

Inflammatory bowel disease patient-reported quality assessment should drive service improvement: A national survey of UK IBD units and patients

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Summary

Background & Aims: Healthcare service provision in inflammatory bowel disease (IBD) is often designed to meet targets set by healthcare providers rather than those of patients. It is unclear whether this meets the needs of patients, as assessed by patients themselves. This nationwide study assessed patients' experience of IBD and the healthcare they received, aiming to identify factors in IBD healthcare provision associated with perceived high-quality care.

*Members of the IBD UK Board and/or contributors to the IBD UK Task & Finish Group are listed in Appendix 1.

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Methods: Using the 2019 IBD Standards as a framework, a national benchmarking tool for quality assessment in IBD was developed by IBD UK, comprising a Patient Survey and Service Self-Assessment.

Results: In all, 134 IBD services and 9757 patients were responded. Perceived quality of care was lowest in young adults then increased with age, was higher in males and those >2 years since diagnosis. No hospital services met all the National IBD Standards for recommended workforce numbers. Key metrics associated with patient-reported high-quality care were as follows: identification as a tertiary centre, patient information availability, shared decision-making, rapid response to contact for advice, access to urgent review, joint medical/surgical clinics and access to research (all $p < 0.001$). Higher numbers of IBD nurse specialists in a service was strongly associated with patients receiving regular reviews and having confidence in self-management and reporting high-quality care.

Conclusions: This extensive patient and healthcare provider survey emphasises the importance of aspects of care less often measured by clinicians, such as communication, shared decision-making and provision of information, and demonstrates that IBD nurse specialists are crucial to meeting the needs of people living with IBD.

1 | INTRODUCTION

Ulcerative colitis (UC) and Crohn's disease (CD) are the principal forms of inflammatory bowel disease (IBD).

In the United Kingdom (UK), approximately 500,000 people live with IBD and the incidence and prevalence continue to increase across all age groups.¹⁻³ In the coming decade, it is anticipated that the prevalence of IBD will surpass 1% of the population.² This has the potential to impact service provision and the overall quality of care for patients with IBD. Therefore, it is crucial to define what high-quality IBD care should look like, to define workforce composition, numbers and desirable attributes for optimal service delivery, and to benchmark services against performance indicators to drive improvement in quality of care.

In 2019, the third UK IBD Standards for adults and children were published following extensive patient and healthcare professional consultation and several rounds of Delphi, providing a gold standard against which to benchmark IBD services.⁴ The IBD Standards comprise 59 statements covering seven domains: service design and delivery; pre-diagnosis referral pathways; management of the newly diagnosed patient; flare management including self-management and timely access to specialist advice; surgery including pre-operative and post-operative care; inpatient medical care; and ongoing long-term treatment and monitoring in both secondary and primary care. Importantly, the 2019 IBD Standards were aspirational and were intended to act as a framework to facilitate extensive quality improvement (QI).

Standards for the provision of IBD care have also been developed in many countries, including Australia,⁵ Canada,⁶ New Zealand,⁷ Spain⁸ and USA⁹ highlighting the importance placed internationally on defining the quality of care patients living with IBD should expect.

Although significant emphasis has been placed on meeting these standards of care, it remains unclear whether doing so meets the needs of patients, as assessed by patients themselves, nor is it clear which quality indicators are most important to patients' perceived quality of care, and given the reality of limited resources it is essential to determine which should be prioritised in service delivery.

To date, there has been a paucity of comprehensive and representative patient data to assess and support QI in IBD services. This led to IBD UK, a partnership of 17 national bodies, developing a UK-wide benchmarking tool; comprising a service self-assessment exercise to assess hospitals' IBD workforce provision and perception of the care they deliver, and a patient survey to measure patients' views of how their IBD care matched up to the IBD Standards.

1.1 | Aims

The primary aim of the benchmarking exercise was to provide a detailed assessment of the quality of IBD care in the UK from patients' perspective. The secondary aims were to compare patient-reported experience of care with healthcare-reported service performance data; and to define the most important targets and strategies to facilitate local and national quality improvement.

2 | METHODS

2.1 | IBD UK

IBD UK is a partnership of 17 national bodies: Royal Colleges, professional societies, patient charities (<https://ibduk.org/about-ibd-uk>)

and leading stakeholders in IBD care, with the central aim of providing all patients with consistent, safe, high quality, personalised care independent of age, geography or disease phenotype. Further aims of IBD UK are to encourage healthcare services to recognise areas of high-quality service provision and areas where improvement is necessary. To facilitate this, IBD UK developed a UK-wide benchmarking tool in the form of the IBD Service Self-Assessment (SSA) and a national Patient Survey (PS).

2.2 | IBD service self-assessment

The Service Self-Assessment (SSA) question framework aimed to assess IBD services' structure and workforce provision, and whether services met standards of care laid out in the 2019 IBD Standards.⁴ The SSA was developed by Crohn's & Colitis UK and a working group of IBD UK board members, then piloted by five UK IBD services (Figure 1). Refinements to questions and guidance were made based on feedback.

The final SSA contained a total of 187 questions, 28 of which covered the service's structure and personnel. Included in the SSA were 53 sets of tiered questions to identify the extent to which a Standard was met, where responses could range from A (highest) to D (lowest) quality.

The SSA was open from 1 October 2019 to 31 January 2020. All UK services were invited to participate, were encouraged to complete the survey as a team, and use local audit, database or registry data where available. Promotion was through IBD UK member organisations via digital channels and relevant events. The full SSA is presented in Appendix S1.

2.3 | IBD patient survey

The content of the Patient Survey (PS) was based on the 2019 IBD Standards⁴ and survey questions were developed through extensive consultation with people affected by IBD through Crohn's & Colitis UK, Crohn's and Colitis in Childhood Research Association (CICRA) and the Ileostomy & Internal Pouch Association, as well as IBD UK board members (Figure 1). Patients (through Crohn's & Colitis UK) were consulted at all stages of development of both surveys and through data analysis and dissemination. Questions were tested in two focus groups of six people with IBD, telephone interviews and were adjusted to ensure clarity. Survey questions followed a hierarchical logic with further sub-questions only if patients experienced certain aspects of care (e.g. diagnosis questions if diagnosed in the past 2 years, in-patient questions if admitted in the past year, and transition if moved from paediatric to adult care). The number of questions for each participant therefore ranged from 66 to a maximum of 98.

The PS focused on patient experience in the preceding 12 months, and experience regarding diagnosis if within the last 2 years. Most were multi-option questions with only two open-ended comments questions (see qualitative data methodology below). In all, 16 questions covered patient demographics and their IBD.

The PS was conducted from 8 July 2019 to 22 November 2019 and was widely promoted via printed flyers available in IBD clinics, emails, social media and the IBD UK website. Most completed the survey online, but hard copies and translations were available on request.

Patient demographic data were compared to other large UK datasets (The Health Improvement Network (THIN), from which the King et al epidemiology study was drawn ($n = 63,953$)³; Lothian IBD epidemiology study (Jones et al $n = 10,499$)²; UK corticosteroid use in IBD survey (Selinger $n = 1176$)¹⁰; Office for National Statistics England and Wales population estimates 2014–2016 (ONS $n = 57$ million)¹¹ and IBD BioResource ($n = 34,766$)¹² to determine representativeness of patients completing the PS. The full PS is presented in Appendix S2.

2.4 | Visual dashboards

A visual summary was produced to give an overview of service quality from a patient and IBD team perspective at different points in the patient journey (diagnosis, treatment, ongoing care) and overall service provision. Each area was broken into themes (access, patient empowerment, quality and coordinated care). Methodology is shown in Appendix S3.

2.5 | Workforce provision

The whole time equivalent (WTE) workforce numbers for each staff group (such as gastroenterologists or IBD nurse specialists) per 250,000 population were used in conjunction with the general population that hospital IBD service covered to calculate whether a service met the optimal recommended 2019 IBD Standards for each professional group (1.0 WTE is 10×3.5 h sessions per week).⁴

2.6 | Quantitative data analysis plan

All quantitative statistical analysis was undertaken using SPSS Software v26 (IBM). Data were presented in a descriptive manner using median and range or interquartile range. Adult and paediatric patients were analysed separately. Adult data only are presented in detail in this paper.

