

Evaluation of emergency hospital admissions for Inflammatory Bowel Disease as a possible marker of quality of care of British IBD Inflammatory Bowel Disease units

Christian P Selinger,^{1,2} Alex Bottle³, Christopher Lamb,^{4,5} Rachel Ainley,⁶ Ruth Wakeman,⁶ Barney Hawthorne^{7,8}

1. Leeds Gastroenterology Institute, Leeds Teaching Hospitals, UK
2. Leeds Institute of Medical Research at St James's, University of Leeds, UK
3. School of Public Health, Imperial College London, UK
4. Translational and Clinical Research Institute, Newcastle University, Newcastle upon Tyne, UK
5. Department of Gastroenterology, Newcastle upon Tyne Hospitals National Health Service Foundation Trust, Newcastle upon Tyne, UK
6. Crohn's & Colitis UK, Hatfield, UK
7. Department of Gastroenterology, Cardiff & Vale University Health Board, Cardiff, UK.
8. Centre for Trials Research, Cardiff University, Cardiff, UK.

Corresponding Author:

Dr Christian Selinger

Leeds Gastroenterology Institute

Leeds Teaching Hospitals NHS Trust

St James University Hospital

Bexley Wing

Leeds

LS9 7TF

United Kingdom

Telephone: +44 113 206 8768

Email: Christian.selinger@web.de

Authorship contributions:

CPS designed the study and performed the analysis. All authors interpreted the results. CPS wrote the draft manuscript. All authors critically reviewed the draft manuscript and approved the final manuscript.

Conflict of interest statement:

CPS has received unrestricted research grants from Warner Chilcott, Janssen, Celltrion and AbbVie, has provided consultancy to Warner Chilcott, Dr Falk, AbbVie, Takeda, Fresenius Kabi, Galapagos, Ferring, RedX, Arena and Janssen, and had speaker arrangements with Warner Chilcott, Dr Falk, AbbVie, MSD, Pfizer, BristolMyersSquibb, Celltrion and Takeda.

AB's Unit has received grants from Dr Foster (a wholly owned subsidiary of Telstra Health) and Medtronic. AB has provided consultancy to Ireland's HSE, AZ and Lilly.

Funding statement:

The study did not receive any external funding.

What is already known on this topic?

- Key performance indicators (KPI) can facilitate quality improvement for Inflammatory Bowel Disease (IBD)
- Several service factors correlate highly with patient reported quality of care

What this study adds?

- On a per patient level hospital admissions for IBD correlate with patient reported quality of care
- On a per unit basis there is no correlation between emergency hospital admission for IBD with patient reported quality of care

How this study might affect research, practice or policy?

- Further work is required to determine whether hospital admissions could be a useful KPI for IBD

Abstract

Background:

Key performance indicators (KPI) are required to facilitate quality improvement for Inflammatory Bowel Disease (IBD). Emergency admissions for IBD may represent a possible KPI.

Methods:

IBD emergency admissions for 2018-19 from Hospital Episodes Statistics for England were compared per population and per IBD cases with patient-reported quality of care from the IBD Patient Survey 2019. Patient-reported accident and emergency (A&E) attendances and hospital admissions for IBD were also compared with patient-reported quality of care.

Results:

For 124 IBD services within England we found only a weak and not statistically significant correlation between IBD admissions per 100,000 population and patient-rated quality of care (Spearman's $\rho=0.171$; $p=0.057$). Similarly, there was no significant correlation between IBD admissions per case and patient-rated quality of care (Spearman's $\rho=0.164$; $p=0.113$). Patients with ≥ 2 A&E attendances (odds ratio [OR] 0.72 95% CI 0.57-0.91; $p<0.001$) were less likely to report quality of IBD care as good or very good compared with those without A&E attendances. Patients with ≥ 2 admissions were less likely to rate their care as good or very good (OR 0.75 95% CI 0.65-0.88; $p<0.0001$) compared with those without hospital admissions.

