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Original Article

Patient-reported Outcomes: the ICHOM Standard Set for Inflammatory Bowel Disease in Real-life Practice Helps Quantify Deficits in Current Care

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Abstract

Background: Patient-reported outcome measures [PROMs] are key to documenting outcomes that matter most to patients and are increasingly important to commissioners of health care seeking value. We report the first series of the ICHOM Standard Set for Inflammatory Bowel Disease [IBD].

Methods: Patients treated for ulcerative colitis [UC] or Crohn's disease [CD] in our centre were offered enrolment into the web-based TrueColours-IBD programme. Through this programme, e-mail prompts linking to validated questionnaires were sent for symptoms, quality of life, and ICHOM IBD outcomes.

Results: The first 1299 consecutive patients enrolled [779 UC, 520 CD] were studied with median 270 days of follow-up (interquartile range [IQR] 116, 504). 671 [52%] were female, mean age 42 years (standard deviation [sd] 16), mean body mass index [BMI] 26 [sd 5.3]. At registration, 483 [37%] were using advanced therapies. Median adherence to fortnightly quality of life reporting and quarterly outcomes was 100% [IQR 48, 100%] and 100% [IQR 75, 100%], respectively. In the previous 12 months, prednisolone use was reported by 229 [29%] patients with UC vs 81 [16%] with CD, p <0.001; 202 [16%] for <3 months; and 108 [8%] for >3 months. An IBD-related intervention was reported by 174 [13%] patients, and 80 [6%] reported an unplanned hospital admission. There were high rates of fatigue [50%] and mood disturbance [23%].

Conclusions: Outcomes reported by patients illustrate the scale of the therapeutic deficit in current care. Proof of principle is demonstrated that PROM data can be collected continuously with little burden on health care professionals. This may become a metric for quality improvement programmes or to compare outcomes.

Key Words: Inflammatory bowel disease; patient reported outcomes; ICHOM

1. INTRODUCTION

Ulcerative colitis [UC], Crohn's disease [CD], and inflammatory bowel disease unclassified [IBD-U] are inflammatory bowel diseases [IBD] that cause chronic symptoms that can reduce quality of life, social functioning, and occupational productivity.[1–4] Whereas clinicians caring for patients with IBD consider metrics such as stool frequency, rectal bleeding, biochemical, endoscopic and histological parameters important for ascertaining disease control, these may not reflect what matters to patients.[5–7] There is also significant heterogeneity in real-world, clinician-reported quantification of symptom severity.[8] Clinical trial and provider outcome reports are shifting to include patient-reported outcome measures [PROM],[9] which are important for value-based health care where value is defined as outcomes that matter most to patients divided by the cost of that care.[10]

The International Consortium for Health Outcomes Measurement [ICHOM] has developed 'Standard Sets' of outcomes for a diverse range of medical conditions to focus on value-based health care. These Standard Sets have been used to collect PROM data across multiple specialties including obstetric medicine, ophthalmology, oncology, and rheumatology.[11–14] A Standard Set for IBD was published in 2018 using the ICHOM evidence-based framework.[15] This incorporates both patient- and clinician-based outcome measures across domains including symptoms and quality of

life, disease control, health care utilisation, and disutility of care. Experience with the IBD Standard Set has not yet been published.

TrueColours-IBD [TC-IBD] is a comprehensive web-based, real-time, software programme which allows remote entry and monitoring of PROMs.[16] Participation in TC-IBD is offered to all patients with IBD being treated at the Oxford University Hospitals NHS Foundation Trust [John Radcliffe Hospital and Horton Hospital], but was implemented in a staged fashion: patients with UC were enrolled first [from June 2018], followed by CD [from Jan 2019]. This report collates the first 24 months of patient data. Through e-mail prompts linked directly to validated questionnaires, patients can record a range of information relating to symptoms, quality of life, and ICHOM outcomes. For symptoms [prompted daily or weekly], patients with UC or IBD-U complete the Simple Clinical Colitis Activity Index [SCCAI] and those with CD complete the Harvey–Bradshaw Index [HBI]. The original clinician-reported version of the HBI was modified to a patient-facing version in order to exclude items that required physical examination, focusing on general well-being, abdominal pain, and stool frequency. Reliability of patient data collection for SCCAI using TC-IBD through item response theory has been reported,[17] showing that only four items [rectal bleeding, diurnal stool frequency, nocturnal stool frequency, and urgency] contribute to the total SCCAI, with negligible contributions from reporting of extraintestinal manifestations.