A chi-squared test for independence was used to assess categorical (nominal or ordinal) data between the independent groups. For 5-point Likert scales (from strongly disagree to strongly agree) and other ordinal data, the chi-squared test for trend (linear-by-linear test association) was applied. If expected cell counts were <5 in tables larger than 2×2 , then categories were grouped. We tested internal consistency by comparing PS questions covering very similar areas using the chi-square test, and did the same for SSA questions. PS and SSA responses were also compared. The PS question 'Overall, how would you rate the quality of your Crohn's or Colitis

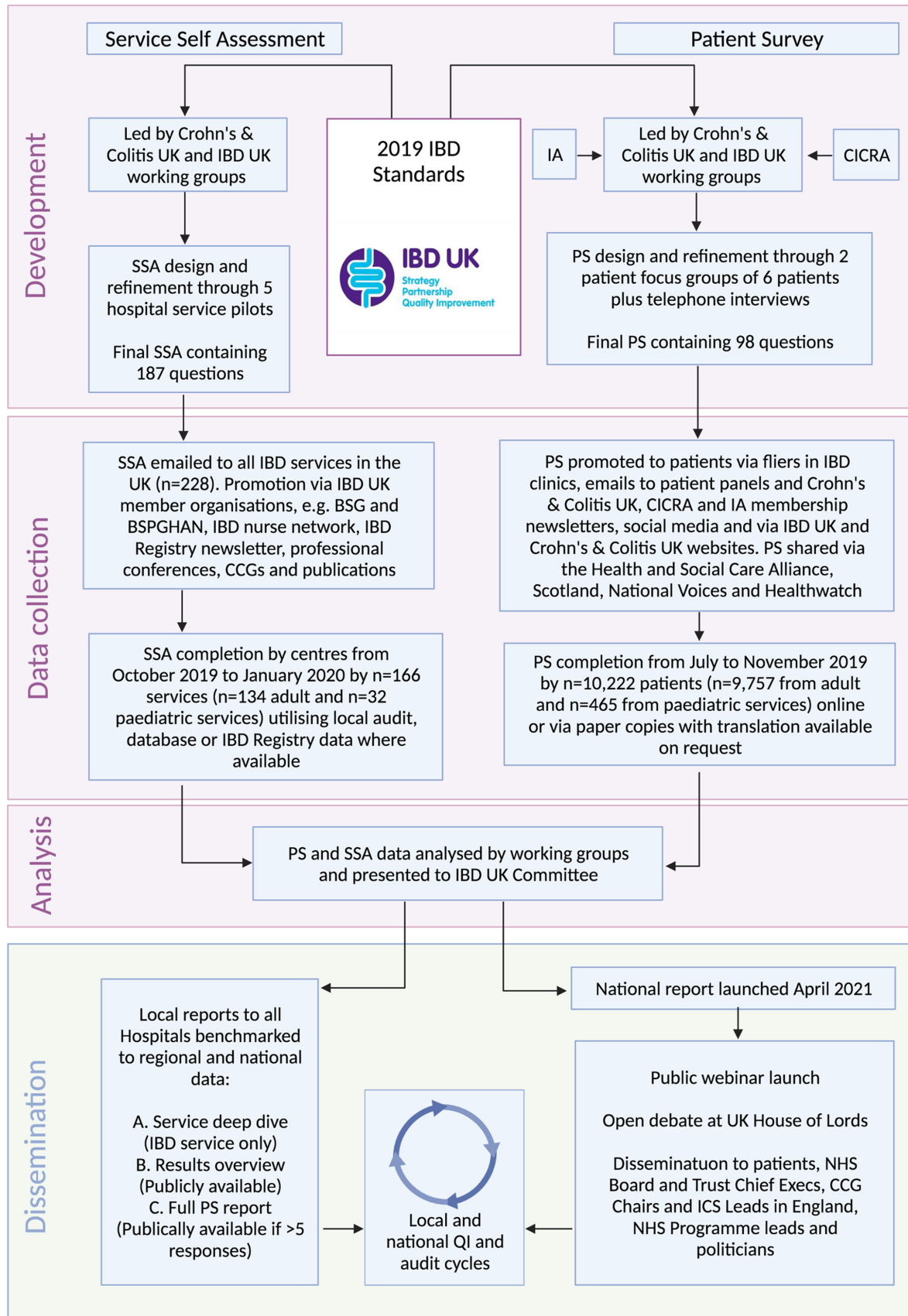


FIGURE 1 Flow chart showing development of patient survey and service self-assessment based on the UK IBD standards 2019. CCG, Clinical commissioning group; CICRA, Crohn's and colitis in childhood research association; IA, Ileostomy and internal pouch association; PS, patient survey; QI, Quality improvement; SSA, Service self-assessment.

care over the last 12 months?' was used as an overall measure of patient satisfaction. SSA and PS responses association with this question response in binary form (poor or fair, versus good, very good or excellent) were evaluated throughout this study in a binary logistic regression model. Patient factors (such as age, gender, disease activity) were explored using binary logistic regression, and those with independent association with overall satisfaction were used in all subsequent binary logistic regression analyses adding each patient question of interest singly to the model to explore their independent association with overall satisfaction. Ethnicity was explored by comparing white British (UK and Irish) against other ethnic groups pooled together (due to small numbers).

Multiple patients from individual hospitals completed the PS. Thus when comparing a PS question with an SSA question, the same SSA response was used repeatedly for all patients attending that hospital (we excluded those patients whose IBD service did not complete the SSA). In an exploratory analysis, we used binary logistic regression with multi-level modelling (MLwiN 3.05), using overall satisfaction as the dependent variable, and compared a two-level model where patients nested within their hospital, versus a single-level model. The outcomes did not differ and so a single-level model was used (SPSS).

The analysis involved a very large number of potential comparisons. The choice of comparison was based on clinical relevance, and was not applied randomly to all possible combinations. For this reason, we did not correct *p*-values for multiple comparisons. PS unanswered questions were coded as 'Missing', as were those answered with 'Not Applicable' and 'Do not Know' options. Numbers of respondents are included in all PS tables. Within-survey and between-survey alignments and disagreements were noted in results.

2.7 | Qualitative data analysis plan

Everyone, who completed the PS, was offered the opportunity to provide free-text comments at the end of the survey, in relation to the following two questions: 'Please tell us one thing your service could improve on?' and 'Is there anything else you would like to say?'. The questions were not compulsory, each person could choose to answer and there was no accompanying guidance text.

Thematic analysis of the comments was undertaken by identifying the main themes and topics the respondents referred to. The comments were 'coded', that is, allocated to the topics based on the subject matter of the comments. During coding, some comments were fully or partially redacted to protect particularly sensitive information and/or to ensure patient anonymity.

3 | RESULTS

In all, 134 adult hospital IBD services completed the SSA and 9757 patients completed the PS. Hospitals responding to the SSA had a median of 68 (range 8–174) patients that responded to the PS. Of

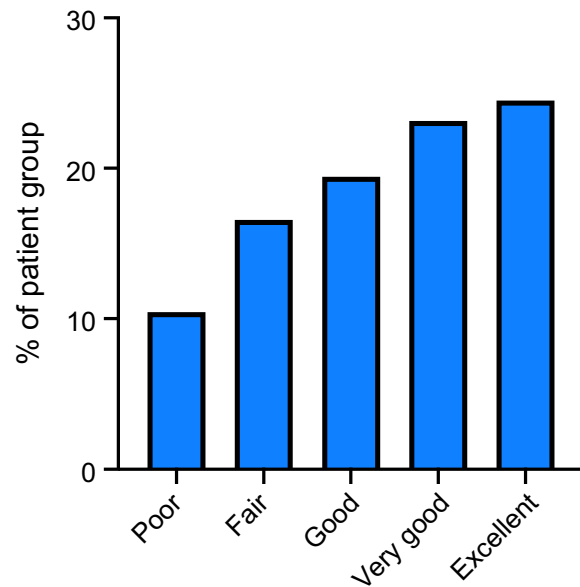


FIGURE 2 Patient rating of quality of care over 12 months

FIGURE 2 Patient assessment of quality of care in past year according to 5-point Likert scale ($n = 9183$).

the 9757 patients completing the PS, 20% were cared for in an IBD service that did participate in the SSA. In response to the key global question, 'Overall, how would you rate the quality of your Crohn's or Colitis care over the last 12 months?' 71% of adults reported their overall care to be good, very good or excellent (Figure 2).

3.1 | IBD service self-assessment participating centres

In all, 166 hospital IBD services (134 adult and 32 paediatric) across the four UK nations of England, Scotland, Wales and Northern Ireland completed the SSA (Figure S1). This represents 70% of the 191 adult and 86% of the 37 paediatric IBD services nationally, and collectively these hospitals reported caring for an estimated 347,973 patients. Paediatric hospitals had smaller numbers of patients, and patient satisfaction was much greater. Only adult hospital service data are presented in this paper, although 100/9745 (~1%) patients cared for in these adult centres were below 18 years age and are included. Of those completing the SSA, there were 134 adult IBD services (Table 1). 23% of IBD services were self-designated in the survey as tertiary centres. Reported data were derived from databases in 27 (20.2%) of services, and the remainder estimated numbers. The estimated number of patients noted above, when extrapolated to the UK population, however matches closely with UK prevalence which would estimate the number of patients cared for by these services at 350,000.³ 94% of services reported a defined MDT led by a named clinician, but none met the 2019 IBD Standards for workforce provision for all professional groups in relation to the population served. Having too few gastroenterologists, IBD nurses or colorectal surgeons to meet the IBD Standards was no more likely to occur in smaller IBD services compared to those designated as tertiary.

3.1.1 | Impact of participating centres' service delivery on patient perception of overall quality of care

In a binary logistic regression model adjusting for patient factors (age, gender, date of diagnosis and ability to cope with IBD in past

year), each hospital factor was investigated for its effect on patients' perception of overall quality of care (Table 1). Tertiary centres were significantly associated with patients' positive perception of quality of service ($p = 0.004$, O.R. 1.34 [1.19–1.51]), as were hospitals with larger numbers of patients with IBD ($p = 0.03$, O.R. 1.06 [1.01–1.12]).

