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ORIGINAL RESEARCH

Variation in the Care of Children with Inflammatory Bowel Disease Within and Across Canadian Provinces: A Multi-Province Population-Based Cohort Study

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On behalf of the Canadian Gastro-Intestinal Epidemiology Consortium

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Purpose: The incidence of childhood-onset inflammatory bowel disease (IBD) is rising. We described variation in health services utilization and need for surgery among children with IBD between six and 60 months following IBD diagnosis across Canadian pediatric centers and evaluated the associations between care provided at diagnosis at each center and the variation in these outcomes.

Patients and Methods: Using population-based deterministically-linked health administrative data from four Canadian provinces (Alberta, Manitoba, Nova Scotia, Ontario) we identified children diagnosed with IBD <16 years of age using validated algorithms. Children were assigned to a pediatric center of care using a hierarchical approach based on where they received their initial care. Outcomes included IBD-related hospitalizations, emergency department (ED) visits, and IBD-related abdominal surgery occurring between 6 and sixty months after diagnosis. Mixed-effects meta-analysis was used to pool results and examine the association between center-level care provision and outcomes.

Results: We identified 3784 incident cases of pediatric IBD, of whom 2937 (77.6%) were treated at pediatric centers. Almost a third (31.4%) of children had ≥1 IBD-related hospitalization and there were 0.66 hospitalizations per person during follow-up. More than half (55.8%) of children had ≥1 ED visit and there were 1.64 ED visits per person. Between-center heterogeneity was high for both

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outcomes; centers where more children visited the ED at diagnosis had more IBD-related hospitalizations and more ED visits during follow-up. Between-center heterogeneity was high for intestinal resection in Crohn's disease but not colectomy in ulcerative colitis.
Conclusion: There is variation in health services utilization among children with IBD and risk of undergoing intestinal resection in those with Crohn's disease, but not colectomy among children with ulcerative colitis, across Canadian pediatric tertiary-care centers. Improvements in clinical care pathways are needed to ensure all children have equitable and timely access to high quality care.

Plain Language Summary: Inflammatory bowel disease (IBD) is a chronic health condition of the gastrointestinal system, which is becoming more common in children. They require lifelong treatment and receiving high quality care is important for preventing complications. We determined if outcomes of children with IBD was different across Canada. We also tested if differences in care at diagnosis was related to outcomes. More than three-quarters of children with IBD were treated at pediatric hospitals. Children treated at some hospitals were more likely to be hospitalized and visit the emergency room when compared to children treated at other hospitals. Children with Crohn's disease (one type of IBD) were more likely to have surgery at some hospitals when compared to children treated at other hospitals. We should improve care to make sure children living with IBD have timely access to high quality specialist care.

Keywords: Crohn's disease, ulcerative colitis, health administrative data, variation in care, health services utilization, surgery

Introduction

The incidence of pediatric-onset inflammatory bowel disease (IBD) is rising globally.[1] Studies have demonstrated persistent significant variation in the care provided to children with IBD at diagnosis despite the introduction of clinical practice guidelines.[2,3] Although some variation is expected, variation not based on patient and caregiver preferences or disease characteristics suggests some patients receive lower quality care.[4,5] Equitable access to high quality care is vital for all children in order to minimize long-term complications while maximizing quality of life and long-term potential.[6]

In this multiprovince population-based study, we (1) describe variation in health services utilization and need for surgery among children with IBD between six and 60 months following diagnosis across Canadian pediatric centers and (2) evaluate the associations between the care provided at diagnosis at each center at diagnosis and the variation in these outcomes between centers.

Materials and Methods

This study was approved by the Research Ethics Boards at the Children's Hospital of Eastern Ontario (14/128X), University of Manitoba (HS17823), IWK Health Center (1018685), and University of Calgary (REB16-2375).

Study Design and Data Sources

We conducted a population-based retrospective cohort study using health administrative data in four Canadian provinces (Alberta, Manitoba, Nova Scotia, Ontario) with universal healthcare coverage for all legal residents (>99% of the population), comprising 57% of the Canadian population.[7] All healthcare encounters and demographic characteristics are recorded in provincial health administrative databases (Table S1). Databases are linked deterministically within each province using an encrypted identification number. Databases are available to researchers in an uncleaned and unedited format.[8] Provincial data holders are allowed to collect and analyze health care and demographic data, without consent, for health system evaluation and improvement.

We included all incident cases of pediatric-onset IBD diagnosed <16 years using validated algorithms based on diagnosis codes for IBD (International Classification of Disease (ICD)-9: 555.x, 556.x; 10-CA [Canadian enhancement]: K50.x, K51.x).[9–12] Algorithms and province-specific study start and stop dates are in Table S1. A validated three-year washout period differentiated incident from prevalent cases (not required for those with full continuously available data from birth).[9]

Assigning Cases to a Pediatric Center

Children with IBD were assigned to a pediatric center using a hierarchical approach based on where they received care in the first six months following IBD diagnosis (Figure 1). First, we identified whether patients had a hospital admission at a pediatric center with an IBD diagnosis code (ICD-9: 555.x, 556.x; ICD-10: K50.x, K51.x) as the most responsible