Conclusions:

There is a clear association for Individual patients with ≥ 2 admissions or A&E attendances with a lower perceived quality of care. In contrast we found no correlation on a per unit basis for IBD admissions derived from Hospital Episode Statistics with patient-assessed quality of care. Further work is required to determine whether hospital admissions could be a useful KPI for IBD.

Introduction

Inflammatory Bowel Disease (IBD), comprising Crohn's disease and ulcerative colitis, covers mainly chronic inflammatory conditions affecting the gastrointestinal tract.(1) IBD affects over 500,000 patients in the United Kingdom, ranging from early childhood to old age.(2) While more effective therapies have been developed in the last 20 years, there remains a considerable disease burden for many patients, with incomplete symptom control, need for repeated courses of steroids, hospital admissions and resection surgery.(3-8) Quality improvement initiatives have shown considerable variation in care approaches and quality of care for patients with IBD.(7, 9-12)

In the United Kingdom (UK) IBD UK, a partnership of health care professional organisations and patient organisations, has developed standards of care for IBD that were last updated in 2019.(13) In an effort to understand the landscape of IBD care in the UK, a patient survey and service self-assessment was undertaken in 2019.(9) Feedback from 9757 adult patients and 134 adult services revealed significant variations in the provision and quality of care. No single service met all the IBD UK standards (see below), and considerable investment and quality improvement are required to improve the care for patients with IBD in the UK.(9)

We reported that patient-reported quality of care and satisfaction with care is a very useful marker for assessing IBD services. We found high correlation between patient reported quality of care and important aspects of the IBD standards including 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 $p < 0.001$).⁽⁹⁾ In order to facilitate impactful quality improvement programs key performance indicators (KPI) are required to allow services to benchmark their performance and measure the effect of service changes. The British Society of Gastroenterology has recently published four IBD KPIs including 1) time from referral to diagnosis, 2) time from diagnosis to treatment, 3) steroid use, and 4) advanced therapy safety screening and efficacy assessments.⁽¹⁴⁾ These will allow longitudinal assessments of services but require regular data collection for repeated audit cycles.

Routinely collected health care data in contrast may allow for a more effortless assessment of services. Potentially avoidable emergency admissions are being examined as a candidate marker of performance of the UK health care system.⁽¹⁵⁾ Emergency admissions for IBD hospital care are seen may therefore be a potentially useful measure of performance based on the assumption that less effective and slow to respond outpatient services could lead to avoidable emergency admissions. Our hypothesis was therefore that emergency admissions for IBD are associated with worse patient reported quality of care. We aimed to test this hypothesis by examining data from the National Health Service (NHS) Hospital Episodes Statistics (HES) and assessing for correlations with patient satisfaction from the IBD Patient Survey 2019.

Methods

IBD patient survey and service self-assessment

A patient survey assessing several aspects of experience of IBD care and patient rated quality of care was distributed via IBD clinics, emails, social media and the IBD UK website. The survey was conducted from 8 July 2019 to 22 November 2019. For this study we restricted the data set to English services only to match the HES data sets, which are only available for services under NHS England. We extracted for each IBD service the proportion of patients reporting their care as good, very good or excellent from the patient survey. In addition, data regarding the general population covered by the NHS service in which the IBD units are placed were taken from the service self-assessment. Where there were no responses for the service self-assessment, we ascertained the population covered from publicly available information provided by the NHS services. The number of patients with IBD cared for by a service was extracted from the service self-assessment. Where this figure was not available, we excluded the sites from the analyses focussing on the per IBD cohort rather than per population aspects.