Evidence that digital data collection by patients is an effective approach to collecting such outcomes in practice is sparse. Our aims were to test the feasibility of collecting ICHOM data for IBD at scale; and to quantify the outcomes achieved in routine practice at an IBD centre as a metric for our quality improvement programme.

2. METHODS

2.1. Design

This report details a single-centre, prospective, observational study of the first 24 months of patient-reported outcome data collected using the TrueColours-IBD platform. All patient responses are held on a secure Oxford Health server. Data exported for analysis and publication are de-identified. The current report relates to the patient-reported component of the ICHOM Standard Set captured at the time of enrolment into the TC-IBD programme.

2.2. Inclusion and exclusion criteria

All patients attending outpatient IBD clinics within the Oxford University Hospitals NHS Foundation Trust were offered participation in TrueColours-IBD. Exceptions were that patients with either stomas or ileoanal pouches were excluded, owing to their lack of validated symptom indices.

2.3. Disease classification

Disease activity for SCCAI was classified as remission ≤2, mild 3–5, moderate 6–11, and severe ≥12, and for HBI as remission ≤3, mild 4–6, moderate 7–11, and severe ≥12. For patient-reported disease control [prompted fortnightly], patients complete the IBD-Control-8.[18] All other ICHOM outcomes are asked at baseline [covering the previous 12 months] and entered with the assistance of a health care professional [HCP], and are then submitted 3-monthly by patients individually. Haemoglobin results within 3 months of the ICHOM questionnaire being completed were entered into TC-IBD. To test the representativeness of the patient population enrolled, all patients in TC-IBD included in this study were audited by UK postcode and compared with all patients enrolled on the Oxford Infoflex IBD database.

2.4. IBD Standard Set—Patient-Reported Questions

The IBD Standard Set of questions is the same for UC and CD. Integral to the IBD ICHOM Standard Set is quality of life as defined by the IBD-Control questionnaire.[14] This is a simple outcome tool designed to capture information regarding disease control and quality of life from the patient's perspective. The validated tool applies both to UC and to CD. The IBD-Control-8 score is a validated index using a subset of the full IBD-Control questionnaire, with scores ranging from 0 [worst] to 16 [best] [Table 1]. A score of ≥13 identifies patients with quiescent disease. An additional question from the full tool, 'Over the past 2 weeks, have your bowel symptoms been getting worse, getting better, or not changed?', was also collected.[18]

ICHOM Standard Set also includes baseline questions that capture 'case mix variables' including demographic characteristics such as height, weight, education level, and smoking status. Disease-specific questions include disease duration, extent, extraintestinal manifestations, and comorbidities, entered with the assistance of an HCP at baseline. Assessment of disutility of care includes questions related to duration of oral prednisolone use over the preceding 12 months, complications relating to an intervention for IBD and its outcome, emergency department presentations, hospital admissions [excluding admissions for day case infusions], and total duration of hospitalisation. A history of a diagnosis of bowel cancer is also sought. Adherence to the longitudinal schedule of questionnaires was calculated for each patient as an overall percentage. Reporting of admission data was cross-referenced with Oxford hospitals admission data to estimate accuracy, acknowledging that information regarding admissions to other trusts or health services would not be accessible.

2.5. Statistical analysis

Continuous data are presented as summary statistics using mean [standard deviation, sd] for normally distributed variables

Table 1. IBD Control-8

Do you believe that:
1. Your IBD has been well controlled in the past *two weeks*?
2. Your *current treatment* is useful in controlling your IBD?
In the past 2 weeks did you:
1. Miss any planned activities because of IBD?
2. Wake up at night because of symptoms of IBD?
3. Suffer from significant pain or discomfort?
4. Often feel lacking in energy [fatigue]?
5. Feel anxious or depressed because of your IBD?
6. Think you needed a change to your treatment?