No. of hospital IBD services—UK	Adult service	Service characteristics assessed in BLR model ^a to evaluate independent association with overall perception of quality of care	
	134	<i>p</i> -value	Odds ratio (95% confidence interval)
England	107 (80%)	Reference	
Northern Ireland	6 (4%)	0.09	1.24 (0.97–1.59)
Wales	11(8%)	0.16	0.86 (0.70–1.06)
Scotland	10 (7%)	0.67	1.04 (0.87–1.24)
Population served [median(IQR)] in 000s	400 (270–564)	0.06	0.95 (0.89–1.00)
Number of patients in service (median [IQR])	2000 (1482–3500)	0.03	1.06 (1.01–1.12)
Newly diagnosed patients in past year (median [IQR])	100 (60–182)	0.70	0.99 (0.93–1.05)
Tertiary referral centre? (self-designated)	31/134 (23%)	<0.001	1.34 (1.19–1.51)
Defined MDT led by a named clinician (% Yes)	126/134 (94%)	0.10	1.26 (0.96–1.66)
IBD team numbers meets the WTE requirements of the IBD Standards 2019 for team members per 250,000 population (%Yes):			
Gastroenterologists (2 WTE)	41/134 (31%)	0.30	1.07 (0.94–1.20)
Colorectal surgeons standard (2 WTE)	22/125 (18%)	0.96	0.97 (0.85–1.17)
IBD nurses standard (2.5 WTE)	19/132 (14%)	0.004	1.39 (1.17–1.65)
Stoma nurses standard (1.5 WTE)	31/90 (34%)	0.12	1.12 (0.97–1.28)
IBD Pharmacist (0.6 WTE)	18/66 (27%)	0.99	1.00 (0.84–1.19)
Dietitians standard (1 WTE)	9/98 (9%)	0.11	1.23 (0.96–1.57)
Psychologists standard (0.5 WTE)	3/17 (18%)	0.90	1.03 (0.66–1.60)
GI Radiologists standard (0.5 WTE)	50/115 (44%)	0.72	0.98 (0.87–1.10)
GI Pathologists standard (1 WTE)	11/90 (12%)	0.82	1.02 (0.84–1.24)
IBD administrators standard (0.5 WTE)	33/70 (47%)	0.05	0.87 (0.75–1.00)
Services meeting IBD Standards across all professional groups for WTE workforce	0/134 (0%)	—	—

TABLE 1 Features of IBD hospital services including whole time equivalent workforce numbers

Abbreviations: BLR, binary logistic regression; IQR, interquartile range; MDT, multidisciplinary team; WTE, whole time equivalent.

^aEach service factor assessed singly in BLR model including age, gender, time from diagnosis and ability to cope with IBD in the past year.

Of the workforce data, it is striking that IBD nurse specialist numbers were associated with perception of quality ($p < 0.01$; O.R. 1.39 [1.17–1.65]). There was no difference in perception of quality between the four nations (Table 1). Patients from hospitals participating in the SSA were more likely to rate the quality of their care as good, very good or excellent, compared with patients from non-participating hospitals (73% vs 66%, $p < 0.001$; O.R. 1.3 [1.2–1.5]).

3.2 | Hospital-assessed measures of service quality

The SSA questions (Appendix S1) were all based on the IBD Standards 2019.⁴ The majority of questions were tiered giving a grade from A (best) to D (worst) for each Standards statement.

Regarding service organisation, the majority of services scored A or B for IBD team leadership, MDT meetings, availability of nutritional support, continuing professional development support for IBD team members and opportunities for research (Table 2).

Very few centres actively participated in audit, and there was poor provision of information for patients. Less than a third of hospitals scored A or B on transition services from paediatric to adult care. In pre-diagnosis, the histology reporting times were poor, with other aspects all >50% A or B. In newly diagnosed patients, assessment of bone, nutritional status, infection and mental health; and communication with GP were worse than other aspects assessed. In flare management, access to specialist review and response times to telephone advice lines were reported as good (78% by the end of the next working day). Surgery scores in general were good; however, just 20% of services reported access to complex surgery.

For in-patient care, it was notable that fewer than 50% scored well for provision of toilets onwards, and for in-patient specialist pharmacist support. Long-term outpatient follow-up was generally reported worse than other categories. 49% reported availability of personalised care plans, and just 21% reported availability of self-management plans, with low figures also for communication with primary care, long-term care protocols, and management of pain and fatigue.

3.2.1 | Association of hospital SSA responses with patient perception of overall quality of care

A number of these factors had significant positive associations with patient perception of overall quality of care as shown in Table 2. Within the service organisation category, these included pharmacist involvement, referral pathways, availability of database for clinical and audit purposes, research and patient information. It is striking that the reported provision for these aspects of care was poor. In other areas of the patient pathway, communication, information provision and self-management are often associated with patient perception of care quality. Access to urgent specialist review, joint medical/surgical clinics, admission to a specialist gastroenterology ward when an in-patient, management of acute severe UC and

access to IBD nurses when an in-patient are all associated with positive patient perception of quality care.

3.3 | Patient survey population description

The PS received 9757 patient responses from adult IBD centres, of which 51% had a diagnosis of CD, 45% a diagnosis of UC and 3% inflammatory bowel disease—unclassified (IBD-U) (Figure S2A). The remaining 1% had microscopic colitis. The PS population was compared to other UK IBD population datasets to determine representativeness (Figure S2A–D).

CD patients were over-represented (51%) compared to UC (45%), when compared to other national cohorts (Figure S2A). The survey captured responses from patients in all age categories, in proportions broadly in keeping with the prevalent IBD population in the UK (Figure S2B).³ Men however were under-represented, comprising just 33% and 36% of CD and UC respondents, respectively, whereas epidemiological studies suggest men make up approximately 45% and 52% of the CD and UC population respectively (Figure S2C).^{2,3} Black and Asian patients were under-represented in respondents compared to Office for National Statistics (ONS) population figures (Figure S2D).¹¹ It is likely the survey represents a sample of the IBD population with relatively severe disease as 48% and 52% of CD and UC patients reported receiving corticosteroids in the previous 12 months, compared with just 30% of patients with IBD in a recent UK multi-centre audit.¹⁰ Increased disease severity may also account for over-representation of CD compared to UC patients.

3.4 | Patient factors affecting perception of overall quality of care

In all, 9757 patients responding to the PS were analysed for gender, age, date of diagnosis and disease activity, in relation to responses to this question (Table 3).

There was a significant correlation between self-reported difficulties of coping with IBD symptoms and perception of quality of care (Table 3). Among patients who reported finding it hard to cope with IBD 'all of the time' just 46% rated their service good, very good or excellent compared with 90% of those who reported no difficulties of coping with IBD symptoms.

Gender, age, ability to cope with IBD over the past year, and whether diagnosed in the past 2 years were all independently associated with perception of quality of care when assessed in the binary logistic regression model (Table 3). Those who never had difficulty coping with IBD over the past year were four times as likely to rate their service good, very good or excellent, compared to the group with difficulty coping with IBD all the time (OR 4.1, 95% CI 3.4–4.8). The effect of age on overall perception of service quality was mostly due to the under 18-year-old group, who were nearly three times as likely to report their care as good or better (OR 2.9, 95% CI 1.4–5.7) compared to those aged 75 years or more (note that these are patients under 18 years being managed in adult IBD services). Male

TABLE 2 Quality of care self-assessed by IBD teams from 134 hospital IBD services. Each domain based on UK IBD standards 2019, and represents three tiered questions giving a grade (A to D) with proportion of services achieving A or B shown

	IBD UK standard 2019 ⁴ (see Appendix S4)	Proportion of services graded A or B on 4-point scale for quality of service	Association with patient perception of overall service quality ^a	
			p-value	Odds ratio (95% confidence interval)
Service organisation				
IBD team leadership	1.4	99 (74%)	0.19	1.1 (0.95–1.3)
Occurrence of MDT meetings	1.2	92 (69%)	0.55	1.1 (0.73–1.8)
Referral pathway for support services (e.g. rheumatology, dermatology, ophthalmology)	–	24 (18%)	0.006	1.7 (1.2–2.4)
Pharmacist involvement in IBD team leadership	1.5	46 (34%)	0.012	1.2 (1.0–1.4)
Availability of nutrition support	1.15	86 (64%)	0.31	1.2 (0.71–0.97)
Presence of adolescent transition services	1.3	42 (31%)	0.62	1.0 (0.90–1.2)
Engagement with audit	1.6	46 (34%)	0.36	1.1 (0.91–1.3)
Database for clinical and audit work	1.8	22 (16%)	<0.001	1.4 (1.2–1.7)
Patient feedback and involvement in service design and delivery	1.7	31 (23%)	<0.001	1.7 (1.4–1.9)
Availability of patient information regarding local IBD service	1.9	25 (19%)	0.008	1.3 (1.1–1.7)
Professional support and development for local IBD team	1.16	97 (72%)	0.10	1.2 (0.97–1.5)
Availability of participation in research	1.17	102 (76%)	<0.001	1.5 (1.3–1.7)
Pre-diagnosis				
Waiting times for elective and urgent endoscopy and imaging ^b	1.10	83 (62%)	0.05	1.1 (1.0–1.3)
Histology reporting times for elective and urgent requests	1.11	34 (25%)	0.90	0.99 (0.82–1.2)
Waiting times for primary care referrals to IBD clinics ^c	2.2	74 (55%)	0.25	1.1 (0.94–1.3)
Patient information regarding waiting times for new referrals	2.4	87 (65%)	0.081	1.2 (0.98–1.4)
Newly diagnosed				
Review of newly diagnosed patients	3.1	59 (44%)	0.015	1.28 (1.0–1.6)
Assessment of nutrition, bone health, infection and mental health after diagnosis	3.2	32 (24%)	0.11	1.3 (0.94–1.8)
Provision of written information after diagnosis	3.3	115 (86%)	<0.001	2.0 (1.4–2.9)
Treatment initiation after diagnosis	3.4	68 (51%)	0.02	1.3 (1.0–1.6)
Provision of information about support organisations	3.5	90 (67%)	0.001	1.4 (1.1–1.7)
Communication between clinic and GP after diagnosis	3.6	29 (22%)	0.009	2.0 (1.2–3.3)
Written policy on use of biologics and immunomodulators	1.12	79 (59%)	0.78	1.0 (0.87–1.2)
Flare management				
Provision of information regarding flare management	4.2	59 (44%)	0.02	1.5 (1.1–2.1)
Access to specialist review urgently	4.4	97 (72%)	<0.001	2.0 (1.6–2.5)