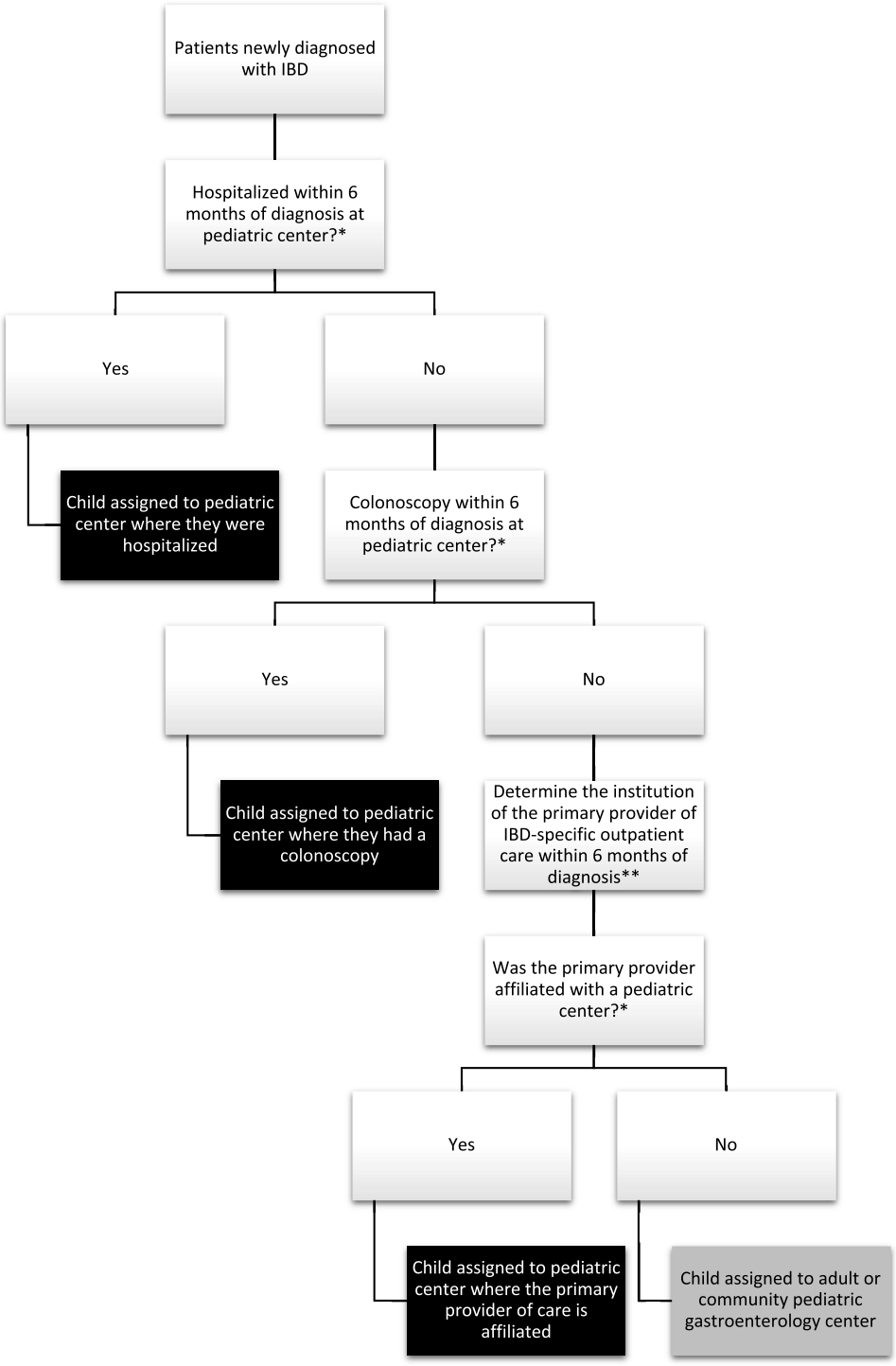

Figure 1 Flow diagram depicting the hierarchical process of assigning children diagnosed with IBD to a pediatric tertiary-care center based on where their IBD care was provided in the first six months following diagnosis. *If a child had encounters at both pediatric and adult centers, the child was assigned to the pediatric center. If the patient had encounters at multiple pediatric hospitals, the child was assigned to the pediatric center where the most recent care was provided. **If care was provided by both pediatric and adult gastroenterologists, the child was assigned to the center where care was provided by a pediatric gastroenterologist.

diagnosis, pre- or post-admission comorbidity, or most responsible for a patient transfer. Patients admitted to a pediatric tertiary care center were assigned to the center where they were admitted. If patients were not hospitalized, or were hospitalized at a non-pediatric tertiary care center, we used a database containing outpatient procedures (Alberta: Alberta Ambulatory Care Reporting System and Canadian Institute for Health Information [CIHI] National Ambulatory Care Reporting System; Manitoba and Nova Scotia: CIHI-Discharge Abstract Database [includes outpatient procedures, such as endoscopy]; Ontario: CIHI Same Day Surgery) to identify children undergoing endoscopy within six months of diagnosis at a pediatric center. The CCI (Canadian Classification of Health Interventions) and CCP (Canadian Classification of Diagnostic, Therapeutic, and Surgical Procedures) procedural codes listed in Table S2 were used to identify children undergoing endoscopy. Patients were assigned to the center where the endoscopy took place. If patients were not hospitalized, did not have an endoscopy, or only had an endoscopy at non-pediatric center within six months of IBD diagnosis, we assigned them to the center where they received their IBD-specific outpatient care within the first six months following diagnosis. IBD-specific outpatient care included outpatient visits with a diagnosis code for IBD. If IBD-specific outpatient care was provided by both pediatric and adult gastroenterologists (see Table S1 for specialist definitions), children were assigned to the pediatric center where their outpatient IBD care was provided. Patients receiving all care at adult institutions or community practices were assigned to a single group.

There were five pediatric tertiary centers in Ontario, two in Alberta, and one each in Manitoba and Nova Scotia (Table S1). Children with IBD living in the Ontario Census Metropolitan Area of Kingston at IBD diagnosis or treated at the pediatric center in Kingston, Ontario center were excluded due to missing shadow billing data which could impact estimates of variation (n=72). Children who could not be assigned to any center were excluded (Manitoba: n=8; Ontario: n=35).

Outcomes

We identified all IBD-specific and IBD-related health services utilization occurring between six and 60 months after IBD diagnosis (hereafter referred to as follow-up). IBD-specific encounters had a IBD diagnosis code. IBD-related encounters had a diagnosis code for IBD or an IBD sign, symptom, or extra-intestinal manifestation (Table S2).

Hospitalizations and Emergency Department Visits

We determined the (1) proportion requiring ≥1 hospitalization; (2) time to first hospitalization; and (3) mean number of hospitalizations per person. The same three outcomes were determined for emergency department (ED) visits.

IBD-specific and IBD-related hospitalizations required that codes were the most responsible diagnosis, a pre- or post-admission comorbidity, or most responsible for a transfer between services. Only hospitalizations ≥48 hours were included to exclude pre-planned short-term hospitalizations for bowel preparation prior to colonoscopy or biologic infusions.

Surgery

We identified children with Crohn's disease (CD) requiring intestinal resection and with ulcerative colitis (UC) requiring colectomy during follow-up using validated procedural codes (Table S3).[13,14] We determined (1) the proportion of children requiring surgery and (2) the time to first surgery. Analyses of surgical outcomes were conducted separately for CD and UC.