Best possible score = 16, worst possible score = 0; each question has three categorical responses, scored as 0 for the least favourable and 2 for the most favourable.
IBD, inflammatory bowel disease.

Table 2. Demographics at enrolment.

	IBD diagnosis			
	Ulcerative colitis, *n* = 779 [60%]		Crohn's disease, *n* = 520 [40%]	
Age, mean [sd]	43	[16]	41	[15]
Female, *n* [%]	413	[53]	258	[50]
Education level				
Nil formal, *n* [%]	41	[5]	33	[6]
Primary, *n* [%]	12	[2]	7	[1]
Secondary, *n* [%]	271	[35]	204	[39]
Tertiary, *n* [%]	455	[58]	276	[53]
Smoking status				
Never, *n* [%]	463	[59]	282	[54]
Former, *n* [%]	275	[35]	175	[34]
Current, *n* [%]	41	[5]	63	[12]
BMI, median [IQR]	25.0	[22.1, 28.6]	24.6	[22.0, 29.1]
Self-reported disease extent [Montreal],[a] *n* [%]				
Proctitis [E1]	169	[22]	-	
Left-sided [E2]	169	[22]	-	
Extensive [E3]	216	[27]	-	
Unsure	225	[29]	-	
Ileal [L1]	-		225	[43]
Colonic [L2]	-		87	[17]
Ileal & colonic [L3]	-		140	[27]
Upper GI [L4]	-		4	[1]
Other	-		64	[12]
Reported extraintestinal manifestations	231	[30]	209	[40]
Previous infections				
HIV, *n* [%]	2	[0.3]	0	[0]
Hepatitis B, *n* [%]	1	[0.1]	1	[0.2]
Tuberculosis, *n* [%]	7	[0.9]	3	[0.6]

IBD, inflammatory bowel disease; sd, standard deviation; IQR, interquartile range; BMI, body mass index; GI, gastrointestinal.
[a]Correlation with documented disease extent detailed under 3.2..

and median [interquartile range, IQR] for non-parametric variables. Student's t test or the Wilcoxon rank-sum test were used for these data where appropriate. Categorical data are presented as number [percentage]. Fisher's exact test or a chi square test were used where appropriate. Adherence to the longitudinal schedule of questionnaires was calculated for each patient as the percentage of the expected number of returned questionnaires based on the duration of enrolment in the TC-IBD programme. Reproducibility of the validated scores [IBD-Control-8, SCCAI, and modified HBI] was assessed by comparing the scores of patients a fortnight apart and during a 4-week period of self-reported 'no change' in disease control.

3. RESULTS

3.1. Patient population

Within 24 months, 1299 patients registered through the TC-IBD programme, of whom 671 [52%] were female, with a mean age at baseline response of 42 years [sd 16 years, range 16, 85 years]. Median body mass index [BMI] was 24.9 kg/m^2 [IQR 22.1, 28.7] and 104 participants [8%] identified as current smokers. The group was skewed towards having completed higher education; demographic characteristics are summarised in Table 2. Median duration of follow up was 270 days [IQR 116, 504 days] with a total of 453 068 person-days of follow-up. Post code analysis showed 74% with an OX [local] postcode and 13% with a regional code [HP/RG/SN/MK]; 13% came from further afield, consistent with the predominantly secondary care service of the Oxford IBD service. Comparison of the 1299 patients with 4272 patients on our Infoflex IBD database of all our patients showed no significant difference in clinical characteristics or post code proportions [p = 0.25, Supplementary Table S1].