Hospital Episode Statistics

HES is a database that mainly contains details of admissions to NHS hospitals in England. Data regarding the type of admission (elective versus emergency), length of admission, procedures and diagnoses are entered by clinical coders at each hospital. We included only emergency admissions to hospitals and excluded emergency room (A&E) only visits, outpatient appointments and day case admissions. Admissions were classed as IBD admissions if the primary diagnosis was an ICD10 code for IBD (K50 and K51) or if a secondary diagnosis of IBD was combined with a primary diagnosis compatible with an IBD admission. We included all IBD admissions for the financial years 2018 and 2019. NHS services were included in the study if the site provided acute hospital care within the catchment area. NHS services with fewer than 100 IBD emergency admissions in the study period and specialist hospitals not covering gastrointestinal conditions were excluded.

Patient reported A&E attendances and hospital admissions

Patients reported the number of A&E attendances for IBD symptoms prior to diagnosis (if they were diagnosed within 2 years) and all patients reported the number of hospital admissions for IBD within the 12 months leading up to the survey. We analysed data by categorising patients into those with an admission, those with a single admission and those with two or more admissions.

Analyses

Descriptive analysis of IBD services, population covered, and patient reported quality of care were undertaken. We performed two analyses focussing on the association between patient-reported quality of care and emergency admissions per 100,000 population (an analysis based on the whole population catchment area of the hospital) and emergency admissions per 1,000 IBD cases (an analysis based on the number of IBD cases reported by the hospital to be under their outpatient IBD service). To examine associations between patient reported quality of care and the outcomes we performed a correlation analysis using Spearman's rho. In addition, we examined the rates of

admissions between the 4 quartiles of sites by patient-reported quality of care. We also stratified the analysis by secondary and tertiary referral care centres.

We have approval from the Secretary of State and the Health Research Authority under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to hold confidential data and analyse them for research purposes (CAG ref 15/CAG/0005). We have approval to use them for research and measuring quality of delivery of healthcare, from the London - South East Ethics Committee (REC ref 20/LO/0611).

Results

Of 124 English IBD services included from the IBD UK survey and service self-assessment, 94 had provided data on the size of their IBD cohort. The IBD services covered a median population of 442,500 (Interquartile Range [IQR] 300,000 – 615,000) and a median IBD cohort of 2433 patients (IQR 1,500 - 3575). The average proportion of patients reporting their care as good, very good or excellent was 0.68 (range 0.33 to 1.00; Standard Deviation 0.12). Emergency admissions per service for the period 2018-2019 ranged from 133 to 1655 (median 400; IQR 266 - 520). A median of 89 (IQR 72 - 113) IBD admissions were recorded per 100,000 population. The median number of IBD admissions was 0.174 per IBD case (IQR 0.122 – 0.228). There were 21 tertiary referral services and 73 secondary care services. Tertiary care services covered greater populations ($p < 0.0001$), had greater IBD cohorts ($p < 0.0001$) and had greater absolute numbers of admissions ($p < 0.0001$; table 1). There were no significant differences in patient reported quality of care, admissions per 100,000 population or admissions per IBD case (table 1).

Per population analysis

We found no significant correlation between IBD admissions per 100,000 population and patient rated quality of care (Spearman's $\rho = 0.171$; $p = 0.057$). No correlations were found when analysing for secondary care hospitals (Spearman's $\rho = 0.149$; $p = 0.138$) or tertiary referral centres (Spearman's $\rho = 0.281$; $p = 0.183$) separately. When admission rates were analysed comparing the services by quartiles according to levels of patient reported quality of care there were numerically more admissions in services with higher quality of care, but this was not significant ($p = 0.32$; table 2). No significant associations were found when analysing IBD admissions separately for secondary care and tertiary care services.

Per IBD case analysis

There was no significant correlation between IBD admissions per case and patient rated quality of care (Spearman's $\rho = 0.164$; $p = 0.113$). When stratifying by hospital status there was no significant correlation for secondary care hospitals (Spearman's $\rho = 0.134$; $p = 0.257$) or tertiary referral hospital (Spearman's $\rho = 0.289$; $p = 0.204$). On analysis by quartiles according to quality of care, services with higher quality of case had again numerically higher rates of IBD admissions, but this was not significant ($p = 0.65$; table 2). Separate analysis for secondary and tertiary care services revealed no significant associations.