Characteristics of the Care Provided at Each Center at Diagnosis

Diagnostic Delay

We generated a list of diagnosis codes and associated lookback periods (eg five years for intestinal obstruction, one year for abnormal weight loss) that were potentially indicative of a future diagnosis of pediatric-onset IBD.[15,16] IBD experts were surveyed and ask to rank each diagnosis code and lookback pairing on a five-point Likert scale indicating their likelihood of indicating a future IBD diagnosis in the pediatric population. A score of 5 was indicative of a diagnosis code most likely to indicate a future IBD diagnosis and 1 was indicative of a diagnosis code least likely to indicate a future IBD diagnosis. Diagnosis codes with a mean score ≥4 were included. Table S4 summarizes the diagnosis codes and associated lookback periods used to define diagnostic delay.

In provinces where ED data were available (Alberta and Ontario), we identified all outpatient visits, ED visits, and hospitalizations with these codes. In provinces where ED data were not available (Manitoba and Nova Scotia), we identified all outpatient visits and hospitalizations with these codes. Diagnostic delay was the time between first healthcare encounter with a diagnosis code indicative of a future IBD diagnosis and the date of IBD diagnosis. We calculated the mean diagnostic delay for each center and included it in the analysis as a center-level predictor of variation (continuous).

Emergency Department Visit or Hospitalization at Diagnosis

For each center, we determined the proportion of children with an ED visit or hospitalization within the first month of diagnosis with an IBD-specific diagnosis code. Hospitalizations were only included if IBD was the most responsible diagnosis, a pre- or post-admission comorbidity, or diagnosis most responsible for transfer and had a length of stay ≥48 hours. ED visits and hospitalizations were analyzed separately.

Gastroenterologist as the Primary IBD-Care Provider

For each center, we determined the proportion of children with a gastroenterologist as the primary provider of outpatient IBD-specific care within the first six months of diagnosis (see Table S1 for specialist definitions). The primary provider of IBD-specific care for a patient was the physician who billed the majority of IBD-specific outpatient visits.

IBD-Specific Visits to a Gastroenterologist

For each child, we determined the proportion of their IBD-specific outpatient care that was provided by a gastroenterologist within six months of diagnosis; the denominator was the total number of IBD-specific outpatient visits to any physician. We calculated the mean proportion for each center.

Frequency of Outpatient Visits

We calculated the mean number of IBD-related outpatient visits for each child in the month before and month after IBD diagnosis, then calculated the mean number of visits at each center. Only one outpatient visit per day was counted.

Additional Variables

We report the age, sex, mean neighborhood income quintile (a validated proxy for individual socioeconomic status[17]) and rural/urban residence at the time of IBD diagnosis (Table S1).

Statistical Analysis

Means (standard deviation, SD) and percentages were used to describe continuous and categorical characteristics, respectively, of children included in the study. We used two approaches to evaluate variation in care between centers: (1) mixed-effects meta-analysis[18] using aggregate data from each center and (2) multilevel regression with individual-level data[19] (Ontario).

Mixed Effects Meta-Analysis

Mixed-effects meta-analysis was used to pool results across centers.[20] Because few children were treated outside of pediatric centers, we limited our assessment of between-center heterogeneity to these centers. Mixed-effects logistic regression models were used to pool proportions, where center was the intercept,[18] then converted these proportions to percentages. Mean numbers of events were log transformed for meta-analysis so that estimates of the association between predictors and outcomes could be interpreted as odds ratios (OR). All predictors were included in the models as continuous variables. Heterogeneity between centers was quantified using I^2 (variation in pooled event rates) and τ^2 (variance of true event rates),[21] using the Paule-Mandel method to estimate τ^2.[22]

We used generalized linear mixed-effects models to examine the association between outcomes and center-level predictors as well as province. Scatterplots were used to visualize associations and assess the linearity assumption for continuous predictors. R^2 quantified residual heterogeneity in outcomes not attributable to center-level predictors or provincial differences. The residual I^2 estimated residual variation in pooled event rates. The residual τ^2 estimated residual variance in the true event rates. In the absence of heterogeneity (I^2=0), the association between outcome and

predictor was not assessed. We used logistic regression to examine the association between the dichotomous outcomes and center-level predictors and province and linear regression to assess the association for continuous outcomes on the log-scale.

Multilevel Regression

This analysis was limited to data from Ontario because individual-level data could not be shared across provincial borders and the remaining three provinces only had few pediatric centers. For this analysis, children treated outside the four Ontario centers (by community or adult gastroenterologists) were combined into one group.

Frailty models[23] described variation across centers in the time to first hospitalization, ED visit, and surgery during follow-up. Mixed-effects Poisson regression assessed the variation across centers in the number of hospitalizations and ED visits during follow-up. Regression models included a random intercept for center. This allowed us to estimate variation in outcomes between centers and account for similarities in medical practices within the same center.

Variation in frailty models was expressed using median hazards ratio (MHR) and Kendall's τ.[24] In Poisson models, variation was reported using the median rate ratio (MRR) and the intraclass correlation coefficient (ICC).[25] The MHR and MRR represent the median increase in risk and rate, respectively, of the outcome when comparing someone treated at a center with a higher vs lower outcome rate.[24,25] The MHR and MRR are >1; higher numbers indicate greater variation. If the effect estimate (hazard ratio [HR] or rate ratio [RR]) describing an association between a covariate (age, sex, rurality, income) and the outcome was greater than the MHR/MRR or less than its inverse, this characteristic was considered more important than center of care in a patient's risk of the outcome.[24]

Kendall's τ describes the percentage of variation in the outcome resulting from between-center variation.[24] Higher values indicate that the variation results from between-center differences while lower values indicate variation due to between-person differences. The ICC similarly describes the percentage of variation, with higher values indicating greater between-center variation.

All regression models were adjusted for age at IBD diagnosis (continuous), sex, rural/urban residence, and mean neighborhood income quintile. We included center-specific characteristics of the care provided at diagnosis (mean diagnostic delay, percentage of patients at each center with a gastroenterologist as their primary provider of IBD care; both continuous) to evaluate their impact on between-center variation. These two predictors were selected based on discussion with IBD experts due to high collinearity with other predictors, prior to conducting any analyses.

Analyses were conducted using SAS software, v9.4 (SAS Institute, Cary, NC, USA). Meta-analyses and data visualizations were conducted using the metafor[26] (v3.8.1) and ggplot[27] (v3.4.0) packages in R (v4.2.2).[28]

Results

We identified 3784 incident cases of pediatric-onset IBD, of whom 2937 (77.6%) were treated at a pediatric tertiary care center within six months of IBD diagnosis (Table 1).