3.2. IBD characteristics

In all, 779 patients [60%] had UC and 520 [40%] patients had CD. Those with UC had a median disease duration of 6.4 years [IQR 1.8, 13.9] vs 10.8 years [IQR 4.8, 20.0] for CD. HCP-assisted reporting of disease extent at baseline is shown in Table 2. Extraintestinal manifestations of IBD were reported by 440 [34%] patients. These were less likely to be reported by patients with UC [231/779, 30%] than CD [209/520, 41%], p <0.001. Of those with UC, 58% were in clinical remission [SCCAI ≤2] compared with 66% with CD [HBI ≤3, Figure 1]. Mean haemoglobin level was 135 g/L [sd: 14.4]

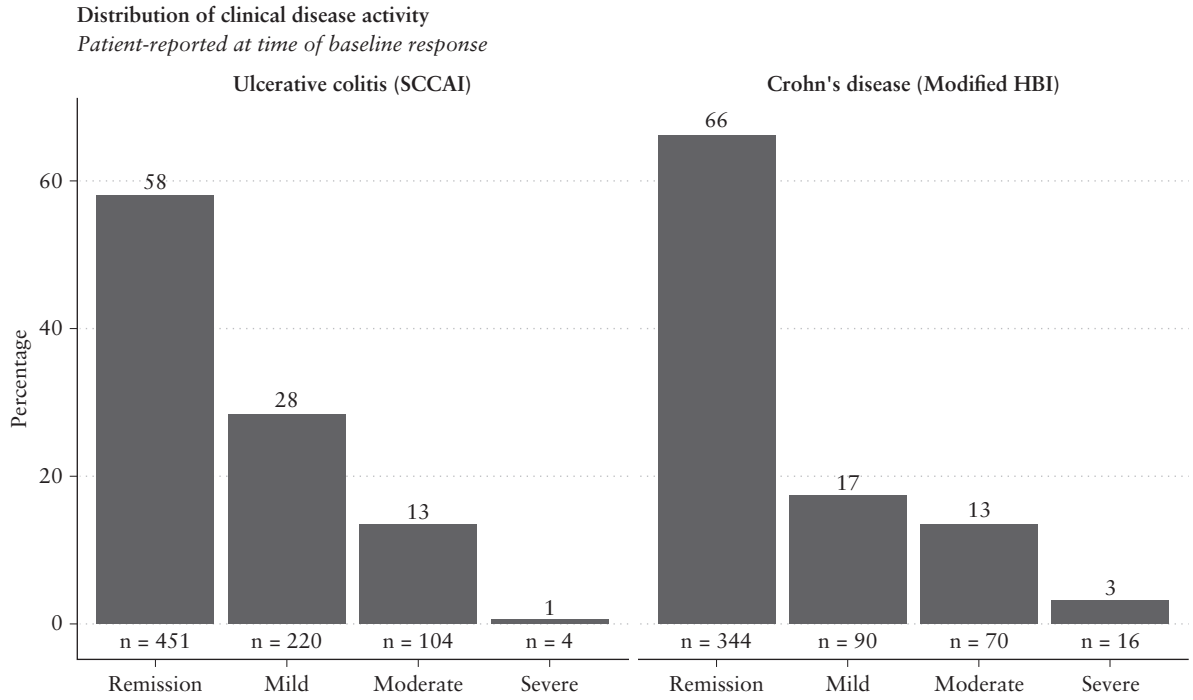

Figure 1. Self-reported disease activity by validated scores at the time of baseline response. Disease activity for SCCAI was classified as remission ≤2, mild 3–5, moderate 6–11, and severe ≥12. Disease activity for Modified HBI was classified as remission ≤3, mild 4-6, moderate 7–11, and severe ≥12. SCCAI, Simple Clinical Colitis Activity Index; HBI, Harvey–Bradshaw Index.

with no difference between UC or CD; 169 [14%] patients were taking no medications at baseline (63 [8%] UC vs 106 [20%] CD). For the remaining 1130 [86%], medication use is detailed in Table 3. Notably, 476 [37%] were using either biologic or small molecule therapy.