TABLE 2 (Continued)

	IBD UK standard 2019 ⁴ (see Appendix S4)	Proportion of services graded A or B on 4-point scale for quality of service	Association with patient perception of overall service quality ^a	
			p-value	Odds ratio (95% confidence interval)
Proportion of telephone advice line support response times by the end of the next working day	4.3	104 (78%)	0.006	1.4 (1.1–1.8)
Protocol for prescribing and audit of corticosteroid prescribing	4.5	29 (22%)	0.43	1.1 (0.9–1.3)
Surgery				
Joint medical and surgical clinics	5.1	75 (49%)	<0.001	1.4 (1.2–1.6)
Written patient information on drug treatment and surgery	1.13	123 (91%)	0.012	1.2 (1.1–1.5)
Elective surgery available within 18 weeks	5.8	85 (63%)	0.04	0.86 (0.74–0.99)
Elective IBD surgery by specialist IBD surgeon	5.2	104 (78%)	0.013	1.9 (1.2–3.2)
Complex IBD surgery	5.3	27 (20%)	0.08	0.66 (0.42–1.1)
Availability of laparoscopic IBD surgery	5.6	131 (98%)	0.39	0.85 (0.58–1.2)
Provision of information regarding surgery	5.4	102 (76%)	0.012	1.3 (1.1–1.5)
Provision of post-operative information and support	5.7	123 (92%)	0.25	0.86 (0.67–1.1)
In-patient care				
Access to GI specialist ward after emergency admission	6.1	97 (72%)	0.001	1.3 (1.1–1.6)
Provision of toilets on gastroenterology ward	6.2	58 (43%)	0.16	0.89 (0.75–1.0)
Specialist assessment and review of acute severe colitis in hospital	6.4	105 (78%)	0.001	1.4 (1.2–1.8)
Joint surgical and medical management of acute severe colitis	6.7	92 (69%)	<0.001	1.4 (1.2–1.6)
In-patient management of nutrition, pain and mental health	6.8	81 (60%)	0.46	1.2 (0.78–1.8)
IBD specialist nurse support for in-patients	6.9	111 (83%)	0.001	1.3 (1.1–1.4)
Specialist pharmacy support for in-patients	6.10	63 (47%)	0.32	1.1 (0.88–1.5)
Quality of discharge process for in-patients	6.11	93 (69%)	0.041	1.2 (1.0–1.3)
Long-term management				
Provision of personalised care plan	7.1	65 (49%)	0.43	1.1 (0.9–1.2)
Provision of support for self-management	7.2	28 (21%)	0.001	1.3 (1.1–1.6)
Quality of shared care management between primary care and hospital	7.3	108 (81%)	0.48	0.93 (0.76–1.1)
Communication quality between primary care and hospital regarding treatment changes	7.5	50 (37%)	0.36	1.1 (0.91–1.3)
Management of pain and fatigue	7.4	12 (9%)	0.004	0.69 (0.53–0.89)
Protocol for long-term review	7.7	35 (26%)	0.77	1.0 (0.88–1.2)
Colorectal cancer surveillance management	7.8	86 (64%)	0.29	0.9 (0.76–1.1)

^aEach service factor entered singly into binary logistic regression model with patient factors (age, gender, recent diagnosis and ability to cope with IBD over the past year, as reported in Table 3). Significance and odds ratios shown for association with patient perception of overall service quality, comparing grade A (highest) against reference grade D (lowest quality).

^b81% services reported that endoscopy and imaging was available in 6 weeks, and within 48 h if acutely unwell or admitted to hospital. 62% services reported elective endoscopy and imaging in 5 weeks, and 47% within 4 weeks.

^c55% services reported wait times within 8 weeks for referral with suspected IBD, and 21% within 4 weeks.

TABLE 3 Patient factors affecting perception of the quality of their IBD service in the preceding year

Patient factor	Category (% of total)	Rating quality of care as good, very good or excellent:		Odds ratio (95% confidence interval)
		Frequency (%)	p-value	
Age (years)	<18 (1)	83/96 (87)	0.003	2.9 (1.4–5.7)
	18–24 (9)	557/813 (69)	0.68	1.1 (0.75–1.6)
	25–34 (21)	1304/1915 (68)	0.76	0.95 (0.67–1.3)
	35–44 (20)	1285/1809 (71)	0.85	0.97 (0.69–1.4)
	45–54 (21)	1340/1929 (70)	0.32	0.84 (0.60–1.2)
	55–64 (16)	1039/1434 (73)	0.42	0.87 (0.61–1.2)
	65–74 (10)	755/952 (79)	0.54	1.1 (0.78–1.6)
	=> 75 (2)	173/223 (78)	Reference	
Gender	Female (33)	4157/6083 (68)	Reference	
	Male (67)	2360/3054 (77)	<0.001	1.3 (1.2–1.5)
Date of diagnosis	>2 years ago (80)	5347/7308 (73)	Reference	
	≤2 years (20)	1169/1835 (64)	<0.001	0.76 (0.68–0.86)
Over the past 12 months, have you found it hard to cope with having Crohn's or Colitis?	All of the time (7)	295/643 (46)	Reference	
	Most of the time (14)	748/1313 (57)	<0.001	1.3 (1.2–1.5)
	Regularly (22)	1318/2024 (65)	<0.001	1.6 (1.3–1.9)
	Occasionally (46)	3325/4246 (78)	<0.001	2.2 (1.8–2.6)
	Never (10)	859/957 (90)	<0.001	4.1 (3.4–4.8)

Note: Patient characteristics as shown assessed in binary logistic regression model to evaluate association with overall perception of quality of care.

gender and a diagnosis more than 2 years prior to the survey had more modest odds ratios for predicting better perception of overall care (Table 3). There was no effect of ethnicity on overall perception of care quality with pooled ethnic groups ($n = 609$) compared to white British in binary logistic regression ($n = 9014$, $p = 0.91$, OR 0.99 [0.81–1.2]), nor did ethnicity affect responses to a range of questions across the patient journey (by chi-squared test), for example, waiting times for diagnosis, investigations, surgery, coordination of care, contact with IBD nurse, having information and skills to manage everyday symptoms. As a result, all SSA and PS questions impacting on the overall perception of service quality were assessed in a binary logistic regression model, adjusting for age, gender, diagnosis (past 2 years or longer than 2 years) and ability to cope with IBD over the past year.

3.5 | Patient-assessed service quality

Relevant questions covering all aspects of the patient journey are shown in Table and are discussed below under relevant subheadings. The PS also contained two questions encouraging free-text responses: 'Please tell us one thing your service could improve on?' and 'Is there anything else you would like to say?'. Overall there were 9534 free-text comments across the two questions from 6600 respondents. A thematic analysis summarising these is shown in Table S1 where responses are grouped by themes and then ordered by frequency. Numerically, the areas that were important include follow-up appointments, reviews and monitoring that were delayed or too few; access to IBD nurses; communications between GPs and hospital and support

with mental health. The themes of insufficient information, and the need for improved communication and access to help came across in most areas of the patient journey. Individual comments are included below in italics to illustrate patient perceptions of care received.

3.5.1 | Pre-diagnosis

... after multiple visits to GP and escalating symptoms [I] was waiting months and then ended up with severe symptoms [in] A&E, time off work ... referrals lost in system ... stress magnified by chasing appointments at every stage... finally had colonoscopy and was diagnosed UC.