Hospitalizations

Mixed-Effects Meta-Analysis

Among children treated at a pediatric tertiary-care center, 29.1% (95% CI 24.0–34.7) had ≥1 IBD-specific hospitalization and 31.4% (95% CI 26.7–36.5) had ≥1 IBD-related hospitalization during follow-up (Figure S1). Province accounted for a large amount of the between-center heterogeneity in the proportion of children with ≥1 IBD-specific and ≥1 IBD-related hospitalization (Table 2). Centers where more children had an ED visit at diagnosis had a higher proportion of children admitted to hospital at least once for IBD-specific but not IBD-related reasons during follow-up (Table 2; Figure S1–S2).

Children with IBD were admitted to hospital a mean of 0.54 times for IBD-specific reasons (95% CI 0.43–0.68) and 0.66 for IBD-related reasons (95% CI 0.55–0.79) during follow-up (Figure S3). Centers where children had more IBD-specific ED visits at diagnosis also had a higher number of IBD-specific and IBD-related hospitalizations during follow-up (Table 3; Figure S4). Province accounted for a high amount of the heterogeneity in hospitalization frequency.

Table 1 Characteristics of Children Included in the Study, Stratified by Province

Characteristic	Alberta (n=703)	Manitoba (n=218)	Ontario (n=2549)	Nova Scotia (n=314)
Age at IBD diagnosis, mean (SD)	10.8 (4.1)	11.8 (2.8)	11.5 (3.3)	11.8 (3.5)
Female, n (%)	307 (43.7)	100 (45.9)	1079 (42.3)	138 (43.9)
Type of IBD				
Crohn's disease	407 (57.9)	126 (57.8)	1511 (59.3)	202 (64.3)
Ulcerative colitis	217 (30.9)	92 (42.2)	858 (33.7)	95 (30.3)
IBD type unclassifiable[a]	79 (11.2)	–	180 (7.1)	17 (5.4)
Rural, n (%)	140 (19.9)	46 (21.1)	256 (10.0)	99 (31.5)
Mean neighborhood income quintile, n (%)[b]				
Quintile 1 (lowest)	115 (16.4)	26 (11.9)	324 (12.7)	74 (23.6)
Quintile 2	142 (20.2)	39 (17.9)	432 (16.9)	55 (17.5)
Quintile 3	141 (20.1)	38 (17.4)	514 (20.2)	58 (18.5)
Quintile 4	115 (16.4)	51 (23.4)	601 (23.6)	55 (17.5)
Quintile 5 (highest)	180 (25.6)	63 (28.9)	672 (26.4)	72 (22.9)
Pediatric Center of Care				
Center A	290 (41.3)	201 (92.2)	894 (26.1)	278 (88.5)
Center B	285 (40.5)	–	400 (15.7)	–
Center C	–	–	344 (13.5)	–
Center D	–	–	245 (9.6)	–
Community-based centers	128 (18.2)	17 (7.8)	666 (35.1)	36 (11.5)

Notes: [a]When algorithms could not differentiate between Crohn's disease and ulcerative colitis (see Table S1), children were identified as having IBD type unclassifiable. The algorithm used in Manitoba does not categorize individuals this way. [b]Total may not equate to 100% due to missing data.
Abbreviation: IBD, inflammatory bowel disease.

Table 2 Impact of Center-Level Predictors on the Variation in the Percentage of Children Treated at Each Center Requiring ≥1 Hospital Admission, Emergency Department Visit, or Surgery in the Time Frame Defined by six and 60 Months Following IBD Diagnosis

	≥1 Hospitalization		≥1 ED Visit		Surgery	
	IBD-Specific	IBD-Related	IBD-Specific	IBD-Related	Crohn's Disease	Ulcerative Colitis
Pooled Percentage (95% CI)	29.1% (24.0, 34.7)	31.4% (26.7, 36.5)	31.1% (28.5, 33.7)	55.8% (40.5, 70.1)	11.7% (8.6, 15.6)	12.4% (10.4, 14.6)
I^2	90.0%	87.4%	45.5%	98.0%	80.0%	0.0%
τ^2 (SE)	0.12 (0.08)	0.09 (0.06)	0.01 (0.01)	0.58 (0.38)	0.18 (0.13)	0.00 (0.04)
Predictor: Diagnostic delay (weeks)						
OR (95% CI)[a]	1.00 (0.98, 1.01)	1.00 (0.98, 1.01)	1.00 (0.98, 1.02)	0.97 (0.89, 1.06)	1.00 (0.98, 1.02)	NA
R^2	0.0%	0.0%	0.0%	0.0%	0.0%	NA
Residual I^2	91.7%	89.4%	56.6%	98.3%	83.4%	NA
Residual τ^2 (SE)	0.15 (0.09)	0.11 (0.07)	0.02 (0.02)	0.65 (0.47)	0.21 (0.16)	NA

(*Continued*)

Table 2 (Continued).

