical subspecialties, as well as those that cross boundaries, centralisation to specialist care has been recognised to provide optimal care.<sup>19–25</sup> Currently there is no consensus that such centralisation should be applied to gastroenterology services for children.

The key issue arising from this study appears to be how to ensure high quality care for those living some distance from specialist centres with a model that takes into account the number of specialists and journey times of families. The British Society of Paediatric Gastroenterology, Hepatology and Nutrition recommends in its guide for purchasers of children's services that all those with suspected IBD should be managed by a specialist paediatric gastroenterology unit.<sup>26</sup>

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