Patient-reported waiting times are shown in Figure 3. (These were designed as categorical responses, rather than an exact length of time, as patients were unlikely to recall an exact wait.) The median wait from first discussion of symptoms with any healthcare professional to diagnosis was 4–6 months (Figure 3A). The median reported wait from referral to clinic assessment was 1–6 months (Figure 3B). 69% of patients reported waiting longer than the IBD Standard of 4 weeks from GP referral to first appointment. This is in line with waits reported by healthcare professionals in the SSA where 79% were reported as waiting more than 4 weeks (Table 2). A reflection of this is the reported number of times patients visited Emergency Departments with their symptoms prior to diagnosis: of 1851 respondents, 331 (18%) had one visit, 193 (10%) 2 visits and 208 (11%) 3 or more visits. In all, 1119 (61%) had no

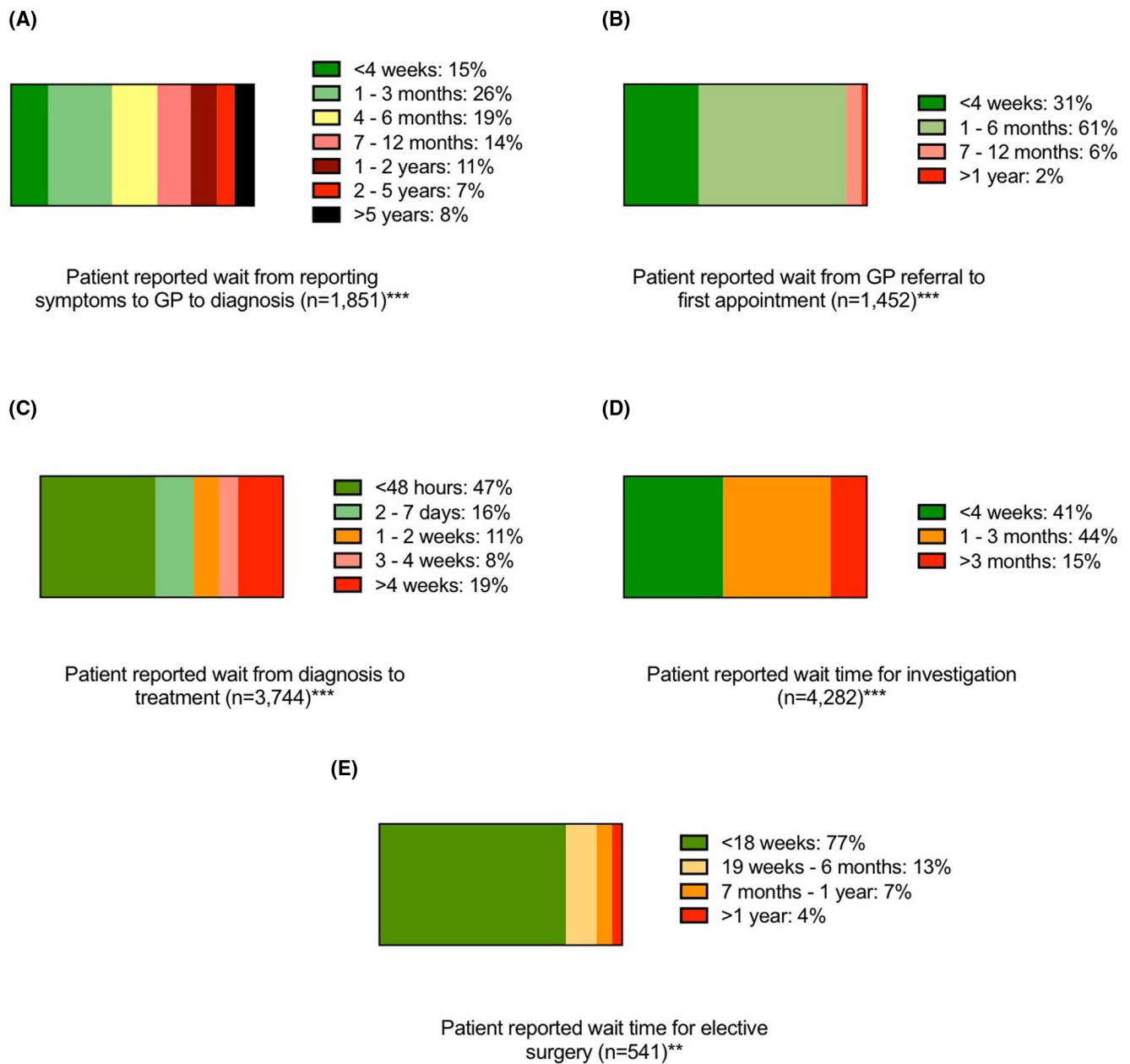


FIGURE 3 Patient-reported waiting times. (A) From reporting symptoms to GP to diagnosis ($n = 1797$), $p = 0.005$, O.R. 2.0 (95% CI 1.2–3.2). (B) From GP referral to first appointment ($n = 1406$), $p < 0.001$, O.R. 5.0 (95% CI 2.2–11). (C) From diagnosis to treatment ($n = 1709$), $p < 0.001$, O.R. 3.2 (95% CI 2.4–4.2). (D) For endoscopy or imaging investigation ($n = 4158$), $p < 0.001$, OR 9.8 (95% CI 6.1–16) and (E) For elective surgery ($n = 52$), $p = 0.003$, OR 4.3 (95% CI 1.7–11). Significance and odds ratios refer to a binary logistic regression model (adjusting for patient age, gender, recent diagnosis and ability to cope with IBD in the past year), measuring the association of the shortest wait, compared to the reference value (longest wait) with patients' perception of quality of service.

visits to the Emergency Department. When the impact of disease subtype on these measures was assessed, patient-reported time to diagnosis after first speaking to a healthcare professional about symptoms differed. The proportion of patients waiting ≥ 1 year was lower in UC at 20%, compared with CD at 34%, and IBD-U at 33% ($p < 0.001$). For other measures including waiting times for a response after contacting the IBD advice line and for investigations for elective surgery, there was no significant difference between UC, CD and IBD-U.

3.5.2 | Newly diagnosed

After diagnosis (Figure 3C), 47% started treatment within 48h, the IBD Standard for those with severe symptoms⁴; but 26% waited longer than 2 weeks, which is the IBD Standard for those with mild symptoms. Waiting times for endoscopy or imaging investigations (Figure 3D) were more than 4 weeks (threshold of IBD Standard for non-emergency investigation) in 59% of respondents (similar to the 53% reported in the SSA).

Once my gastroenterologist exhausted medical treatments (full range experienced from steroids through to biologic infusions) [I] was referred to [a] colorectal surgeon. Delays in waiting [redacted] prior to awaited 2nd stage surgery resulted in 2nd internal abscess requiring emergency hospitalization and added complications I feel could have been avoided.

The Standard for elective IBD surgery (18 weeks—in line with NHS England targets) is already excessively long for patients at risk of complications, as shown in the comment above. Despite this, the Standard was not met by 23% of respondents (Figure 3E).

3.5.3 | Ongoing care and transition

I wish that I could see the team more regularly ... I feel like I am constantly in limbo, waiting to be seen so the next decision can be made for my treatment plan.

64% of patients reported having regular review of their IBD. Clearly, many wait long periods without review, as in the quotation above.

I feel as though the mental health side of Crohn's and Colitis isn't focused on enough. For example, I suffer from extreme body image issues as a result of the bloating I suffer from daily... Help is needed.

I feel like there needs to be more support and understanding when it comes to related conditions and symptoms. I suffer daily with these (e.g. fatigue, food intolerances, anxiety issues, medicine side effects, skin conditions, consequences of surgery) but they are rarely discussed.

Specific issues were however less often dealt with: 30% felt that wider life goals and priorities were discussed in relation to their care; 55% report being asked about pain, 36% were asked about symptoms of fatigue and 23% about mental health and well-being (Table 4).

While 77/1881 (4.1%) respondents reported their diagnosis being confirmed by a private practitioner, and only 40 of 8778 (0.5%) had their ongoing care delivered by private practitioner compared to 8437 in a gastroenterology clinic or IBD service, and 301 in a surgical clinic. Overall satisfaction with the quality of the care was reported as good, very good or excellent by 74% receiving ongoing care in a gastroenterology clinic or IBD service, 30% in a surgical clinic and 47% in a private clinic. These figures differed significantly ($p < 0.001$ compared to gastroenterology or IBD service) but the very small numbers limit the interpretation of these findings.

Please help me transition into adult services better. I am scared and need help, support and [a] coordinated approached. I have limited opportunities at school, life, eating, going out....

In all, 289 patients had undergone transition in the past year. Of these 11% had a named transition coordinator, 14% had attended joint adult/paediatric transition clinics (but less than half of these had also received information about what to expect from transition). Three of 289 patients had received this information and also had an individual transition plan.

3.5.4 | In-patient care and surgery

When admitted to hospital I feel that because you are in a ward that is dealing with multiple problems not all the staff understand your needs. Mainly being close to toilets, and the urgency of needing one free.

[Being] on a general surgical ward after having a total colectomy and stoma was frustrating - I received little pain relief, even when asking every hour or so.

37% of admitted patients reported being on a gastroenterology-specific ward, although a further 23% were subsequently transferred to one.

3.5.5 | Primary care

In UK health services, GPs are key in referral for diagnosis. The importance of a positive relationship between patients and their general practitioner was explored in a series of questions. 34% of patients rated their GP as knowledgeable regarding Crohn's and Colitis and 42% felt their care was well coordinated between primary and secondary care.

I want GPs to know more about my disease, it took 3 years me to be diagnosed and feel like GPs are very uneducated in this sector of health.

... they have no confidence in prescribing for us, they always refer back to Gastro team which takes ages as they are understandably very busy! GPs need to take more control to free up gastro team's time.

3.5.6 | IBD nurse specialists

IBD Nurses are fantastic, they seem the most important [in] pushing the journey forward.