	≥1 Hospitalization		≥1 ED Visit		Surgery	
	IBD-Specific	**IBD-Related**	**IBD-Specific**	**IBD-Related**	**Crohn's Disease**	**Ulcerative Colitis**
Predictor: Percentage of children at each center with an IBD-specific ED visit within 1 month of diagnosis						
OR (95% CI)[b]	**1.11 (1.02, 1.21)**	**1.09 (1.01, 1.18)**	**1.05 (1.02, 1.08)**	**0.84 (0.72, 0.99)**	1.08 (0.93, 1.24)	NA
R^2	56.0%	51.7%	100.0%	41.7%	0.4%	NA
Residual I^2	85.3%	82.9%	0.0%	96.5%	84.9%	NA
Residual τ^2 (SE)	0.08 (0.07)	0.06 (0.05)	0.00 (0.01)	0.34 (0.25)	0.22 (0.19)	NA
Predictor: Percentage of children at each center with an IBD-specific hospitalization within 1 month of diagnosis						
OR (95% CI)[b]	1.00 (0.94, 1.07)	1.00 (0.95, 1.06)	0.98 (0.96, 1.01)	0.98 (0.84, 1.14)	0.98 (0.91, 1.06)	NA
R^2	0.0%	0.0%	8.0%	0.0%	0.0%	NA
Residual I^2	91.6%	89.4%	44.7%	98.5%	82.1%	NA
Residual τ^2 (SE)	0.15 (0.10)	0.11 (0.07)	0.01 (0.02)	0.71 (0.51)	0.21 (0.15)	NA
Predictor: Percentage of children at each center with a gastroenterologist as their primary provider of IBD care						
OR (95% CI)[b]	0.99 (0.97, 1.01)	1.00 (0.96, 1.03)	**0.98 (0.96, 1.00)**	**0.98 (0.96, 1.00)**	1.03 (0.98, 1.10)	NA
R^2	0.0%	0.0%	100.0%	98.8%	7.1%	NA
Residual I^2	72.8%	72.5%	0.0%	2.2%	76.9%	NA
Residual τ^2 (SE)	0.03 (0.04)	0.03 (0.04)	0.00 (0.01)	0.00 (0.01)	0.14 (0.13)	NA
Predictor: Mean percentage of IBD-specific care provided by gastroenterologists among children treated at each center						
OR (95% CI)[b]	0.99 (0.97, 1.01)	0.99 (0.97, 1.01)	**0.99 (0.97, 1.00)**	0.99 (0.97, 1.00)	1.03 (0.99, 1.07)	NA
R^2	0.0%	0.0%	100.0%	52.0%	27.0%	NA
Residual I^2	69.0%	69.1%	0.0%	48.1%	71.7%	NA
Residual τ^2 (SE)	0.02 (0.04)	0.02 (0.03)	0.00 (0.01)	0.01 (0.02)	0.11 (0.11)	NA
Predictor: Mean number of outpatient visits at diagnosis						
OR (95% CI)[c]	1.05 (0.77, 1.42)	1.03 (0.79, 1.34)	1.04 (0.57, 1.89)	0.34 (0.02, 5.27)	0.90 (0.60, 1.33)	NA
R^2	0.0%	0.0%	0.0%	0.0%	0.0%	NA
Residual I^2	91.4%	89.3%	55.6%	98.2%	82.8%	NA
Residual τ^2 (SE)	0.15 (0.09)	0.11 (0.07)	0.02 (0.02)	0.63 (0.46)	0.21 (0.15)	NA
Predictor: Province						
OR (95% CI): MB vs AB[d]	**1.61 (1.04, 2.50)**	1.37 (0.89, 2.10)	NA	NA	1.12 (0.36, 3.42)	NA
OR (95% CI): NS vs AB[d]	**1.88 (1.26, 2.82)**	**1.65 (1.12, 2.45)**	NA	NA	1.02 (0.35, 2.99)	NA
OR (95% CI): ON vs AB[d]	**2.30 (1.73, 3.06)**	**2.03 (1.54, 2.67)**	1.20 (0.94, 1.54)	**0.24 (0.16, 0.35)**	2.03 (0.97, 4.24)	NA
R^2	92.3%	90.1%	34.8%	94.2%	31.0%	NA
Residual I^2	44.4%	44.2%	35.7%	75.2%	77.5%	NA
Residual τ^2 (SE)	0.01 (0.02)	0.01 (0.02)	0.01 (0.01)	0.03 (0.03)	0.12 (0.13)	NA

Notes: Significant parameter estimates from meta-regression are indicated in bold font. [a]Odds ratio corresponds to the relative odds of each outcome per 1-week increase in the mean diagnostic delay. [b]Odds ratio corresponds to the relative odds of each outcome per 1-percent increase in the predictor variable. [c]Odds ratio corresponds to the relative odds of each outcome per additional outpatient visit. [d]Odds ratio corresponds to the relative odds of each outcome in the specified province compared to the reference province (Alberta).

Abbreviations: AB, Alberta; CI, confidence interval; ED, emergency department; IBD, inflammatory bowel disease; MB, Manitoba; NA, not applicable; NS, Nova Scotia; ON, Ontario; SE, standard error.

Multilevel Regression

Little between-center variation was observed in the risk or number of IBD-related hospitalizations among children with IBD in Ontario (Table 4). Patient characteristics (age, sex, rurality, income) were more important predictors of hospitalizations. Patients treated at centers with longer times to diagnosis had a lower risk of hospitalization (HR 0.98, 95% CI 0.96–0.99) and fewer hospitalizations (RR 0.98, 95% CI 0.97–0.99) during follow-up. Patients treated at centers where more patients were treated by gastroenterologists were more likely to have ≥1 IBD-related hospitalization (HR 1.05, 95% CI 1.00–1.10) and had more IBD-related hospitalizations (RR 1.02, 95% CI 1.01–1.03).

Emergency Department Visits

Mixed-Effects Meta-Analysis

During follow-up, 31.1% (95% CI 28.5–33.7) of children had ≥1 IBD-specific ED visit and 55.8% (95% CI 40.5–70.1) had ≥1 IBD-related ED visit (Figure S5). Centers where more children visited the ED at diagnosis also had more children

Table 3 Impact of Center-Level Predictors on the Variation in the Mean Number of Hospitalizations or Emergency Department Visits in the Time Frame Defined by six and 60 Months Following IBD Diagnosis

	Mean Number of Hospitalizations		**Mean Number of ED Visits**	
	IBD-Specific	**IBD-Related**	**IBD-Specific**	**IBD-Related**
Mean number of events (95% CI)	0.54 (0.43, 0.68)	0.66 (0.55, 0.79)	0.54 (0.40, 0.73)	1.64 (0.98, 2.75)
I^2	90.3%	84.8%	91.2%	98.2%
τ^2 (SE)	0.09 (0.06)	0.06 (0.04)	0.13 (0.09)	0.41 (0.26)
Predictor: Diagnostic delay (weeks)				
β (95% CI)[a]	0.00 (−0.01, 0.01)	0.00 (−0.01, 0.01)	−0.02 (−0.06, 0.03)	−0.01 (−0.09, 0.06)
R^2	0.0%	0.0%	0.0%	0.0%
Residual I^2	92.1%	87.5%	92.6%	98.5%
Residual τ^2 (SE)	0.11 (0.07)	0.07 (0.05)	0.15 (0.12)	0.49 (0.35)
Predictor: Percentage of children at each center with an IBD-specific ED visit within 1 month of diagnosis				
β (95% CI)[b]	**0.09 (0.02, 0.17)**	**0.07 (0.01, 0.13)**	**0.08 (0.01, 0.16)**	**−0.15 (−0.28, −0.03)**
R^2	55.3%	56.9%	57.3%	50.5%
Residual I^2	86.3%	78.9%	80.2%	96.0%
Residual τ^2 (SE)	0.06 (0.05)	0.04 (0.03)	0.05 (0.05)	0.20 (0.15)
Predictor: Percentage of children at each center with an IBD-specific hospitalization within 1 month of diagnosis				
β (95% CI)[b]	0.00 (−0.06, 0.05)	0.00 (−0.04, 0.04)	−0.03 (−0.11, 0.04)	0.01 (−0.13, 0.14)
R^2	0.0%	0.0%	0.0%	0.0%
Residual I^2	91.8%	87.3%	91.9%	98.6%
Residual τ^2 (SE)	0.11 (0.07)	0.07 (0.05)	0.13 (0.11)	0.51 (0.37)
Predictor: Percentage of children at each center with a gastroenterologist as their primary provider of IBD care				
β (95% CI)[b]	−0.00 (−0.04, 0.03)	−0.00 (−0.03, 0.02)	−0.02 (−0.05, 0.01)	−0.01 (−0.03, 0.00)
R^2	0.0%	0.0%	38.8%	100.0%