3.3. IBD-Control-8 and symptom scores [SCCAI and modified HBI]

Quality of life and the impact of patients' IBD are summarised in Table 4. Fatigue [50%], and anxiety and depression [23%] were common. Adherence to the schedule of reporting IBD Control-8 was good: patients completed a median 100% [IQR 48, 100%] of the fortnightly follow-up questionnaires. Similarly, patients enrolled for at least 3 months completed a median of 100% [IQR 75, 100%] of the expected number of quarterly follow-up questionnaires. There was no decrement in adherence over time, nor any correlation between adherence and IBD-Control-8 scores. IBD-Control-8 scores were correlated with the SCCAI and modified HBI symptom scores, with Pearson's r being -0.68 [p <0.001] for UC and -0.70 [p <0.0001] for CD. Median IBD-Control-8 scores for those with UC in remission were 15 [IQR 13, 16] vs 8 [IQR 5, 12] for those reporting active disease using SCCAI [p <0.001]. Similarly for CD, median IBD-Control-8 scores for those reporting remission were 14 [IQR 12, 16] vs 7 [IQR 4, 11] for active disease using the modified HBI [p <0.001]. The SCCAI and modified HBI in UC vs CD patients, respectively, were numerically higher in those patients who reported suffering from extraintestinal manifestations of IBD. Reproducibility of the scores was good, with the mean difference 2 weeks apart in patients with self-reported disease stability being close to zero. Likewise, the intraclass correlation coefficient was high [Table 5].

3.4. Disutility of care

A total of 992/1299 [76%] of patients reported no prednisolone use within the preceding 12 months. Prednisolone was used by 223 [29%] patients with UC and 84 [16%] patients with CD [p <0.001], with the statistically significant difference driven by a greater than expected number of UC patients using prednisolone: 202 [16%] reported use of prednisolone for less than 3 months and 105 [8%] reported use for more than 3 months [Figure 2]. Further, 97 [7%] patients reported an IBD-related intervention [endoscopic, radiological, or surgical: 5% UC vs 12% CD, p <0.001], and 82 [6%] reported having had an unplanned IBD-related hospital admission previously [4% UC vs 10% CD, p <0.001]. In all, 291 [22%] patients reported a hospital attendance in the preceding year, of whom 183 [14%] reported requiring at least one hospital admission, exceeded by 224 [17%] who had at least one emergency department presentation in the same period. Of the 183 patients admitted, the median duration of admission was reported to be 5 days [IQR 3, 7] for UC and 4 days [IQR 2, 8] for CD. Following cross-referencing with hospital admission data for the John Radcliffe Hospital, 151/183 [83%] could be verified. A total of 38 [3%] patients were admitted as an inpatient for a period longer than 10 days. Patients from outside the Oxford area would have been admitted to their local hospital. Overall, 177 [14%] patients reported suffering from a complication of their IBD at some time in the preceding 12 months [Table 6].

4. DISCUSSION

Only by publishing internationally agreed patient-reported outcome measures will it be possible to compare individual hospitals or health care systems. This study, the first report

Table 3. Medications.

Medication class, *n* [%]	IBD diagnosis			
	Ulcerative colitis, *n* = 779 [60%]		Crohn's disease, *n* = 520 [40%]	
No medication	63	[8]	106	[20]
Corticosteroids	120	[15]	52	[10]
Aminosalicylates	513	[66]	10	[2]
Conventional immunomodulators	181	[23]	165	[32]
Advanced therapies	204	[26]	271	[52]
Experimental therapies	1	[0]	0	[0]

Prior medication history was not recorded. Corticosteroids include oral and topical preparations. Advanced therapies include all currently licensed medications within the biologic or small molecule classes. The sole experimental [currently unlicensed] therapy was mirikizumab.

Table 4. ICHOM Patient-Reported Outcomes.