TABLE 4 Quality of patient journey from patient survey responses

PS data	Agree or strongly agree (%) unless otherwise stated (shaded row)	Association with patient perception of overall service quality ^a	
		p-value	Odds ratio (95% confidence interval)
Flares			
When I contact the NHS IBD service advice line, I get a response by the end of the next working day (n = 5851)	72	<0.001	10 (8.1-12)
Response to query left with NHS IBD service advice line received within 48 h (n = 4067)	75	<0.001	18 (11-29)
Surgery			
My surgical and medical teams worked well together (n = 575)	72	<0.001	53 (20-139)
I was given information in a format that helped me understand the benefits and risks of surgery	82	<0.001	21 (7.9-56)
In-patient care			
Did you stay on a gastroenterology ward (n = 1986)			
Yes	37	<0.001	2.1 (1.7-2.7)
Transferred from general ward to GI ward during stay	23	<0.001	1.6 (1.1-2.3)
No	39	Reference	
A healthcare professional explained the purpose of the medicines I needed to take at home and possible side effects, in a way I could understand (n = 1920)	68	<0.001	22 (13-43)
Long-term care			
My treatment and care are well-coordinated between my IBD team and any other services I see for other medical needs I have (n = 8029)	47	<0.001	80 (59-109)
I am supported by a team of IBD specialists who help me manage my condition (n = 9483)	64	<0.001	100 (80-130)
We discuss my wider life goals and priorities, as part of planning my Crohn's or Colitis care (n = 9495)	30	<0.001	66 (44-98)
Do you have a regular review for your Crohn's or Colitis, regardless of whether you are well or not? (n = 9646)—Yes (%)	64	<0.001	12 (9.6-16)
Self-management and patient involvement			
Do you have a personalised written care plan? (aa728)—Yes (%)	8	<0.001	7.8 (5.7-11)
I felt what mattered to me was taken into account when making decisions about treatments and care (n = 1868)	52	<0.001	61 (35-106)
These reviews give me the opportunity to discuss what matters to me (n = 8391)	77	<0.001	12 (9.4-16)
I felt what mattered to me was taken into account when making decisions about my operation and care (n = 586)	78	<0.001	26 (9.5-69)
I was involved as much as I wanted to be in decisions about my care and treatment (at diagnosis) (n = 1851)	32	<0.001	44 (30-68)
I was involved as much as you wanted to be in decisions about your care and treatment? (overall) (n = 9556)	47	<0.001	52 (43-64)
GP involvement			
In my opinion, my GP is knowledgeable about Crohn's and Colitis and how to treat the conditions (n = 9029)	34	<0.001	5.1 (4.1-6.4)
In my opinion, my GP supports me to manage my Crohn's or Colitis and live as well as possible (n = 9016)	39	<0.001	4.6 (3.8-5.6)

(Continues)

TABLE 4 (Continued)

PS data	Agree or strongly agree (%) unless otherwise stated (shaded row)	Association with patient perception of overall service quality ^a	
		p-value	Odds ratio (95% confidence interval)
My care is well-coordinated between my GP and gastroenterologist (e.g. blood tests, monitoring drug levels) (n = 9242)	42	<0.001	29 (22-37)
Diet and nutrition			
I have access to specialist advice or support with diet and nutrition if I should want it (n = 8377)	41	<0.001	20 (16-25)
Before my operation, I was assessed for nutritional or dietary support (n = 548)—Yes (%)	35	<0.001	6.5 (3.6-11)
Fatigue, pain and mental health			
During appointments, I am asked about fatigue/tiredness and treatment options are discussed to manage this (n = 9251)	36	<0.001	43 (31-59)
During appointments, I am asked about pain and treatment options are discussed to manage this (n = 9158)	55	<0.001	56 (43-73)
During appointments, I am asked about my mental health or emotional well-being and treatment options are discussed (n = 9236)	23	<0.001	27 (19-39)

^aResponses entered singly into binary logistic regression model with patient factors (age, gender, recent diagnosis and ability to cope with IBD over the past year, as in Table 3). For each variable significance and odds ratios for association with patient perception of overall service quality, comparing best response on the 5-point Likert scale against reference (worst response) or yes versus no response. Grey boxes refer to yes/no answers. All other boxes refer to 5-point Likert scales.

The two IBD nurses ... are so lovely, so understand[ing] and really want to help you. Their understanding on the emotional side of things is really brilliant, sometimes this is just as important as the physical symptoms.

In UK IBD services, the IBD nurse specialist has an extremely important role, providing patient education, disease management and therapy monitoring, patient support, continuity of care, audit, rapid access for advice and review during disease flares. The role has been shown to improve quality of care and represent value for money.¹³⁻¹⁶ As a result, nurse specialist numbers have risen, but only 14% of services had levels recommended in the 2019 IBD UK Standards⁴ (2.5 per 250,000 population). This was however strongly associated with patients' perception of overall care ($p = 0.004$, OR 1.39 [1.17-1.65] (Table 1). Services reported a median of 2 nurses per service (IQR 1-3). Despite this low number, patients report high levels of contact with their specialist nurse, and rate their knowledge highly, with strong association to overall perceived quality of care (Figure 4A; Table 5).

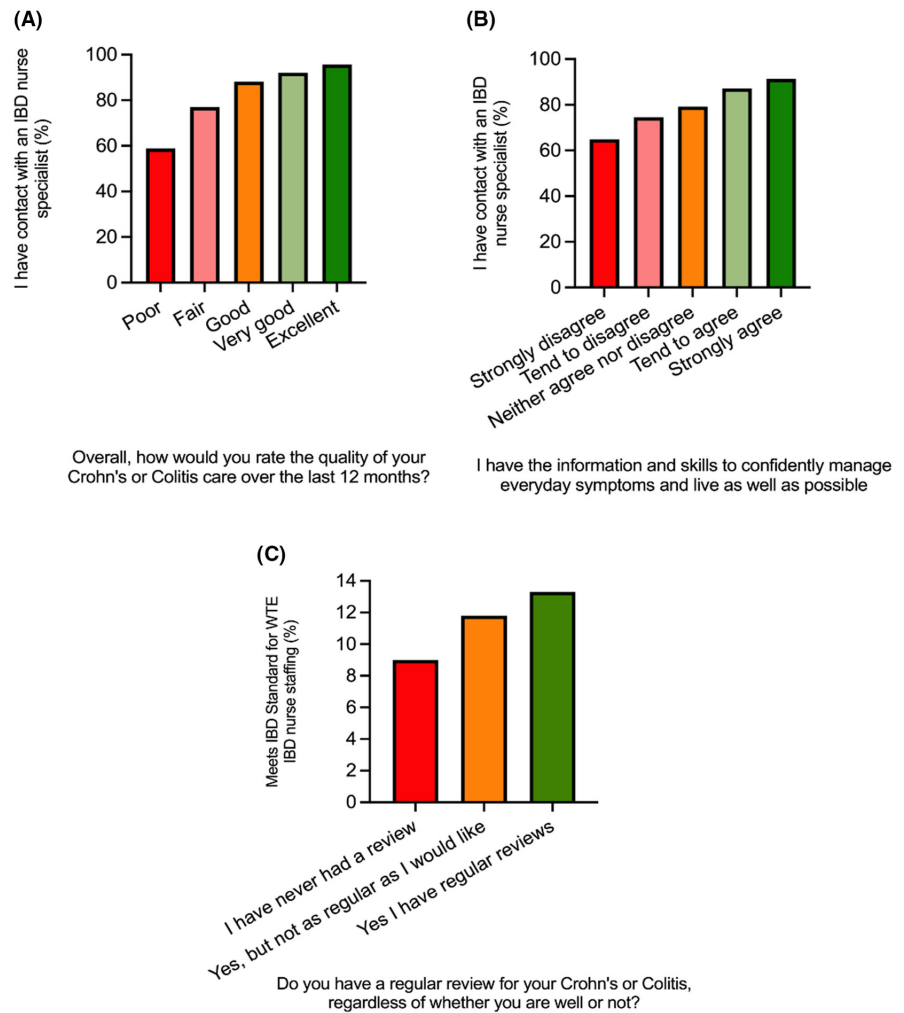
Whilst the IBD nurses are brilliant, the waiting time for responses from IBD nurses are not acceptable. At times I have become more unwell because I have been made to wait to access advice and then medicine. Attending walk in clinics and A&E were my only option and unfortunately the professionals that I saw, referred me back to the IBD nurses, knowing that the service was already overstretched.

In most hospitals, IBD advice lines are staffed by IBD specialist nurses and are a key part of their work. Contacts with IBD advice lines were covered in two questions, one regarding contacts for advice, and the other relating to flare advice specifically (Table 4). For flare advice, 75% received a response within 48 hours (the IBD Standard is by the end of the next working day⁴). This is very similar to results health-care professional reported in the SSA (78% in Table 2).

In addition, contact with a specialist nurse was positively associated with quality of information received by patients at key points in their care including decision-making around medication and surgery ($n = 572$, $p < 0.001$), and provision of more general support with life skills and daily living (Figure 4B). It is notable that reported contact with an IBD specialist nurse remained an independent predictor of patients receiving information and support in a binary logistic regression model ($n = 7247$, $p < 0.001$, OR 5.4 [4.7-6.3]), that included self-designation as tertiary centre ($p < 0.001$, OR 1.5 [1.3-1.7]), the presence of an IBD leadership team ($p = 0.56$, OR 1.0 [0.89-1.2]) and patient-reported response-time to advice line queries ($p = 0.90$, OR 1.0 [0.78-1.3]).

There was a positive association between sufficient specialist nurse numbers, and the likelihood of receiving regular reviews (Figure 4C), highlighting the key role IBD nurse specialists play in coordinating and delivering follow-up services. Receiving a review by the IBD nurse when an in-patient was reported by 45% of those recently admitted, and although not associated with IBD nurse numbers, there was a strong association with patients feeling they had the information and skills to manage their symptoms and live as well as possible ($n = 1981$, $p < 0.001$).

FIGURE 4 Impact of IBD specialist nurses on patient perception of quality of care. (A) Association between contact with IBD nurse and overall quality of care ($n = 9043$, $p < 0.001$). (B) Association between IBD nurse contact, and patient support ($n = 9539$, $p < 0.001$). (C) Association between meeting the IBD nurse standard for WTE staffing, and having regular review ($n = 7612$, $p = 0.001$).