(*Continued*)

Table 3 (Continued).

	Mean Number of Hospitalizations		Mean Number of ED Visits	
	IBD-Specific	**IBD-Related**	**IBD-Specific**	**IBD-Related**
Residual I^2	79.8%	67.8%	59.7%	0.0%
Residual τ^2 (SE)	0.03 (0.04)	0.01 (0.02)	0.01 (0.02)	0.00 (0.01)
Predictor: Average percentage of IBD-specific care provided by gastroenterologists among children treated at each center				
β (95% CI)[b]	−0.01 (−0.02, 0.01)	−0.01 (−0.02, 0.01)	−0.01 (−0.03, 0.00)	−0.01 (−0.02, 0.00)
R^2	0.0%	0.0%	50.6%	66.7%
Residual I^2	77.0%	62.2%	54.2%	13.3%
Residual τ^2 (SE)	0.02 (0.03)	0.01 (0.02)	0.01 (0.02)	0.00 (0.01)
Predictor: Mean number of outpatient visits at diagnosis				
β (95% CI)[c]	0.02 (−0.25, 0.28)	0.04 (−0.17, 0.25)	−0.53 (−1.92, 0.86)	−0.60 (−2.97, 1.77)
R^2	0.0%	0.0%	0.0%	0.0%
Residual I^2	91.8%	87.0%	92.1%	98.5%
Residual τ^2	0.11 (0.07)	0.07 (0.05)	0.14 (0.12)	0.48 (0.35)
Predictor: Province				
β (95% CI): MB vs AB[d]	**0.62 (0.20, 1.03)**	**0.42 (0.05, 0.80)**	NA	NA
β (95% CI): NS vs AB[d]	**0.56 (0.19, 0.94)**	**0.51 (0.18, 0.84)**	NA	NA
β (95% CI): ON vs AB[d]	**0.74 (0.47, 1.01)**	**0.60 (0.36, 0.84)**	0.51 (−0.02, 1.03)	**−1.20 (−1.36, −1.05)**
R^2	90.4%	94.6%	47.2%	99.7%
Residual I^2	52.0%	26.7%	84.7%	14.0%
Residual τ^2 (SE)	0.01 (0.01)	0.00 (0.01)	0.07 (0.06)	0.00 (0.01)

Notes: Significant parameter estimates from meta-regression are indicated in bold font. [a]β is interpreted as the change in the natural logarithm of the mean number of events per 1-week increase in the mean diagnostic delay. [b]β is interpreted as the change in the natural logarithm of the mean number of events per 1-percent increase in the predictor variable. [c]β is interpreted as the change in the natural logarithm of the mean number of events per additional outpatient visit. [d]β is interpreted as the change in the natural logarithm of the mean number of events in the specified province relative to the reference province (Alberta).

Abbreviations: AB, Alberta; CI, confidence interval; ED, emergency department; IBD, inflammatory bowel disease; MB, Manitoba; NS, Nova Scotia; SE, standard error.

with >1 IBD-specific ED visit during follow-up (OR 1.05, 95% CI 1.02–1.08). Centers where more children had gastroenterologists as the primary IBD care provider had fewer children with ≥1 IBD-specific ED visit (OR 0.98, 95% CI 0.96–1.00) (Table 2; Figure S6). Both predictors accounted for a high degree of between-center variation in IBD-specific ED visits. The proportion of children with ≥1 IBD-related ED visit during follow-up were lower among centers where more patients visited the ED at diagnosis (OR 0.84, 95% CI 0.72–0.99) and where more children had a gastroenterologist as their primary IBD care provider (OR 0.98, 95% CI 0.96–1.00).

Children had a mean of 0.54 (95% CI 0.40–0.73) IBD-specific and 1.64 (95% CI 0.98–2.75) IBD-related ED visits during follow-up (Figure S7). Centers where more children visited the ED at diagnosis had more IBD-specific ED visits (β 0.08, 95% CI 0.01–0.16) but fewer IBD-related ED visits during follow-up (β −0.15, 95% CI. −0.28 to −0.03) (Table 3; Figure S8). Specialist care at diagnosis and the province of residence accounted for some or all between-center heterogeneity in the frequency of ED visits during follow-up (Table 3).

Table 4 Variation in IBD-Related Health Services Utilization and Risk of Surgery Between Six and 60 Months Following Diagnosis Among Children with IBD in Ontario, Estimated Using Multilevel Cox Proportional Hazards (Frailty) and Poisson Models