Metric	Ulcerative colitis, *n* = 779 [60%]		Crohn's disease, *n* = 520 [40%]	
IBD-Control-8, median [IQR]	13	[9-16]	13	[8-15]
Do you believe that: *n* [%]				
Your IBD has been well controlled in the past fortnight?	542	[70]	358	[69]
Your current treatment is useful in controlling your IBD?	557	[72]	314	[60]
In the past 2 weeks did you: *n* [%]				
Miss any planned activities because of IBD?	113	[15]	96	[18]
Wake up at night because of symptoms of IBD?	184	[24]	166	[32]
Suffer from significant pain or discomfort?	237	[30]	166	[32]
Often feel lacking in energy [fatigue]?	372	[48]	275	[53]
Feel anxious or depressed because of your IBD?	174	[22]	119	[23]
Think you needed a change to your treatment?	141	[18]	59	[11]
Over the past fortnight have your symptoms been: *n* [%]				
Better	152	[20]	61	[12]
Unchanged	505	[65]	369	[71]
Worse	122	[16]	90	[17]
Disutility of care				
Duration of prednisolone over the past 12 months, *n* [%]				
None	556	[71]	436	[84]
<3 months	144	[18]	58	[11]
>3 months	79	[10]	26	[5]
Health care utilisation over the past 12 months, *n* [%]				
Admitted to hospital	103	[13]	80	[15]
Presented to emergency department	129	[17]	95	[18]
Colorectal cancer, *n* [%]	2	[0.3]	4	[0.8]

The IBD-Control-8 questionnaire is one of the patient-reported outcome metrics collected by the ICHOM Standard Set for IBD. Results are reported as number [percentage] of 'Yes' responses to the items.
ICHOM, International Consortium for Health Outcomes Measurement; IBD, inflammatory bowel disease; IQR, interquartile range.

using the ICHOM Standard Set for inflammatory bowel disease, demonstrates the feasibility of collecting ICHOM data directly from patients using a specific digital solution. It not only serves as a benchmark for outcomes in real-world practice at a major centre, but reveals the stark deficit in current care for patients with IBD. The ICHOM Standard Set captures information spanning multiple domains that together provide a comprehensive picture of the disease experience from the patient perspective. The web-based TC-IBD platform is the vehicle by which the data are captured in real time, which also enables data to be captured longitudinally, so that trends can be identified and the impact of changes in practice [or treatment] can be measured. Integrating this process into routine clinical care enables a focus on the primary purpose of medicine—to improve the quality of life for our patients.

One stark reality of care for IBD is the much higher proportion than expected [8%] of the overall cohort reporting steroid use for greater than 3 months in the past 12 months, at a centre where much effort is spent on avoiding this outcome. Previous

internal audit had indicated a figure close to 0%. From these data it is unclear whether this is being driven by the specialist physician, general practitioners, or the patients themselves; nor is it known whether this is better than, worse than, or the same for other hospitals with similar case-mix variables. It serves to benchmark practice and as a focus for measures to achieve steroid-free remission. Although it is better than the 58% of patients reporting steroid use for greater than 3 months over a 2-year period in the IBD2020 patient survey that covered over 7500 patients in eight countries,[19] there is much room for improvement. It highlights the need for further education, both for patients and for clinicians, of the importance of reducing corticosteroid use. It also serves to quantify steroid dependency despite the prevalent use of advanced or steroid-sparing therapies [39% using biologic/small molecule therapy and 30% taking an immunomodulator] at a major centre. The provision of digital self-monitoring tools for IBD provides an opportunity to explicitly track steroid use, with potential for alerts to reinforce strategies aimed at minimising steroid exposure.

Table 5. Reproducibility of instrument scores.

Instrument	Mean difference [sd]	Intraclass correlation [95% CI]
IBD Control-8	0.02 [1.9]	0.86 [0.84–0.87]
SCCAI [UC only]	0.002 [1.2]	0.85 [0.82–0.87]
Modified HBI [CD only]	-0.09 [2.0]	0.85 [0.81–0.88]

SCCAI, Simple Clinical Colitis Activity Index; UC, ulcerative colitis; HBI, Harvey–Bradshaw Index; CD, Crohn's disease; sd, standard deviation; CI, confidence interval.