Patient reported A&E attendances and hospital admissions

Within the IBDUK patient survey 1807 adult patients diagnosed with IBD for the first time in the two years leading up to the survey reported whether they had any A&E attendances for symptoms of IBD. Of these, 1088 had no A&E attendances, 328 one attendance and 391 more than one A&E attendance. Patients with two or more A&E attendances (odds ratio [OR] 0.72 95% CI 0.57-0.91; $p < 0.001$) were less likely to report their quality of IBD care as good or very good compared with those without A&E attendances for IBD symptoms, but there were no differences for those with one attendance only (OR 1.24, 95% confidence interval [CI] 0.95-1.61; $p = 0.118$).

Within the IBDUK patient survey 9131 adult patients reported whether they had any hospital admissions for IBD in the last 12 months. Of these, 7053 had no admissions, 1285 had one admission, and 793 had two or more admissions. Patients with two or more admissions were less likely to rate their care as good or very good (OR 0.75 95% CI 0.65-0.88; $p < 0.0001$) compared with those without admissions, but there were no differences for those with one admission only (OR 0.98 95% CI 0.86-1.12; $p = 0.740$).

Discussion

There is an urgent need for KPIs in IBD to enable quality improvement programs. Ideally, these would routinely be available in health care systems rather than from de novo data collection for clinical audit purposes. We compared IBD emergency hospital admissions with the patient-reported quality rating, which highly correlates with several of the IBD UK standards.^(9, 13) We found divergent results for individual patients and results on a per unit basis.

The personal perception of quality of care was clearly correlated with the personal experience of requiring ≥ 2 A&E attendances prior to diagnosis or requiring ≥ 2 hospital admission in the preceding 12 months. In keeping with our study hypothesis those patients reported significantly worse quality of care. In contrast, there was no significant correlation between IBD admissions derived from Hospital Episode Statistics and patient-reported quality of care on a per unit basis. Indeed, we found slightly numerically higher rates of admissions in units with higher patient-reported quality of care.

There may be several explanations for our divergent findings. While individual experiences likely influence individual patient reporting of quality of care, analyses on a per unit basis pose further challenges. First, over 75% of patients who took part in the IBD patient survey did not experience a hospital admission in the preceding 12 months. When breaking the responses down by individual units, the number of patients with admissions may have been too small to affect the overall quality of care rating for the unit.

Second, the association between A&E attendances or hospital admission with quality of care was only present for those with ≥ 2 episodes. Based on the IBD patient survey we can assume that most patients requiring hospital admission reported by Hospital Episodes Statistics for England will have only had a single admission in the preceding year. This may have impacted the results of the patient survey on a per unit basis as only a small proportion of patients taking part in the survey had ≥ 2 episodes of admission.

Third, IBD admissions occur for complex reasons including many unforeseeable flares, obstructive episodes, or abscesses due to the unpredictable nature of IBD. Patients experiencing such events may not rate the quality of care as low if they do not attribute their admission to poor outpatient care received prior to admission.

A number of emergency admissions may indeed be preventable with better outpatient care and responsive IBD flare hotlines, but it remains unclear how many IBD admissions fall into this category. IBD admissions may also be influenced by other centre-specific factors. Tertiary services provide services to a higher proportion of complex cases, and services with higher patient-reported quality of care may ultimately attract more patients, thereby having more admissions per population compared with other services.

Many patients have been reporting significant symptoms prior to diagnosis of IBD and it is likely that in some of these cases opportunities for an earlier diagnosis were missed and outcomes were worse with longer time to diagnosis.⁽¹⁶⁾ Time from primary care referral to IBD diagnosis and treatment are part of the new BSG KPIs.⁽¹⁴⁾ Further work is looking at how symptom onset can be incorporated in IBD quality improvement work.