Patient-level Characteristics	Hospitalizations				ED Visits				Time to Intestinal Resection (CD) HR (95% CI)		Time to Colectomy (UC) HR (95% CI)	
	Time to First HospitalizationHR (95% CI)		Number of Hospitalizations RR (95% CI)		Time to ED Visit HR (95% CI)		Number of ED Visits RR (95% CI)					
	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]
Age at IBD diagnosis (continuous, per 1-year increase)	**1.03 (1.01–1.05)**	**1.03 (1.01–1.05)**	**1.03 (1.01–1.05)**	**1.03 (1.01–1.05)**	**1.03 (1.01–1.05)**	**1.03 (1.01–1.05)**	1.01 (0.99–1.02)	1.01 (0.998–1.02)	**1.06 (1.00–1.11)**	**1.06 (1.00–1.11)**	**1.08 (1.01–1.15)**	**1.09 (1.02–1.16)**
Female (ref: male)	**1.20 (1.05–1.36)**	**1.20 (1.05–1.36)**	**1.39 (1.25–1.53)**	**1.38 (1.25–1.52)**	**1.30 (1.16–1.46)**	**1.30 (1.16–1.46)**	**1.28 (1.12–1.46)**	**1.29 (1.12–1.47)**	1.07 (0.82–1.41)	1.07 (0.82–1.41)	**1.61 (1.07–2.42)**	**1.60 (1.07–2.42)**
Rural (ref: urban)	0.86 (0.68–1.08)	0.87 (0.69–1.10)	**1.46 (1.24–1.71)**	**1.46 (1.24–1.73)**	1.09 (0.90–1.31)	1.09 (0.90–1.32)	0.93 (0.80–1.10)	0.97 (0.83–1.13)	1.06 (0.69–1.61)	1.04 (0.68–1.59)	1.04 (0.55–1.97)	1.05 (0.55–1.98)
Mean neighborhood income quintile (ref: Quintile 5; highest)												
Quintile 1 (lowest)	0.95 (0.76–1.19)	0.96 (0.77–1.20)	**1.37 (1.02–1.85)**	**1.37 (1.01–1.87)**	1.13 (0.92–1.37)	1.12 (0.92–1.37)	1.13 (0.77–1.65)	1.13 (0.77–1.65)	0.94 (0.58–1.52)	0.93 (0.58–1.51)	1.06 (0.48–2.34)	1.07 (0.49–2.38)
Quintile 2	0.97 (0.79–1.20)	0.98 (0.80–1.20)	1.10 (0.89–1.36)	1.09 (0.88–1.36)	1.12 (0.93–1.34)	1.11 (0.93–1.34)	1.17 (0.96–1.42)	1.16 (0.94–1.44)	1.05 (0.69–1.60)	1.05 (0.69–1.59)	**1.95 (1.01–3.78)**	**1.98 (1.02–3.85)**
Quintile 3	1.00 (0.82–1.21)	1.00 (0.82–1.21)	**1.29 (1.03–1.62)**	**1.29 (1.03–1.62)**	**1.23 (1.04–1.45)**	**1.23 (1.04–1.45)**	1.08 (0.80–1.46)	1.07 (0.79–1.44)	1.25 (0.85–1.85)	1.25 (0.85–1.85)	1.68 (0.89–3.16)	1.67 (0.88–3.14)
Quintile 4	1.07 (0.90–1.28)	1.08 (0.90–1.29)	1.10 (0.89–1.35)	1.09 (0.89–1.35)	1.12 (0.95–1.32)	1.12 (0.95–1.32)	1.10 (0.93–1.30)	1.10 (0.93–1.30)	1.03 (0.71–1.5)	1.03 (0.71–1.50)	1.78 (0.95–3.33)	1.78 (0.95–3.34)

(*Continued*)

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Table 4 (Continued).

Patient-level Characteristics	Hospitalizations				ED Visits				Time to Intestinal Resection (CD) HR (95% CI)		Time to Colectomy (UC) HR (95% CI)	
	Time to First HospitalizationHR (95% CI)		Number of Hospitalizations RR (95% CI)		Time to ED Visit HR (95% CI)		Number of ED Visits RR (95% CI)					
	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]	Model 1[a]	Model 2[b]
Center-level Characteristics												
Mean time to diagnosis (per 1-week increase)		**0.98 (0.96–0.99)**		**0.98 (0.97–0.99)**		1.00 (0.98–1.01)		0.99 (0.98–1.01)		1.01 (0.99–1.04)		0.99 (0.96–1.02)
Percentage of patients at each center with a gastroenterologist as the primary provider of IBD care (continuous, per 10% increase)		**1.05 (1.00–1.10)**		**1.02 (1.01–1.03)**		0.96 (0.93–1.004)		**0.96 (0.92–1.00)**		1.03 (0.89–1.19)		1.09 (0.95–1.26)
Variation												
Kendall's τ (Cox); ICC (Poisson)	0.52%	0.01%	1.55%	0.20%	0.11%	0.01%	0.14%	0	1.79%	1.40%	0.38%	0.01%
MHR (Cox); MRR (Poisson)	1.10	1.01	1.06	1.02	1.05	1.01	1.03	1	1.20	1.18	1.09	1.01

Notes: Significant findings are indicated in bold font. Patient-level characteristics deemed to be more important than center-level variables (as determined by their magnitude relative to the MHR/MRR and its inverse) are indicated in italic font. [a]Model 1: Adjusted for individual-level characteristics (age at IBD diagnosis, sex, rural/urban residence at diagnosis, mean neighborhood income quintile at diagnosis). [b]Model 2: Adjusted for individual-level (same as Model 1) and center-level variables (mean time to diagnosis and proportion of patients at each center with a gastroenterologist as their primary provider of IBD care.

Abbreviations: CD, Crohn's disease; CI, confidence interval; HR, hazard ratio; IBD, inflammatory bowel disease; ICC, intraclass correlation coefficient; MHR, median hazard ratio; MRR, median rate ratio; RR, rate ratio; UC, ulcerative colitis.

Multilevel Regression

There was minimal variation in ED visits across Ontario centers (Table 4). Diagnostic delay and specialist care were not associated with risk of having ≥1 ED visit. Children cared for at centers with a higher proportion of children cared for by gastroenterologists had fewer ED visits (RR 0.96, 95% CI 0.92–1.00).

Surgery

Mixed-Effects Meta-Analysis

During follow-up, 11.7% (955 CI 8.6–15.6) of children with CD required an intestinal resection (Figure S9). Some of between-center heterogeneity could be accounted for by province of residence and mean percentage of IBD-specific care provided by gastroenterologists among children treated at a center (Table 2; Figure S10).

During follow-up, 12.4% (95% CI 10.4–14.6) of children with ulcerative colitis required a colectomy (Figure S9). There was no variation.

Multilevel Regression

Between-center variation accounted for little of the variation in the risk of intestinal resection among children with CD or in the risk of colectomy among children with UC (Table 4). Patient characteristics were more important predictors of surgery.

Discussion

Health services utilization by children with IBD varied across Canadian pediatric centers in the six to 60 months following IBD diagnosis, despite universal health care. The proportion of children with CD undergoing intestinal resection also varied, but the proportion of children with UC undergoing colectomy was similar across centers. Some between-center variation is inherent to provincial differences in healthcare utilization patterns and could not be explained by center-level care at IBD diagnosis. However, centers with higher ED utilization at diagnosis had a higher ED utilization during follow-up. Center-level access to specialist care at diagnosis was the only other characteristic of the care provided at each center that meaningfully accounted for some variation in outcomes, most notably ED utilization.