3.5.7 | Dietitian, pharmacist and psychological support

The importance of diet seems to be grossly underestimated and access to an NHS dietician too restricted and used as a last resort whereas, when I eventually saw her, she recognised my dietary problems and aims and was extremely helpful. I am only permitted one visit without repeat referral from the GP.

41% of patients reported access to dietary advice when needed, and only 35% in the preoperative period. This compares poorly with the much more optimistic SSA assessment with 64% of centres reporting grade A or B for provision of nutritional support (Table 2). The question relating to 'provision of information about potential treatments and care (including potential benefits and side effects), to be able to make informed decisions' during ongoing care (Table S2) was associated to whether the hospital service met the standards for IBD pharmacist numbers (0.6 WTE per 250,000 population, $p = 0.003$).

23% of patients report discussion of mental health in clinic encounters (Table 4), suggesting that services may not recognise patients' needs regarding psychological support. This fits with only

three hospitals reporting they meet the IBD Standards 2019 for psychologist provision (Table 1).

Patients reported that after being in hospital, 68% had an explanation of the purpose, and side effects of take-home medications. This may have been provided by ward nurse, or IBD nurse specialist, and not necessarily a pharmacist. The SSA reported that although 61% of teams have input from pharmacists to the IBD leadership team, 22% have the support of a pharmacist with IBD expertise. 18% of 66 hospitals responding, reported meeting IBD Standards 2019 for pharmacist numbers.

3.5.8 | Provision of information, self-management and communication

I would like to have more control over my treatment.

Listen to what the patient says as they know their body better than anyone...

A plan would be good, I don't have one and I feel like I'm swimming alone. I'm new to this and don't know what to expect.

Patient survey data	Agreement	Association with patient perception of overall service quality ^a	
		p-value	Odds ratio [95% confidence interval]
Do you have contact with an IBD nurse specialist? (n = 9593)—% Yes	84%	<0.001	5.7 [5.0–6.5]
In my opinion, the IBD nurse specialists who treat me are knowledgeable about Crohn's and Colitis and how to treat the conditions (n = 7792)—% who tend to agree or strongly agree	87%	<0.001	2.2 [1.7–2.9]
Were you offered the opportunity to speak to an IBD nurse specialist while you were an inpatient? (n = 1988)—% Yes	45%	<0.001	4.3 [3.9–5.4]

^aResponses entered singly into binary logistic regression model with patient factors (age, gender, recent diagnosis and ability to cope with IBD over the past year, as in Table 3). For each variable significance and odds ratios for association with patient perception of overall service quality, comparing yes versus no, or best response on the 5-point Likert scale against reference (worst response).

23% of patients report being given a written first treatment plan (Table S2), and only 8% provision of a personalised care plan (Table 4). This contrasts sharply with the SSA data, where 49% of services reported having a defined care planning process in place, and 28% reporting that all patients should have a care plan.

When asked 'Please tell us one thing your service could improve on?' one patient said 'Information provision. I did my own research but some might not know how to find information...' Generally less than two-thirds of patients report provision of adequate information, with the exception of information about benefits and risks of surgery (Table S2). Overall these data show the high degree of association between information and overall perception of care, with odds ratios between 3.7 and 69.

3.5.9 | Differences in PS responses between UK nations

A comparison of respondents from the four UK nations showed that there were small but significant differences in waiting times for first appointment after GP referral, and for start of treatment after diagnosis, and waiting times for endoscopy or radiology investigation, but not for waiting times for elective surgery, or for response to advice line calls regarding flares. Comparing specific countries, wait times were slightly but significantly longer for Wales, when compared to England, for wait from first GP contact to confirmed diagnosis (median 7–12 months [Wales], 1–3 months [England], $p = 0.011$), although median waits for other factors did not differ.

TABLE 5 Assessment of the role of IBD nurse specialists

3.5.10 | Association of patient PS responses with patient perception of overall quality of care

The most striking finding was that all PS responses shown in Tables 4, 5 and Table S2 were associated with patient perception of overall quality of care by binary logistic regression (corrected for patient factors). The question 'I am supported by a team of IBD specialists who help me manage my condition' (Table 4) had the largest odds ratio in its association with patient perception of quality of service ($p < 0.001$, O.R. 100 [95% CI 80–140]). The odds ratios varied widely but it is important to note that these are influenced by the number of respondents particularly in the reference group for these binary logistic regression analyses, resulting in sparse data bias. Waiting time responses from patients were all strongly associated with patients' perception of quality of service. Most nurse-related measures included in both the SSA and the PS were also strongly associated with patients' overall perception of service quality, and all of the questions in Table 4 had a very strong association with patients' overall perception of quality.

3.6 | Visual dashboard

The visual dashboard summary for the SSA data (Figure 5A) highlights areas of generally low-quality care: the worst relating to quality of diagnosis (reflecting long waiting times for diagnosis, and difficulties in referrals for dietetics, and other complications of disease in the newly diagnosed), and the best relating to coordination of care regarding treatment. Similar summary data from

	Service Self-Assessment			
	DIAGNOSIS	TREATMENT	ONGOING CARE	IBD SERVICE
ACCESS	B	B	B	C
PATIENT EMPOWERMENT	B	B	B	C
QUALITY	D	C	B	B
CO-ORDINATED CARE	C	A	B	B

	Patient survey			
	DIAGNOSIS	TREATMENT	ONGOING CARE	IBD SERVICE
ACCESS	B	B	B	
PATIENT EMPOWERMENT	B	B	B	
QUALITY	B	C	C	
CO-ORDINATED CARE	B	B	C	

FIGURE 5 (A) Median service self-assessment grades across 134 UK adult services. Diagnosis, treatment, ongoing care and IBD service columns relate to stages in the patient journey. Access—access to the IBD service across the patient journey, including for diagnosis following GP referral, investigations and treatment initiation, rapid specialist review during flares and to IBD advice lines. Patient empowerment—provision of information to patients, including signposting to patient organisations, information about treatment options, shared decision-making, support for self-management and patient involvement in service development. Quality—provision of holistic assessment for newly diagnosed patients, relevant treatment protocols, ongoing cancer surveillance and IBD team leadership, planning and development, with involvement in audit and research. Coordinated care—communication and shared care across primary and secondary care, pathways to supporting services, inpatient access to an IBD nurse specialist, surgical and medical joint working, MDT meetings and the transition service. (B) Median patient service assessment grades for adult patients. Categories as above (IBD service column blank as patients not asked about this).

the PS are shown in [Figure 5B](#). Patients were not asked about details of the IBD service, so this column is omitted. In general, most aspects of care scored higher than in the SSA summary. It should be noted that 20% of patients were assessing services that did not submit an SSA, so for this and other reasons (fewer data from hospital services than patients, and differences in format of questions and responses) between-survey comparisons should be treated with caution.

4 | DISCUSSION

The IBD UK Benchmarking process is unprecedented as the most in-depth nationwide service assessment of IBD care, reporting patient experience alongside more traditional service-reported quality measures. The Patient Survey (PS) and the Service Self-Assessment (SSA) were designed to measure the quality of care in the UK against the 2019 National IBD Standards,⁴ highlighting the areas of service that could be targeted locally for quality improvement in an iterative process.

The first national effort to understand the quality of IBD care in the UK was delivered through four rounds of national IBD audit from 2005 to 2017, run by the Royal College of Physicians.¹⁷ After the first round, subsequent audits were aligned to the UK IBD Standards 2009 and 2013, highlighting specific areas that should be the focus for future assessment of IBD services.¹⁷ These included the following: speed of access to specialist assessment at referral and relapse, appropriate provision of IBD nurse specialists, dietetic access and psychological support, patient education opportunities, involvement

of patients in service planning, and a need for improved communication between primary and secondary care. This led to improvements in care and helped identify consistent inequalities in healthcare provisions.

The current benchmarking again assesses the quality of care measured against the most recent IBD Standards. The primary aim was to measure quality of care from the patient's perspective, and secondary aims were to compare this to the IBD Services' assessment of care provision, and to develop local and national quality improvement targets.

The PS data on waiting times relating to pre-diagnosis and newly diagnosed patients showed poor results, with comments demonstrating the impact of delays on patients' physical and mental health. In contrast, the response rates to contacting the service with flares are somewhat better. The quality of other areas are variable with high scores regarding joint surgeon/physician working and information in relation to surgery, but much lower scores for experience during in-patient stays, interaction with primary care and aspects of long-term care. Nearly a tenth of all free-text comments relate to follow-ups, reviews and monitoring, demonstrating how important this is to patients. Very few had a personalised care plan, and the management of pain, fatigue and mental health are particularly lacking. The quality of transition care is clearly poor as reported by the relatively small number experiencing this process recently. This is a key issue as this is the first introduction to adult IBD services for an important group of young people, at a crucial stage in their lives.

It is important to note that the global measure of patient perception of quality of care was associated with virtually all patient

responses and the strength of association was the only way we were able to assess the importance of that factor to patients. The perceived quality of care was influenced by other independent patient factors including age, gender, time since diagnosis and disease severity that must therefore be taken into account during service improvement initiatives. The impact of gender,¹⁸ age, ill-health¹⁹ and other factors²⁰ on patient satisfaction surveys is well documented. The association between several markers of active disease and the patient perception of service quality could be, at least in part, due to patients regarding service quality as worse because they perceive it has failed to improve their health, or due to a more general effect of chronic ill-health on satisfaction.