Another reality is the impact that IBD has on psychosocial function and quality of life. The high prevalence of fatigue [50%] and anxiety or depression [23%] is similar to other studies showing a prevalence of fatigue in 41%, anxiety in 31%, and depression in 40% of large IBD cohorts using validated questionnaires.[20,21] The IBD2020 patient survey reported that over 50% of patients described significant fatigue and anxiety or depression.[19] Nevertheless, when these data are seen to apply to one's own cohort of patients, they serve as a reality check. That these data might be collected in any hospital, by applying the ICHOM Standard Set for patients to report themselves in routine practice, is a relevant message. Despite the impact of these highly prevalent manifestations of IBD, there exists a poor framework for their management. The move towards value-based health care, where value is defined as outcome divided by the cost of care,[10] will need to address this deficit measured by individual patients communicating their unmet needs to clinicians via PRO collection, using web-based systems as a vehicle.

The unpredictability of IBD is a constant anxiety for many patients. Hospitalisation rates in our cohort were 14% in the preceding 12 months, which compares with a self-reported 28% hospitalisation rate in the IBD2020 report.[19] Admission was unplanned in 80 patients [6%], but 221 [18%] patients had at least one emergency department presentation during the same period. Given the impact of emergency department presentation on radiation exposure and steroid prescription,[22–25] this is a transferrable metric on the overall quality of care for patients with IBD in a health care system. Data from the Qorus initiative in the USA reports similar figures with 14% corticosteroid use, 18% with emergency department presentations, and 14% hospitalisation rates. Importantly however, use of a structured quality improvement programme focused on IBD care resulted in a meaningful decline in all of these metrics within 17 months of implementation.[26]

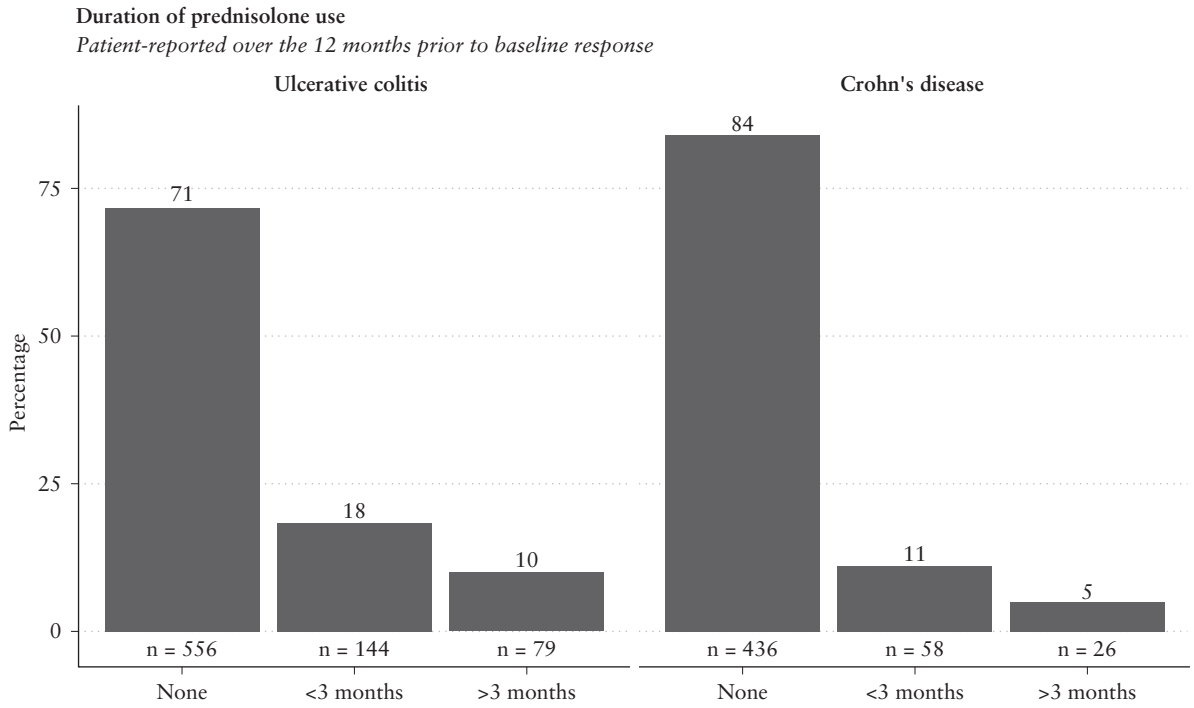

Figure 2. Patient-reported duration of prednisolone use during the 12 months prior to completing the baseline questionnaire.