The 'Getting It Right First' program has examined IBD emergency admissions as a proportion of all IBD admissions including day case admissions as a possible quality marker.⁽¹⁷⁾ This approach has so far not been validated against established quality markers. The denominator for any admissions is

highly dependent on the number of day case and/or elective admissions. This approach is becoming increasingly problematic as units providing more day case biologic infusions rather than home-administered biologics or novel small molecules would be deemed to provide higher quality care inappropriately.

In our view, IBD hospital admission rates derived from Hospital Episodes Statistics data may therefore not be useful as a simple key performance indicator at this stage. Further work is required to understand how admission on a per unit basis may be used to assess quality of care. For ease-of-use data that are already routinely captured on a national level on an electronic basis should be preferred for inclusion as KPIs. We recommend that any future formed on this basis KPI should be validated against the IBD patient survey and also against the recently established BSG IBD KPIs. By triangulation with these two assessment, it is likely that useful automatically collected KPIs can be derived.

There are a few limitations to our work as we relied on clinical coding for case identification, and the accuracy of IBD cohort estimation is not verified. Our analysis was limited to England, and the sample size may be too small for assessing teaching hospitals separately. Patient-reported A&E attendances and hospital admissions could not be cross-checked with hospital records due to the anonymous nature of the IBD patient survey. The patient survey was distributed via IBD clinics, emails, social media and the IBD UK website, which may have led to a selection bias towards more social media savvy patients. By excluding units with less than 100 admission we aimed to reduce bias from incorrect coding and very small services. This may have however also excluded a small number of DGHs with IBD services.

In conclusion, for IBD units emergency admissions per population or IBD case load are not associated with established patient reported quality of care markers for IBD, but reported quality of care for individuals is significantly associated with a history of A&E attendances or hospital admissions for IBD.

References:

1. Lamb CA, Kennedy NA, Raine T, Hendy PA, Smith PJ, Limdi JK, et al. British Society of Gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults. *Gut*. 2019.
2. Taita LJ. Epidemiology Summary: Incidence and Prevalence of IBD in the United Kingdom: Crohns and Colitis UK; 2022 [Available from: <https://crohnsandcolitis.org.uk/media/4e5ccomz/epidemiology-summary-final.pdf>].
3. Corte C, Saxena P, Tattersall S, Selinger C, Leong R. When to Use Biological Agents in Inflammatory Bowel Disease. *J Gastroenterol Hepatol*. 2011.
4. Selinger CP, Carbery I, Al-Asiry J. The role of biologics in the treatment of patients with inflammatory bowel disease. *Br J Hosp Med (Lond)*. 2018;79(12):686-93.
5. Sandborn WJ, Baert F, Danese S, Krznanic Z, Kobayashi T, Yao X, et al. Efficacy and Safety of Vedolizumab Subcutaneous Formulation in a Randomized Trial of Patients With Ulcerative Colitis. *Gastroenterology*. 2020;158(3):562-72 e12.
6. Al-Bawardy B, Shivashankar R, Proctor DD. Novel and Emerging Therapies for Inflammatory Bowel Disease. *Front Pharmacol*. 2021;12:651415.
7. Selinger CP, Parkes GC, Bassi A, Limdi JK, Ludlow H, Patel P, et al. Assessment of steroid use as a key performance indicator in inflammatory bowel disease-analysis of data from 2385 UK patients. *Aliment Pharmacol Ther*. 2019;50(9):1009-18.
8. Frolkis AD, Dykeman J, Negrón ME, Debruyen J, Jette N, Fiest KM, et al. Risk of surgery for inflammatory bowel diseases has decreased over time: a systematic review and meta-analysis of population-based studies. *Gastroenterology*. 2013;145(5):996-1006.
9. Hawthorne AB, Glatter J, Blackwell J, Ainley R, Arnott I, Barrett KJ, et al. Inflammatory bowel disease patient-reported quality assessment should drive service improvement: a national survey of UK IBD units and patients. *Aliment Pharmacol Ther*. 2022;56(4):625-45.
10. Wolloff S, Moore E, Glanville T, Limdi J, Kok KB, Fraser A, et al. Provision of care for pregnant women with IBD in the UK: the current landscape. *Frontline Gastroenterol*. 2021;12(6):487-92.
11. Kuenzig ME, Stukel TA, Kaplan GG, Murthy SK, Nguyen GC, Talarico R, et al. Variation in care of patients with elderly-onset inflammatory bowel disease in Ontario, Canada: A population-based cohort study. *J Can Assoc Gastroenterol*. 2021;4(2):e16-e30.
12. Weaver KN, Kappelman MD, Sandler RS, Martin CF, Chen W, Anton K, et al. Variation in Care of Inflammatory Bowel Diseases Patients in Crohn's and Colitis Foundation of America Partners: Role of Gastroenterologist Practice Setting in Disease Outcomes and Quality Process Measures. *Inflamm Bowel Dis*. 2016;22(11):2672-7.
13. Kapasi R, Glatter J, Lamb CA, Acheson AG, Andrews C, Arnott ID, et al. Consensus standards of healthcare for adults and children with inflammatory bowel disease in the UK. *Frontline Gastroenterology*. 2020;11(3):178-87.
14. Quraishi MN, Dobson E, Ainley R, Din S, Wakeman R, Cummings F, et al. Establishing key performance indicators for inflammatory bowel disease in the UK. *Frontline Gastroenterology*. 2023:flgastro-2023-102409.
15. Trust N. Potentially preventable emergency admissions 2023 [Available from: https://www.nuffieldtrust.org.uk/resource/potentially-preventable-emergency-hospital-admissions?gclid=Cj0KCQjw1OmoBhDXARIsAAAYGSFiyD2QLLOJdvvyPh7RQ_eQU0mSsV3KAAytDlvDAF_imJ9jYodkuUIUaAmtVEALw_wcB].
16. Jayasooriya N, Baillie S, Blackwell J, Bottle A, Petersen I, Creese H, et al. Systematic review with meta-analysis: Time to diagnosis and the impact of delayed diagnosis on clinical outcomes in inflammatory bowel disease. *Alimentary Pharmacology & Therapeutics*. 2023;57(6):635-52.
17. Oates B. Gastroenterology - GIRFT Programme National Specialty Report. NHS England; 2021.

Table 1: Differences between secondary care hospitals and tertiary referral hospitals

	Secondary Care Hospitals	Tertiary Referral centres	p-value
Population covered	400,000 (IQR 297,500 – 531,250)	637,500 (IQR 487,500 – 762,500)	p<0.0001
IBD cohort	2000 IQR (1,475 -3,000)	4400 IQR (3,800 -5,000)	p<0.0001
Patient-rated quality of care	0.675 SD 0.128	0.682 SD 0.121	p=0.81
Admissions total	372 (IQR 254 – 479)	523 (IQR 468 -479)	p<0.0001
Admission per population	87 (IQR 73-109)	99 (IQR 75 – 137)	p=0.36
Admissions per IBD case	0.18 (IQR 0.13-.024)	0.15 (IQR 0.1 – 0.18)	p=0.66

Figures presented as median with interquartile range (IQR) or mean with standard deviation (SD)

Table 2: IBD admissions by quartile of patient-reported quality of care

Patient-rated quality of care	Mean admissions per 100,000 population	Standard deviation	Mean admissions per IBD case	Standard deviation
1 st quartile	86.9	25.5	0.17	0.10
2 nd quartile	96.3	45.4	0.18	0.09
3 rd quartile	105.5	47.6	0.19	0.06
4 th quartile	103.4	49.8	0.21	0.17

No significant associations found (per population $p=0.32$; per IBD case $p=0.65$).