Our study builds on previous work demonstrating variation in the IBD care provided across North American pediatric tertiary-care centers at diagnosis, including in medication utilization.[2,3] Unlike our study, there was minimal variation in the care provided by the 3rd year following IBD diagnosis; this included a similar risk of intestinal resection among children with CD.[3] Rates of unplanned hospital admissions among children with IBD across primary care trusts in the United Kingdom were also highly variable.[29] However geographic differences in the epidemiology of IBD could have resulted in this finding, since hospitalization rates were reported per total population rather than per IBD population.

Our findings suggest that ED use around the time of diagnosis begets more ED use during follow-up. Children treated at centers where more care was provided by gastroenterologists had fewer ED visits. Adequate access to specialist care may reduce the reliance on the ED. Previous studies have acknowledged the importance of having regular gastroenterology care in improving outcomes for adults living with IBD, including reducing ED visits.[30–32]

Clinical practice guidelines for the management of pediatric-onset IBD exist.[33–37] Furthermore, the Canadian pediatric IBD community is engaged in coordinated research and clinical care.[38,39] Despite these standards, we report significant variation in the outcomes of children with IBD across Canada – particularly intestinal resection for CD and ED utilization. This may stem from limited access to specialist care at diagnosis or during follow-up (eg ED visits may result from inadequate access to gastroenterologists in outpatient clinics). Improved care pathways are needed to minimize diagnostic delay and ensure children and caregivers can access adequate care when needed (eg facilitated by IBD specialist nurses).[40]

Our study is subject to limitations inherent with the use of health administrative data. We used validated algorithms to identify individuals with IBD and surgical procedures to minimize misclassification bias.[9–14] Provincial differences may have resulted from variable structure and coding practices across provinces[41] rather than differences in clinical care. However, hospitalization data were obtained from the Canadian Institute for Health Information's (CIHI)'s Discharge Abstract Database in all provinces, which collects data nationally with trained, certified professional coders, likely minimizing coding variation. Data for ED visits were more heterogeneous. Both Alberta and Ontario derived ED visits from CIHI's National Ambulatory Care Reporting System. In Ontario, ED visits were additionally identified from the

ERCLAIMS database, which includes physician billing records from care provided in the ED. This may explain the differences in IBD-related ED visit rates observed. However, there was no significant difference in IBD-specific ED visit rates between provinces, indicating database differences cannot fully explain the variation observed.

Our health administrative data lack information on clinical characteristics, including disease phenotype and medication utilization. Thus, we were not able to describe how centers included in this study may have differed in their initial treatment approaches. In addition, we did not have access to information on the availability of allied healthcare professionals (eg IBD specialist nurses); centers where patients had better access to nursing care may have experienced better outcomes.[40]

Conclusions

There is variation in the health services utilization among children with IBD and risk of undergoing intestinal resection in those with CD, but not colectomy among children with UC, across Canadian pediatric tertiary-care centers. Improvements in clinical care pathways are needed to ensure that all children with IBD have equitable and timely access to high quality care.

Abbreviations

AB, Alberta; CD, Crohn's disease; CI, confidence interval; CIHI, Canadian Institute for Health Information; ED, emergency department; HR, hazard ratio; IBD, inflammatory bowel disease; ICC, intraclass correlation coefficient; ICD, International Classification of Diseases; MB, Manitoba; MHR, median hazard ratio; MRR, median rate ratio; NS, Nova Scotia; ON, Ontario; OR, odds ratio; RR, rate ratio; SD, standard deviation; SE, standard error.

Data Sharing Statement

This is a multiprovince study whereby province-specific datasets are provided to investigators in each province and analyzed locally. Province-specific data availability statements are provided below:

- Alberta: To comply with Alberta's Health Information Act and in order to minimize the possibility of unintentionally sharing information that can be used to re-identify private information, the dataset cannot be made publicly available. The data from the present study are held securely in de-identified form on a secure server at the University of Calgary and was provided by the Alberta Strategy for Patient Oriented Research Support Unit (AbSPORU). Legal data-sharing agreements between the researchers, AbSPORU, and the data providers (eg, health care organizations and government) prohibit researchers from making the data set publicly available. The underlying the analytic code is available from the authors upon request.
- Manitoba: This study is based in part on de-identified data provided by Manitoba Health and the data used in these analyses are owned by the government of Manitoba. We were given permission to use the data to conduct the analysis. However, we do not have permission to share the data. Researchers interested in replicating results, can apply to the ministry of health to access the data through the Provincial Health Research Privacy Committee. Instructions can be found at https://www.rithim.ca/phrpc-overview. The interpretation and conclusions contained herein are those of the authors and do not necessarily represent the views of the Government of Manitoba.
- Nova Scotia: This study is based in part on de-identified data provided by Health Data Nova Scotia. The interpretation and conclusions contained herein are those of the researchers and do not necessarily represent the views of the Government of Nova Scotia. Neither the Government of Nova Scotia nor Health Data Nova Scotia expressed any opinion in relation to this study.
- Ontario: The dataset from the Ontario portion of this study is held securely in coded form at ICES. While legal data sharing agreements between ICES and data providers (eg healthcare organizations and government) prohibit ICES from making the dataset publicly available, access may be granted to those who meet pre-specified criteria for confidential access, available at www.ices.on.ca/DAS (email: das@ices.on.ca). The full dataset creation plan and underlying analytic code are available from the authors upon request, understanding that the computer programs may rely upon coding templates or macros that are unique to ICES and are therefore either inaccessible or may require modification.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Jennifer Jones has received honoraria for speaking and consulting for AbbVie, Janssen, Pfizer, Shire, and Takeda.

Sanjay Murthy has previously participated in advisory board meetings for AbbVie, Janssen, Takeda, Pfizer, Shire and Ferring and as a speaker at educational events sponsored by Janssen, AbbVie and Pfizer.

Eric Benchimol holds the Northbridge Financial Corporation Chair in Inflammatory Bowel Disease, a joint Hospital-University Chair between the University of Toronto, The Hospital for Sick Children, and the SickKids Foundation. He has acted as a consultant for the Dairy Farmers of Ontario and McKesson Canada for matters unrelated to medications used to treat inflammatory bowel disease. He has also acted as a consultant for the Canadian Agency for Drugs and Technology in Health.

The authors report no other conflicts of interest in this work.

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