Table 6. Patient-reported complications.

Reported complication	IBD Diagnosis	
	UC *n* = 779	CD *n* = 520
Thiopurine pancreatitis	5	6
Other drug reaction/intolerance	35	29
Infection[a]	5	7
IBD progression	10	32
Postoperative complication	4	16
Other[b]	8	1
Total	67 [9%]	91 [18%]

IBD, inflammatory bowel disease; UC, ulcerative colitis; CD, Crohn's disease.
[a]Pyelonephritis [1], shingles [2], gastroenteritis [1], pneumonia [1].
[b]Depression, pregnancy, brain tumour, visual disturbance, bowel obstruction from capsule endoscopy, haematuria, rash.

There are a number of limitations in our report. It may be questioned whether patients in Oxford are representative of a wider population, but 87% had a local or regional postcode, indicating the dominance of secondary care in our service. Selection bias remains possible due to patients not being recruited consecutively, but comparison of the patients in this study with those in our full database shows no difference from those enrolled into TC-IBD. Furthermore, disease characteristics and ICHOM data in the preceding 12 months at baseline were largely entered with the assistance of an HCP, but subsequent outcomes are patient-reported, so there may be inaccuracies. This is compounded by potential concerns about the validity and reliability of patient-reported data relating to disease characteristics and disutility of care, due to the wording of these items being generated *de novo*. The psychometric robustness of the items was not tested prior to data collection, but supportive evidence for the performance of these items is indicated by the fact that hospital admissions and emergency department visits could be confirmed [for the John Radcliffe Hospital] in the large majority. The report also lacks data on clinician-reported aspects of the ICHOM Standard Set, since the TC-IBD system has yet to be integrated into the electronic patient record. In addition, the TC-IBD programme is currently Oxford-centric, making translatability of our experience to other centres unclear. Other UK centres are in the process of starting the programme, which will shed light on whether digital solutions, such as TC-IBD, can reliably initiate the shift towards genuine patient engagement in the development of quality improvement initiatives. At this time these programmes may be a useful adjunct to standard clinical care, allowing capture of contemporaneous patient-reported outcome data, and may aid in patient investment in their health outcomes. However, direct clinical applicability cannot be drawn from this study; in its current form, the TC-IBD platform is solely a data capture and visualisation tool without a system of alerts or back office monitoring to flag metrics of concern to the treating team. Also, it is not yet possible to group patterns of future disease behaviour according to severity, owing to variable time points of data entry and case-mix variables. Mathematical modelling is essential to this analysis, and that is in progress, as well as a cost-benefit analysis. The current paper is an important step in describing the feasibility of such data collection in a busy IBD service, regarding disease activity, quality of life, and outcomes not only in more than a thousand patients, but with many thousands of data points.

This study demonstrates the feasibility of collecting longitudinal patient-reported outcome data using the ICHOM Standard Set for inflammatory bowel disease. The data quantify the deficit in current care for IBD by measuring outcomes agreed with and by patients, in contrast to disease outcomes which are the typical focus of clinician-driven encounters. It represents a step towards value-based delivery of IBD care. The approach has the potential to act as a metric for quality improvement programmes.

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Conflict of Interest

No authors report financial conflicts of interest. ST led the international group that developed the ICHOM Standard Set, of which KB was a member. None of the other authors have any conflict of interest in relation to publication of this work.

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Data Availability

The data underlying this article cannot be shared publicly, to protect the privacy of the individuals who participated in the study. The data will be shared on reasonable request to the corresponding author.

Author Contributions

Concept and design of study—DW, LM SPLT, AW. Analysis and interpretation—DW, RK, KB, SPLT, AW. Data acquisition—all authors. Critical revisions—DW, RK, JG, KB, SPLT, AW.

Supplementary Data

Supplementary data are available at *ECCO-JCC* online.

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