Three key areas of importance to patients emerge. The first is the provision of patient information. Availability of information was important across multiple aspects of care including diagnosis, medical and surgical treatments, availability of research and access to specialist advice lines and flare reviews. Linked to this a second key area was support and communication: patients feeling supported by a team of IBD specialists had a strong association with perception of quality of care. Third, the patient data reinforce the key role that IBD specialist nurses play in providing this support. Evidence presented shows that services with IBD nurse specialist numbers meeting the IBD Standards recommendation⁴ have patients who report higher perception of quality of care, and are more likely to have regular reviews. Contact with an IBD nurse specialist is associated with higher confidence in self-management and greater ability to cope with the diagnosis. This may be because nurse specialists provide support and information, more continuity of care, and often act as a key interface between patients and the rest of the IBD service. However, our data also show low levels of IBD nursing availability with fewer than 1 in 8 services meeting the IBD Standard for WTE IBD nurses according to the population served. In spite of the evident funding constraints limiting IBD workforce numbers in the UK and linked to long waiting times, the PS is surprisingly positive about many aspects of care received.

The SSA data report on organisational aspects of IBD care that are not included in the PS questions, as well as reporting on aspects of care along the patient journey. Centres with larger numbers of patients with IBD, and tertiary centres, had patients rating the overall quality of care more highly, as did those with a clinical database, involvement in research and those with a pharmacist involved in IBD team leadership. Like the patient survey, better information, communication between GPs and hospitals, and patients involved with service design and delivery were associated with higher global ratings of quality from patients in that service. Very few services had IBD staff numbers in line with the IBD standards, and having enough staff to meet the standards was not more likely in tertiary centres.

There was good agreement between the SSA and PS in many questions across the pathway, including the relationship between staff numbers (e.g. pharmacists and IBD nurse specialists) and patient-reported measures of their activity. Regarding dietitian support however, the SSA gave an overoptimistic assessment compared to patients' reported experience. Waiting times reported in both PS and SSA were comparable.

Internal consistency of responses in similar areas within SSA and PS surveys was generally good, perhaps best illustrated by the strong association between overall perception of care and most specific questions in the PS. It is clear that the PS question regarding overall service quality provides a vital measure of quality that should be adopted as a key performance indicator in future service assessment. It is also clear that the PS gives a different perspective to the SSA emphasising the importance of information provision, communication between patients and their team, and patient involvement in decisions about their care. This is supported by the large number of free-text comments in the areas of information provision and support, and holistic and personalised care.

The benefits of this dataset are relevant at a local, regional and national levels. Locally, this will support services looking to secure additional funding for service design, improvement and expansion of the multidisciplinary team, in particular IBD nurse specialists. Regionally, they will support the appropriate distribution of services to target the areas of greatest need, and nationally they are a key information source to inform national strategy and further iterations of the IBD Standards.

One of the most important outcomes of this dataset is to drive Quality Improvement (QI). As noted above, we have identified core themes that are present on a national basis and all sites that participated have received a detailed site-specific report. This details their results in an A–D scheme and highlights the key targets for QI for their service, many of which do not require significant resource, allowing a more targeted QI approach. Examples in five key areas are shown in [Box 1](#). Further rounds of the SSA and PS will allow sites to monitor their progress and refine their QI plans. The UK IBD audit drove significant improvement in care using a traditional QI audit cycle. It is hoped that this renewed focus, working with patients in true co-design and co-production, keeping patients at the centre of this initiative will realise greater benefits in care for those individuals with IBD.

These data hugely expand the existing, limited international literature identifying areas of most importance to patients in the delivery of high-quality care, thereby providing a framework for QI. The importance of quality standards for IBD care has been formally recognised by the publication of many country-specific IBD standards,^{5–9} while the European Crohn's and Colitis Organisation has clearly defined quality standards across countries and different health systems.²¹ Some have used quality standards to provide accreditation for IBD units.²² Our results are therefore of importance to an audience of UK and international healthcare providers and patients with IBD. The UK system is relatively homogeneous in comparison to healthcare delivery in USA, Canada and Australia, and has similarity to nationally coordinated healthcare in Scandinavia and other European countries. Patient assessed care quality concerns in the UK system are relevant to services with more variability, where the issues may be more widespread but difficult to quantify. Our data, with the clear message about the value of patient information and communication, are consistent with an international patient questionnaire from 2013 to 2014. This study, from the IBD 2020 group, included 851 UK patients, demonstrated that perceived

BOX 1 Quality improvement initiatives in IBD care highlighted by this study

Diagnosis:

- Use of faecal calprotectin to fast-track direct colonoscopy, with better training and awareness for referrers (and the public) regarding IBD versus irritable bowel syndrome.
- Rapid e-referral and response systems to provide feedback and advice for referrers to avoid unnecessary appointments and reduce waiting times to specialist clinics.

Information:

- Work with local patient representatives to identify where and how information can be provided.
- Ensure availability of high-quality information sheets in paper and/or electronic form regarding IBD (provided by national patient groups), and regarding local service provision, contact details and useful services.
- Provide patient education via online interactive presentations at regional (or local) level.

Personalised care and self-management:

- Provide personalised care plans (considering patients' life goals and including individualised actions in event of flare) and extend throughout service over time.
- Re-organise clinic follow-up so stable patients have supported self-management with fewer routine appointments (but monitoring to ensure surveillance and that monitoring is adhered to), but more capacity for drop-in flare clinics and telephone access for advice.

Faster access to specialist advice and treatment:

- Improve availability and staffing of telephone/email advice lines (expanding specialist nurses and clerical support).
- Improve access to consultant physicians and surgeons (electronic communication from other healthcare professionals and increased specialist IBD clinic provision).

Leadership and regular meetings of the multidisciplinary team:

- IBD leadership team (named lead doctor/nurse/manager) with regular meetings.
- Ensure job-planning provision for physicians, surgeons, radiologists and dietitians as core members of the MDT with availability of other groups where needed.

quality of care was related to five key variables: quality of specialist communication; review consultation being long enough; failure to share information; no access to a dietitian and speed of advice.²³ Our data extend this type of study with broader assessment of patient-reported experience of care, matched with healthcare reported information and a larger sample size. Our data also correspond closely

to the recommendations from the international 2012–2015 IBD Expert Alliance initiative.²⁴ Other multinational surveys have focused mainly on quality of life of respondents and not perceptions of the healthcare system or professionals treating them and how this associates with markers of care quality.^{25,26} As well as evaluating IBD service structure, and process, we have emphasised the importance of a number of measures that include corticosteroid use, emergency admissions and disease activity that align with quality indicators recommended by the Crohn's Colitis Foundation of America.²⁷

The strength of the benchmarking process was the uptake and coverage of the majority of UK services, the comprehensive scope of the IBD service, and the cross-comparison between SSA and PS. The mixed quantitative and qualitative method approach provided factual information combined with compelling feedback on the service individuals received. There were also weaknesses that are important to recognise. Some patient responders attended hospitals who did not participate in the SSA, and some services had few PS responses. Survey participants were weighted towards females, more with active disease and/or recent diagnosis and more CD compared to UC. This may be because those with CD or active disease have more hospital contact. The latter factors may have resulted in less favourable PS responses overall. Ethnic minority groups were under-represented in the survey respondents (although responses did not differ significantly between minority groups included and white British respondents).

The SSA was a subjective assessment by the IBD team of their own service, and it is likely that for many services comprehensive audit, database or registry data would not have been available for all metrics requested. This may have limited the quality of some quantitative data such as waiting times, estimates of patient populations and WTE staffing dedicated to IBD care. With the expansion of the UK IBD Registry and other electronic management systems, this limitation is anticipated to be less in future rounds of benchmarking. In addition, some staffing measures may have been reported differently by different hospital services, for instance when assessing what proportion of the work of a colorectal surgeon, dietitian or pharmacist is taken up with IBD, when this may be only one aspect of their role. The surveys were not designed to be compared directly, with some of the more objective questions, for example, delays in diagnosis or waiting times for investigations or surgery, having response ranges that were not identical between the healthcare professional-reported and patient-reported tool. The size of ExpB (odds ratio) in binary logistic regression analyses, although giving an idea of the size and direction of effect cannot be used to rank questions because of differences in data collection, samples sizes and possible sparse data bias. Insufficient confounding adjustment and reverse causality can affect interpretation of these data, overcome here by considering clinical implications as well as statistical detail.

In conclusion, the IBD UK Benchmarking Tool provides location-matched service performance and patient experience data and sets an international standard for IBD service assessments. The value of patients' assessment of their service's quality is clear and highlights the importance of information provision, support and

communication, and the IBD specialist nurse role. It complements and adds to service self-assessment, and is essential in shaping IBD services to meet patients' needs.

AUTHOR CONTRIBUTIONS

IBDUK Board IBD Task Finish Group designed, planned and administered the surveys; Alan Nevill, A. Barney Hawthorne, Christopher A. Lamb, Jonathan Blackwell, Jackie Glatter, Rachel Ainley analysed and interpreted the data; A. Barney Hawthorne, Christopher A. Lamb, Christian Selinger, Jonathan Blackwell, Matthew James Brookes, Ian Arnott, Lisa Younge planned and wrote the paper and all authors critically revised the manuscript and approved the final version.

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SUPPORTING INFORMATION

Additional supporting information will be found online in the Supporting Information section.

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APPENDIX 1

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